



**Access to Neurobehavioral  
Services in Virginia**



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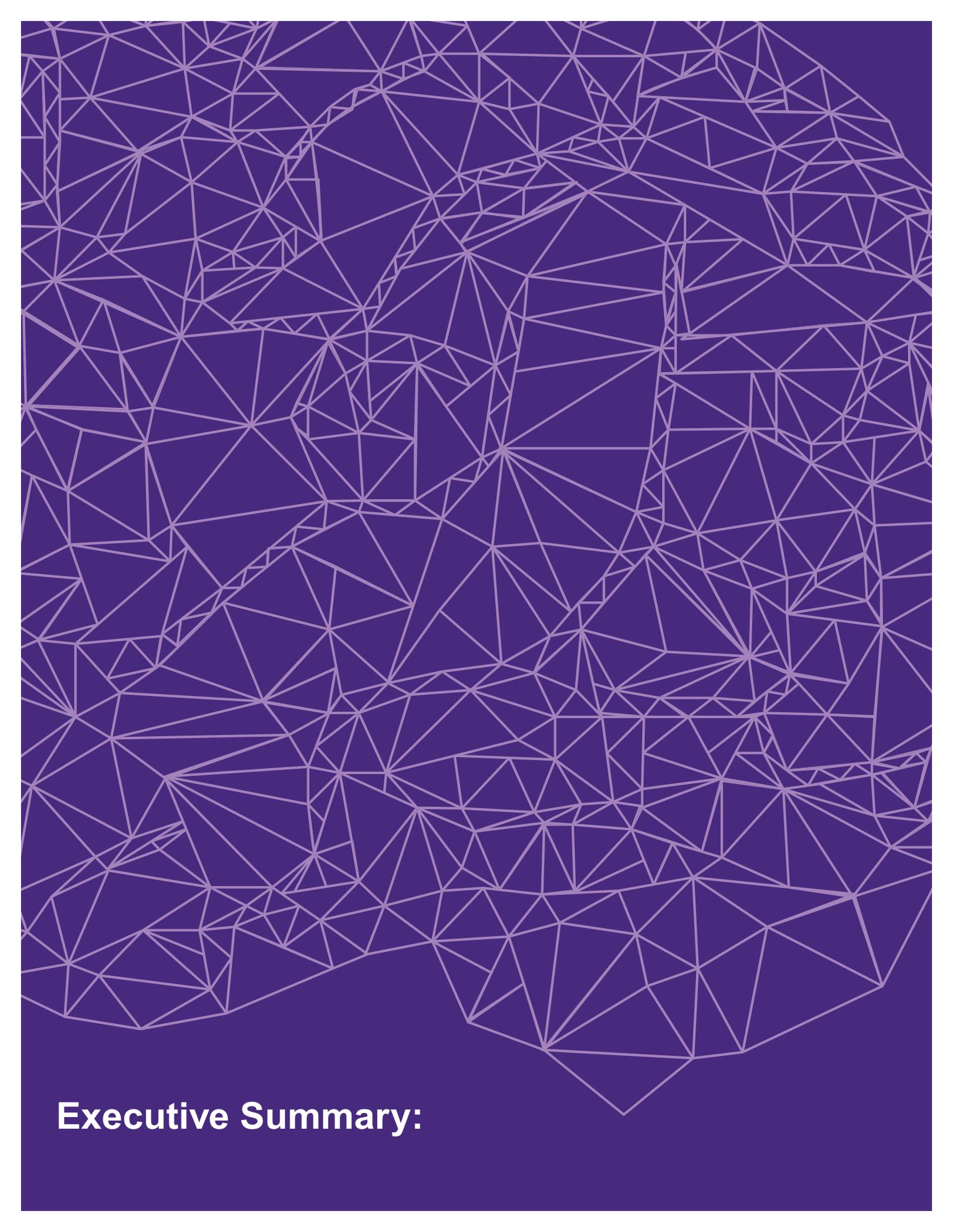
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## **Executive Summary:**

## 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.

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## 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.

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## 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.

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## 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.

## Recommendations Continued

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.

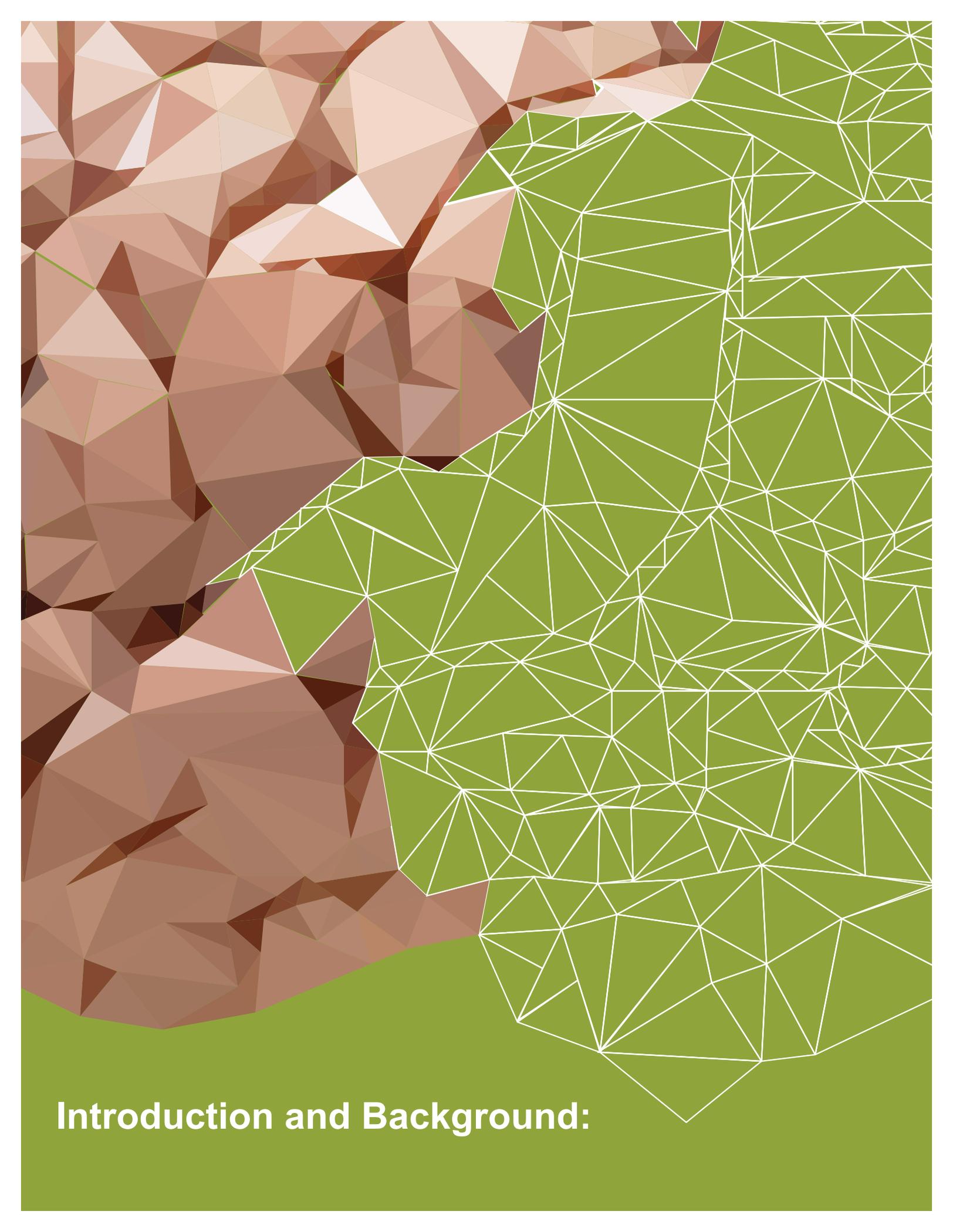
### *Funding model for the provision of short- and long-term residential and community-based supports*

- 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.**

The background features a complex geometric pattern. The left side is dominated by a low-poly, faceted structure in various shades of brown and tan, resembling a rocky or crystalline surface. This structure transitions into a large, irregularly shaped area on the right that is filled with a dense, intricate network of white lines forming a mesh or web-like pattern over a solid green background. The overall composition is abstract and modern.

## Introduction and Background:

# Introduction and Background:

## Scope

This report, *Access to Neurobehavioral Services in Virginia*, was requested by and funded through the Virginia Commonwealth Neurotrauma Initiative (CNI) Trust Fund Advisory Board to address issues of care provision for individuals with acquired brain injury. Drawn from systematic inquiry of brain injury service providers, the recommendations in this report build upon years of work by multiple persons and organizations. The most prominent contributors include the Virginia Brain Injury Council, state and national-level brain injury professionals and policymakers, and the advocacy community (e.g., the Brain Injury Association of Virginia).

In 2010, the Virginia Brain Injury Council delivered *Neurobehavioral Treatment for Virginians with Brain Injury*, the first position paper of its kind to describe neurobehavioral services as well as provide recommendations to address unmet needs. Inextricably connected to the Neurobehavioral Treatment report was Virginia Senate Document Number 15, *Access to State-Funded Brain Injury Services in Virginia*, by the Joint Legislative Audit and Review Commission (JLARC, 2007). Together, these seminal publications have illustrated the need to expand community-based services and provide care for those living with severe neurobehavioral issues.

Although efforts have continued to increase the attention given to brain injury services, the CNI Trust Fund agreed that a sequel to *Neurobehavioral Treatment for Virginians with Brain Injury* remained a significant need. This report describes available resources for Virginians with brain injury; identifies gaps in current services; and provides a set of service development, policy decisions, and funding recommendations. *Access to Neurobehavioral Services in Virginia* documents statewide needs and costs for treatment of brain injuries, evaluates system options and alternatives, assists policymakers and service providers in clearly understanding neurobehavioral issues, and provides an empirical basis for decision-making related to future policy initiatives.

## National and Statewide Landscape

At this time, the Department for Aging and Rehabilitative Services (DARS) oversees the coordination of services for individuals with brain injuries. Although challenges in accessing appropriate neurobehavioral care persist as long-standing topics of discussion for patients, families, and providers, definitive solutions to these challenges remain elusive because of limitations within and beyond the Commonwealth of Virginia.

Funding for services following brain injury varies across diagnostic codes, patient ages, and payment sources (private, public, public-pending, or no payer). Although payers generally cover emergent, acute, and rehabilitative needs, *long-term care (e.g., transitional living or community-based services) is not well supported*. Currently, DARS funds eight community-based programs (e.g., case management programs and clubhouses) throughout the state. Because a large proportion of brain injury survivors sustain their injuries between the ages of 15 and 25, individuals with acquired brain injury (ABI) need lifelong care.

Virginians with severe neurobehavioral issues following brain injury are at a significant disadvantage; most payers do not cover the cost of care for high-risk behaviors that may manifest following the stabilization period of acute medical issues. For instance, Virginia Medicaid does not cover necessary long-term neurobehavioral services because these services do not meet corresponding state eligibility criteria. Without an established payer (i.e., no reimbursement or limited reimbursement), there are no providers in the Commonwealth of Virginia that care for individuals with severe behavioral dysregulation as a result of brain injury—except in two specific circumstances: an affluent individual who can self-pay or an individual who receives services paid for by a worker's compensation claim.

The lack of state funding prevents would-be private providers of neurobehavioral services from establishing businesses within the Commonwealth. With the absence of a waiver inclusive of brain injury, individuals and their caregivers have few viable choices for neurobehavioral services. Unfortunately, some Virginians are transferred out-of-state for services, which is a significant cost to the Commonwealth. As of October 2015,

Virginia has shown limited initiative in support of a waiver for persons with neurobehavioral needs. However, the Intellectual Disabilities/Developmental Disabilities (ID/DD) Waiver redesign does afford an opportunity for sister agencies in the Commonwealth, such as the Department of Behavioral Health and Developmental Services (DBHDS), Department of Medical Assistance Services (DMAS), and DARS to expand collaborative efforts on behalf of our citizens in need of supports.

The topic of brain injury and neurobehavioral treatment services has received renewed interest, as evidenced by this position paper as well as the pending report requested from the Virginia Joint Commission on Health Care which is being compiled by Dr. Portia Cole. In addition, within DMAS's *Governor's Access Plan* ([http://www.dmas.virginia.gov/Content\\_pgs/GAP.aspx](http://www.dmas.virginia.gov/Content_pgs/GAP.aspx)) is an increased focus on serious mental illness, which may, given the intersection of neurobehavioral and mental health issues and the potential parallels in care, lead to greater attention paid to brain injury. With the Department of Justice settlement in Virginia related to the *Olmstead* decision (<https://www.olmsteadva.com/>), and more specifically, *Money Follows the Person* ([http://www.dmas.virginia.gov/Content\\_pgs/ltc-mfp.aspx](http://www.dmas.virginia.gov/Content_pgs/ltc-mfp.aspx)), considering neurobehavioral challenges following brain injury as part of the mental health and intellectual/developmental disabilities discussions appears both congruent and timely.

## Deliverables

A systematic investigation of the state of neurobehavioral services in Virginia is provided in this report, which thoroughly updates the Virginia Brain Injury Council's 2010 *Neurobehavioral Treatment for Virginians with Brain Injury* position paper. The report delivers the following:

1. A compilation of a formal literature review and bibliography [references; Appendix A], which includes:
  - a) The development of a common definition of "neurobehavioral treatment and services" for use in Virginia;
  - b) A description of the causes, nature, and prevalence of neurobehavioral issues related to brain injury;
  - c) The identification and description of promising models and interventions to address neurobehavioral issues; and
  - d) The identification and description of promising practices and approaches in other states that could be used in Virginia.
2. A description of the extent of the need for neurobehavioral services in Virginia, including an estimate of the prevalence and general description of individuals with brain injury in Virginia who have neurobehavioral needs;
3. An exploration of where adult Virginians with neurobehavioral treatment needs are currently served, including an identification and description of the array of community-based and residential-based neurobehavioral treatment and rehabilitative services currently available in Virginia;
4. A description of how existing neurobehavioral services in Virginia are paid for with public and private funds;
5. An account for the number and nature of Virginians who receive neurobehavioral treatment and services out of state through partnerships with the Department of Behavioral Health and Developmental Services and the Department for Medical Assistance Services
6. A proposal of general policy recommendations that improve access to neurobehavioral care for Virginians with brain injury; and

## Deliverables *Continued*

7. A suggestion of specific recommendations that address current and future funding needs to support access to a continuum of community-based and residential-based neurobehavioral treatment and services across the Commonwealth, including how efficiently and effectively funding could be allocated and expended to meet service needs.

*Access to Neurobehavioral Services in Virginia* is organized to reflect attention to each of the aforementioned deliverables, beginning with the literature review and concluding with specific recommendations that address current and future funding needs.

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**Literature Review:**

## Literature Review:

### Treatment Definitions and Causes of Neurobehavioral Issues Resulting from Acquired Brain Injury (ABI)

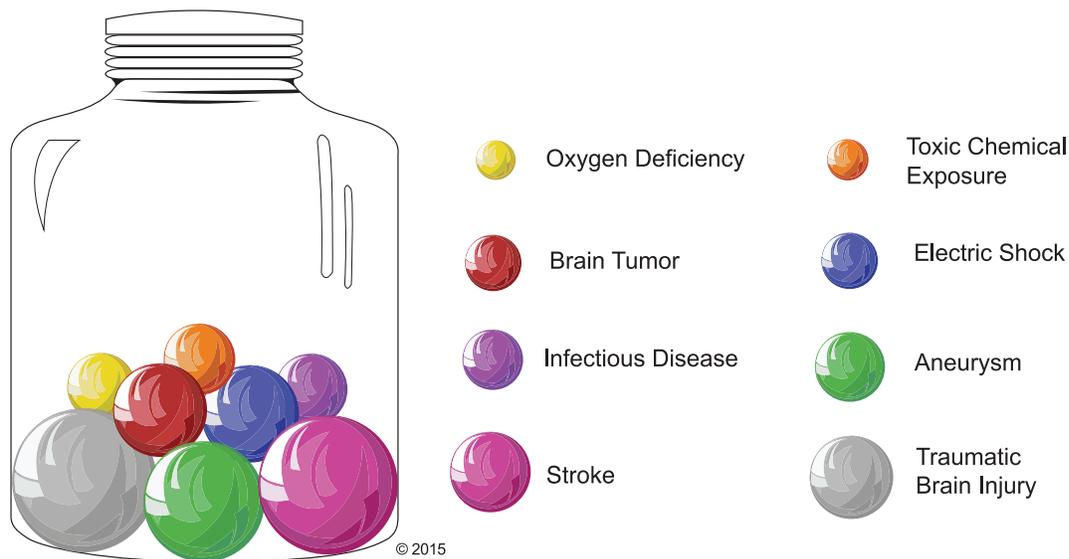
#### Definitions, Issues, Models, and Practices

Individuals with acquired brain injury (ABI) often struggle with subsequent challenging behaviors, which range in frequency and severity, but can be addressed with the proper neurobehavioral treatment and support services (Virginia Brain Injury Council, 2010).

The following definitions are based on those provided by professional organizations (e.g., the United States Centers for Disease Control and Prevention [CDC] and the Virginia Brain Injury Council) and are written to suit a non-expert audience. Before re-writing these definitions, the language was vetted through working professionals in academia, government, and healthcare.

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

**Acquired brain injury (ABI)** refers to brain trauma that occurs after birth. ABI does not include disorders that are a result of a progressive loss of nervous system cells (i.e., neurological diseases) such as Alzheimer's, Parkinson's, and Lou Gehrig's (ALS). Two of the leading causes of acquired brain injury are stroke and traumatic brain injury (TBI). However, ABI can also be caused by oxygen deficiency, infectious diseases (e.g., meningitis), toxic chemical exposure, electrical shock, brain tumors (Virginia Brain Injury Council, 2010), and aneurysms ([http://www.acquiredbraininjury.com/abi\\_manual](http://www.acquiredbraininjury.com/abi_manual)). See Figure 1.



**Figure 1.** Common Causes of Acquired Brain Injury. Graphic designed for this figure by Christopher Katalinas.

**Neurobehavioral needs [issues]**, in the context of this report, are referred to as the compromising cognitive, behavioral, and social changes that result from an acquired brain injury (ABI).

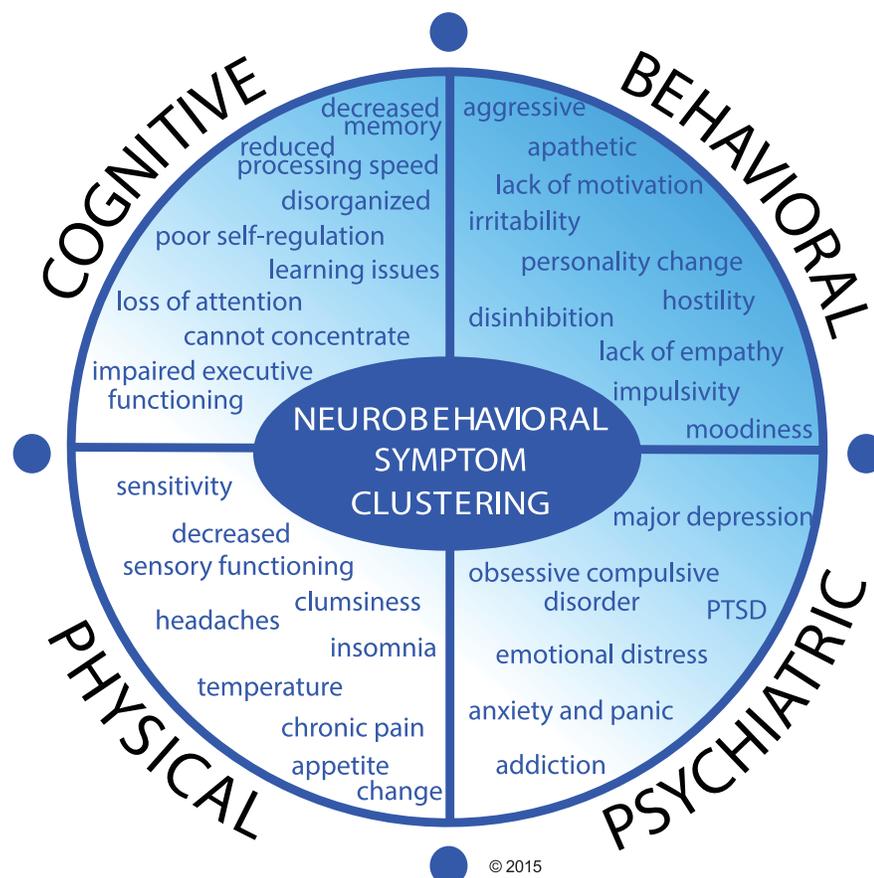
Although neurobehavioral issues vary in duration depending on the severity of the injury, persons with both mild and severe ABI may experience changes in their thoughts and personalities and find everyday problem-solving difficult. Persistent neurobehavioral issues often lead to compromised functional 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).

**Neurobehavioral treatment and services**, proper neurobehavioral treatment and services involve a continuum of care for individuals with neurobehavioral issues and account for a non-linear recovery process. Because neurobehavioral issues are complex, services may change over time. Interdisciplinary approaches are optimal; which combine collaborative efforts of professional providers and treatment across service domains (e.g., mental health and medical). The ideal continuum of care considers education, prevention, crisis mitigation and stabilization, transition to rehabilitation, and reintegration into society (e.g., community-based living).

### Nature of Neurobehavioral Issues

Injuries occurring over a widespread area of the brain (i.e., diffuse), particularly those affecting the frontal lobes, tend to disrupt many neural connections, yielding a high risk for neurobehavioral issues.

Figure 2 summarizes common yet complex neurobehavioral issues that result from brain injury. Together, the symptoms within and across each domain are mutually reinforced, resulting in a detrimental effect on overall functioning and exacerbating the prevalence of psychiatric co-occurrences. Again, the type of injury (i.e., mild versus severe) may dictate the severity of cognitive and behavioral deficits (Jamora & Ruff, 2012).



**Figure 2.** Neurobehavioral Issues that Result from Brain Injury. Graphic design for this figure by Peyton O'Donoghue.

**Cognitive.** Cognitive issues, such as an inability to problem-solve, plan, and self-regulate are often attributed to dysexecutive syndrome, which is likely to result from injury to the frontal lobe (Baddeley, 1986; Evans, 2001). Lesions in the frontal lobe also affect cognitive function by impairing an individual's ability to engage in introspection, understand others' emotions, and perceive experiences in real time (Beer, Heerey, Keltner, Scabini, & Knight, 2003; Wheeler, Stuss, & Tulving, 1997).

## Nature of Neurobehavioral Issues Resulting from Acquired Brain Injury (ABI) *Continued*

**Behavioral.** Behaviorally, deficits may appear in the form of apathy, personality changes, lack of motivation, disinhibition, impulsivity, and unstable moods (Lezak, 1995; Wood, 2001). Injury to the orbitofrontal region of the brain, a common ABI, disrupts social regulation. In other words, people with orbitofrontal injuries have trouble discriminating between appropriate social behaviors for interacting with strangers versus people they know well. For example, Beer et al. (2003) observed individuals with TBI engaging in contextually inappropriate behaviors (such as greeting strangers by kissing them on the cheek or hugging them; making inappropriate jokes; exhibiting less apologizing behavior; and disclosing significantly more and often intimate information when describing events in great detail).

**Physical.** Persistent neurobehavioral issues often compromise physical and functional abilities that prevent individuals from participating in pre-injury professional, social, and educational activities. Severe impairment of executive functions and reduced speed of psychomotor processing are major factors associated with loss of social autonomy and an inability for adults to return to work even years after experiencing a brain injury (Baddeley, 1986; DeGuise et al., 2008; Evans, 2001; Johnstone et al., 2003; Wood, 2001; Zasler et al., 2013).

As defined by the World Health Organization ([WHO], 2002), disabilities are impairments that can result in a loss of social roles and participation in various life activities. Both mild and severe brain injuries may result in neurobehavioral disabilities, though individuals with mild ABI tend to improve over time (Belanger, Curtiss, Demery, Lebowitz, & Vanderploeg, 2005).

**Psychiatric.** In a general population study, Silver, Kramer, Greenwald, and Weissman (2001) found that persons with TBI have a significantly higher risk for anxiety and panic disorder, obsessive-compulsive disorder, phobias, suicidal ideation, and substance abuse. Changes in physical abilities, cognition, social roles, lifestyle, and other functional competencies increase the likelihood of depression for people with ABI, which can occur at any stage following brain injury from the acute hospital stage to years after the traumatic event ([https://www.health.qld.gov.au/abios/asp/mental\\_health/mental\\_health.asp](https://www.health.qld.gov.au/abios/asp/mental_health/mental_health.asp)). In 2004, Jorge et al. indicated that 33% of persons with TBI experienced major depressive disorder, a correlate of reduced left prefrontal gray matter.

**Persistent Neurobehavioral Issues and Risks of Incarceration.** The prevalence of brain injury for incarcerated individuals remains uncertain. Researchers from the New York University School of Medicine found that 25-87% of inmates, including women, report having experienced a head or traumatic brain injury compared to the estimated 8.5% of the non-incarcerated public (Fleishman, 2013; Silver et al., 2001). A 2015 study conducted of jails in Denver, Colorado, found that 96% of the high-risk inmates screened had a history for TBI (Brown, 2015).

Walker, Hiller, Staton, and Leukefeld (2003) state that many prisoners who have had head injuries experience mental health problems, such as severe depression and anxiety, difficulty controlling anger, substance abuse, and suicidal thoughts or attempts. In the 2015 Denver study, 90% of the inmates were found to have mental illness and substance abuse problems (Brown, 2015).

## Incidence and Prevalence of Acquired Brain Injury (ABI)

The incidence and prevalence rates of acquired brain injury (ABI) in the United States are difficult to estimate. Without a visit to an emergency room (ER), or a hospitalization or death, there exists no standardized recordkeeping of acquired brain injury diagnoses. Common misdiagnoses may also skew the accuracy of ABI statistics. For example, an individual with a brain injury arrives at an ER with what appears to be—and is diagnosed as—a mental health concern. In actuality, the individual is experiencing a complex event—a psychotic episode stemming from their neurobehavioral issues. This individual would be more appropriately identified as having co-occurring mental health and brain injury diagnoses.

Several other factors further complicate attempts to provide accurate incidence and prevalence rates of ABI; among them are:

1. Lack of age-specific estimates, with underreporting of individuals 22 years of age or older.
2. Lack of data that pertain to neurobehavioral issues resulting from an ABI (i.e., neurobehavioral issues are absent from many quantitative data reports).
3. The separation of stroke and traumatic brain injury (TBI) statistics (i.e., many organizations report stroke and TBI as separate figures).
4. Limitations associated with current data systems (i.e., International Classification of Diseases [ICD]).

In fact, a CDC report to the U.S. Congress (2014b) identified several critical insufficiencies in the collection of TBI data alone. Section I, as follows, lists recommendations to address gaps identified in the epidemiology and consequences of TBI:

#### Section I. Epidemiology and Consequences of TBI in the United States

- Improve TBI incidence and prevalence estimates to include patients with TBI who are treated in non-hospital settings and those with TBI who are not receiving medical care. Develop or identify sources of non-hospital TBI incidence data, such as data from physician offices and other sources of outpatient medical encounters, to improve estimates. Similarly, develop or identify data sources that capture information from persons who might have experienced a TBI but did not seek medical care for their injury.
- Generate state-specific TBI estimates. Collect and compile health care administrative data in all states to quantify and examine state-level variations in TBI burden. In addition, state-level TBI estimates can be used to inform decisions related to the allocation of preventive and rehabilitative services that are made at the state level.
- Better understand injury mechanisms and their effect on sub-populations. Examine trends in TBI incidence by injury mechanism and within population subgroups (e.g., children, older adults, and others) by using data systems such as Healthcare Cost Utilization Project (HCUP). This can help target prevention resources to populations at greatest risk for TBI.
- Enhance monitoring of sports and recreation concussions. Develop and implement a concussion surveillance system that captures the full range of sports- and recreation related concussions. Current surveillance systems capture only emergency department visits or injuries experienced in organized high school sports, collegiate athletics, and some professional leagues.
- Produce population-level estimates of TBI-related disability. Add TBI-related disability to large, existing national health surveys, and analyze large-scale claims or administrative datasets to produce population-level estimates. (p. 6)

In an attempt to generate more reliable age-specific estimates, Taylor, Greenspan, Xu, and Kresnow (2015) compared information from three separate entities that collected data on TBI-related hospitalizations and ER visits for individuals aged 24-64. The results, summarized in Table 1, suggest that while adults between the ages of 24 and 64 account for 42-43% of TBI-related hospitalizations, this age group does not dominate the percentage of emergency room visits.

**Table 1 Percentages of TBI Hospitalizations and ER Visits Experienced by Individuals 24 to 64 Years Old Nationwide**

	NHDS	HCUP	NHAMCS
Percent of <b>individuals hospitalized</b> for TBI-related injuries that are <b>24 to 64 years old</b>	43%	42%	X
Percent of <b>emergency room visits</b> for TBI-related injuries that are by persons <b>24 to 64 years old</b>	X	36%	33%

*Note.* “X” is that there is no estimate provided; NHDS: National Hospital Discharge Survey; NHAMCS: National Hospital Ambulatory Medical Care Survey; HCUP: Healthcare Cost and Utilization Project.

Despite the aforementioned data-collection and reporting limitations, the CDC approximated TBI incidences to be around 2.5 million in the year 2010 (CDC, 2014b). These reported data constitute injuries documented through hospitalizations and deaths in the United States. Excluded are “those persons who did not receive medical care, had outpatient or office-based visits, or those who received care at a federal facility (i.e., persons serving in the U.S. military or seeking care at a Veterans Affairs hospital)” (as cited in CDC, 2014b, p. 19).

The CDC also estimates that over 795,000 individuals in the United States experience a stroke every year (<http://www.cdc.gov/stroke/facts.htm>). Contrary to public opinion, strokes occur at any age, with an estimated 34% occurring before the age of 65 (Hall, Levant, & DeFrances, 2012). The prevalence of persistent neurobehavioral issues resulting from stroke is unknown.

Several attempts have also been made to estimate the number of adult Virginians who have experienced an acquired brain injury (ABI):

- In the *Neurobehavioral Treatment for Virginians with Brain Injury* position paper, the Virginia Brain Injury Council (2010) gave a final estimate of 80,000 Virginians *living with complications* of ABI.
- An undated report published by the Brain Injury Association of Virginia (BIAV) concluded, “90,000 Virginians are disabled as a result of a TBI; over 95,000 are disabled as a result of a stroke. Therefore, more than 185,000 Virginians have some level of disability due to a brain injury” (BIAV, n.d., Foreword). The BIAV’s number of individuals in Virginia who have a disability due to a traumatic brain injury (90,000) was based on the most current Weldon Cooper Center population estimates and a CDC statistic that indicates 2% of the population has a disability as a result of TBI. The stroke algorithm used in the BIAV report originated in a CDC Mortality and Morbidity Weekly Review (MMWR) and includes the prevalence of stroke in Virginia and non-institutionalized but disabled from stroke.
- The BIAV notes that it is now estimated that 166,526 Virginians are disabled as a result of TBI based on an updated formula. With updated population data, an estimated 97,418 Virginians have a disability as a result of a stroke (personal communication, July 20, 2015).

Current (October, 2015) population estimates in Virginia are around 8.3 million (<http://quickfacts.census.gov>). **Through an integrated analysis of CDC and United States Census Bureau data from 2014, an estimated 106,000 Virginians, ages 18 to 65, are thought to have experienced a traumatic brain injury. In addition, 148,800 Virginians, ages 18 to 65, are estimated to have experienced a stroke. These data suggest that at least 254,400 adult Virginians currently live with an acquired brain injury.**

Although the incidence and prevalence of ABI in the entire United States, and in Virginia in particular, is difficult to estimate, there is a clear need for appropriate neurobehavioral treatment and services.

## Model Systems of Care

The *Access to Neurobehavioral Services in Virginia* researchers held extensive interviews with agency representatives from 10 states with model systems of care for persons with brain injury. To demonstrate both the diversity and complexity of these state care structures, several are profiled briefly. First, a background to Medicaid funding mechanisms is provided.

### *Medicaid Funding*

**Medicaid Waivers.** Excluding Virginia, nearly half of the States fund services for individuals with brain injury through a Medicaid Home and Community-Based Services (HCBS) waiver (NASHIA, 2015). Congress amended the Social Security Act (SSA) in 1981 to allow payment for HCBS; before this change, Medicaid only paid for long-term care services provided in institutional settings (Shirk, 2006). The SSA revision occurred in response to pressure from advocates to move away from institutional care and was based upon the idea that community-based services would be less expensive (Benjamin, 1993).

In some states, waivers were developed as the result of class action lawsuits. The programs funding HCBS are termed *wavers* because, under Sections 1115 and 1915 of the SSA, states may waive various Medicaid regulations, including financial eligibility requirements and stipulations that services be provided in institutional settings, statewide, and to all Medicaid-eligible individuals (Lutzky, Alexchik, Duffy, & Neill, 2000; Schneider, 1997). [For more information on waivers, see Appendix B].

**Brain Injury Waivers.** The HCBS waivers for individuals with brain injury are marked by heterogeneity—there are HCBS waivers focused on rehabilitation, short-term, and long-term service and support needs. These services are funded through Medicaid, which is jointly financed by each state and the federal government. In some states, individuals with brain injury may receive services under HCBS waivers for physical or developmental disabilities, or self-directed care. As NASHIA (2014b) summarizes:

In 1991, Kansas became the first State to implement a HCBS Medicaid waiver for individuals with TBI. Other states soon followed. Some States have since combined their brain injury HCBS waiver with Medicaid waiver programs for individuals with other disabilities or with long-term care waivers. The TBI/ABI HCBS Medicaid Waiver programs vary considerably across the country in terms of numbers served and how the States determine eligibility. Typical services offered by waiver programs include: adult day care, personal assistant, cognitive rehabilitation, homemaker, home accessibility modifications, durable medical equipment, therapies, respite, prevocational services, supported employment, and personal emergency response systems. (p. 1)

### *Profiled States*

**Colorado.** Colorado has 11 waivers, including a Home and Community Based Services (HCBS) waiver that covers brain injury. Some of Colorado's services are premised upon the provision of services that might preclude or mitigate the onset of more severe neurobehavioral issues (personal communication, August 12, 2015). This is further described in the provided excerpt:

Colorado's Home and Community Based Services Brain Injury Medicaid Waiver began in 1995 to provide an intensive cost-effective community-based programme for people with acquired brain injuries who would otherwise remain hospitalized. Although more than half of the states now provide services to consumers with TBI through Waiver programmes, Colorado's Waiver is unique in that it was initially designed to decrease burden of care and length of institutionalization on the front end. Instead of attempting to avert later nursing home admissions, Colorado's programme targets those individuals for whom initial inpatient acute and/or rehabilitation stays might be shortened and makes available to them 11 services in addition to regular Medicaid benefits. (Cusick et al., 2003, p. 932)

One focal point of Colorado's HCBS waiver is the supportive living program: the Brain Injury Transitional Living Program (BI TLP), which costs an estimated \$220 per day (personal communication, February 17, 2015). At the time of interview, 307 individuals were on the waiver; there was not a waiting list. The BI TLP secured a recent rate increase correlative to a more accurate cost of providing services. Individuals with more complex neurobehavioral needs are placed within five acuity tiers based on Mayo-Portland Adaptability Inventory (MPAI) scores; the rate per day ranges from nearly \$350 to \$450 (see Table 2). Higher MPAI scores reflect a greater need which drives additional funding necessary for proper treatment and services. In addition, the "...rate and program redesign of the [BI] TLP is intent on [providing] more intensive services at the beginning of someone's recovery that would help avoid future nursing home or hospital placement as well as work through other complex issues that are best addressed shortly after an injury" (personal communication, February 17, 2015).

**Table 2** *The Brain Injury Transitional Living Program (BI TLP) Acuity Tiers and Rates Per Day*

Description	Rate/Day
	\$347.09
(BI TLP) Acuity Tier 2	\$371.89
(BI TLP) Acuity Tier 3	\$397.70
(BI TLP) Acuity Tier 4	\$425.10
(BI TLP) Acuity Tier 5	\$450.44

Along with the Brain Injury Transitional Living Program that aims to help mitigate future neurobehavioral issues, Colorado provides many different types of services to individuals with varying needs following a brain injury, which have occurred recently or in years-past (personal communication, August 24, 2015).

*Note.* BI TLP: Brain Injury Transitional Living Program

**Iowa.** Iowa also has a Home and Community Based Services-Brain Injury (HCBS-BI) waiver for which a renewal application was filed in 2014 (<http://dhs.iowa.gov/ime/about/initiatives/HCBS/waiver-amend>). Iowa's waiver seeks to transition 50 persons annually from both (skilled) nursing facilities (NF, SNF) and intermediate care facilities for persons with intellectual disabilities (ICF, ID) to the community. According to the Brain Injury Association of Iowa (BIAIA), an estimated 95,000 lowans live with brain injury ([www.biaia.org](http://www.biaia.org)).

Two representatives (personal communication, October 29, 2014; personal communication, August 7, 2015) provided the following data:

- The current HCBS-BI waiver offers 15 services with roughly 600 providers;
- As of July 2015, 1,215 persons are on the waiver. The waiting list is 33 months; 1,322 are waitlisted;
- The waiver cap is \$2,800 per month with cost neutrality having been demonstrated at \$4,900;
- A case manager works with individuals to develop a comprehensive service plan;
- Persons with severe neurobehavioral needs are sent to out-of-state care facilities (e.g., NeuroRestorative in Tampa, Florida).

Intriguingly, the funding mechanism for persons served out-of-state is an exception-to-policy (ETP) (personal communication, June 8, 2015). According to the Iowa Department of Human Services, persons or agents may file an ETP request for a service not otherwise covered by the waiver ([http://dhs.iowa.gov/appeals/exceptions\\_policy](http://dhs.iowa.gov/appeals/exceptions_policy)). Granted at the discretion of the Director of the Department, the ETP is given when the service improves one's quality of life and is cost-neutral or cost saving.

In other words:

Currently, Iowa has noticed administrative rules...to include the provision and reimbursement of community based neurobehavioral rehabilitation. These services have been provided through [the ETP] and have shown to be a cost savings to the state as individuals are transitioning back to Iowa from out-of-state placements or able to avoid going out-of-state for services all together. (personal communication, August 7, 2015)

Criteria utilized to consider granting an ETP ([http://dhs.iowa.gov/appeals/exception\\_review](http://dhs.iowa.gov/appeals/exception_review)) include:

- Is there an extreme need for an item or service?
- Are there exceptional circumstances that justify an exception to policy?
- Would an exception to policy result in net savings to the state?
- Have all other possible sources been exhausted?
- What is the cost to the state and are there funds in the Department's budget?

**Maryland.** Maryland has a HCBS waiver, implemented in 2003 as a result of a class-action lawsuit. The waiver provides residential, day habilitation, and, among other services, supported employment to adults with acquired brain injury (ABI). At present, the ABI waiver is intended to meet the needs of persons with significant neurobehavioral issues and/or significant cognitive and physical deficits resulting from ABI. Due to the Money Follows the Person (MFP) project, the state no longer has an enrollment cap for individuals transitioning from long-term care facilities; about 75 persons were enrolled in August, 2015 with an estimated 110 served in the last 11 years (personal communication, August 10, 2015).

Maryland has five approved providers, including NeuroRestorative and Mary T Maryland. The latter provides a per diem bundled-rate encompassing a neuropsychiatric consult and on-call access; critical for more severe neurobehavioral cases. O'Dea opined that one component of building proper neurobehavioral services is ensuring neuropsychiatric services are available; too many persons with brain injury are treated with the wrong medications or are prescribed too many, which can exacerbate rather than ameliorate neurobehavioral issues.

The state of Maryland offers just a few community-based services but succeeds in its provision of integrative residential placement for chronic cases. Access to care, therefore, is available for those who *need it the most*, though efforts are in place to create other tracks (e.g., transitional care or acute care) for persons post-injury (personal communication, August 10, 2015).

**Massachusetts.** Massachusetts offers two HCBS waivers – residential and non-residential habilitation – supported in part by a class action lawsuit (*Hutchinson v. Patrick*, 2011). To qualify, persons must be living in a nursing home, chronic hospital, or rehabilitation hospital for at least 90 days; have experienced an ABI at 22 years or age or older; and meet other clinical and financial qualifying criteria ([www.mass.gov/mrc](http://www.mass.gov/mrc)). Cantrell (2012) described enrollment for the non-residential habilitation waiver as ongoing, whereas the residential habilitation waiver re-opened. In 2012, cost-neutral expenditures were at a maximum \$99,890 per year for non-residential habilitation and \$194,186 per year for residential habilitation.

Of note to this study is Kindred Hospital in Stoughton, which houses two secure units with 41 neurobehavioral beds. Behavioral self-control is at the center of Kindred Hospital's services, with neuropsychiatry, nursing, behavioral sciences, cognitive therapy, recreation therapy, speech-language therapy, and occupational therapy professionals represented on the treatment team ([www.khstoughton.com](http://www.khstoughton.com)).

## Promising Models, Interventions, Practices, and Approaches to Address Neurobehavioral Issues *Continued*

**Texas.** The Texas Department of Assistive and Rehabilitative Services provides a Comprehensive Rehabilitation Services (CRS) program for individuals with TBI or spinal cord injury. The program was first funded in 1991. CRS is well-supported; the Texas Legislature provides \$26 million from General Revenue Funds and additional funds are garnered through surcharges on felony and misdemeanor convictions. In fiscal year 2013 (FY 2013), funding averaged to be \$56,000 dollars per individual (<http://www.dars.state.tx.us/drs/crs.shtml>; personal communication, October 29, 2014).

According to the Texas Department of Assistive and Rehabilitative Services website (<http://www.dars.state.tx.us/drs/crs.shtml>), in order to be eligible for the CRS program, individuals must be at least 15 years old; have a brain or spinal cord injury that results in an “impediment to functioning independently in the home and the community in terms of mobility, self-care, and/or communication;” have United States citizenship or be a lawful immigrant; have at least six months of residency in Texas or have a primary caregiver who has lived in Texas for six months or more; be sufficiently medically stable to actively participate in the program; be willing to accept treatment; and “not be in the Eligibility, Plan Initiated, or Post-Closure Services phase of another Division for Rehabilitation Services program” (Who Is Eligible section, para. 1).

The stated goal of the CRS program is to improve an individual’s independence at home or in the community. Services include in-patient comprehensive medical rehabilitation (therapy, medical care, and other help as needed); outpatient services (rehabilitation therapies such as physical, occupational, speech, and cognitive); and post-acute traumatic brain injury services (to help individuals who are experiencing forgetfulness, are having problem-solving difficulties, or are experiencing other issues related to their TBI). Each of these services are time-limited: 90 days for in-patient services, 120 hours for outpatient services, and six months of the post-acute TBI services (Neal & Fuller, 2014).

As part of the CRS program, the Texas Department of Assistive and Rehabilitative Services contracts with 21 providers of post-acute services for individuals with brain injury, nineteen of which are tasked solely to work with brain injury assessment referrals and two/three of which are dedicated behavioral support programs (personal communication, October 29, 2014; Neal & Fuller, 2014).

Success is measured by whether individuals return home or are placed in the community upon completion of receiving CRS services. Nine hundred and eight individuals were served in FY 2013, 64% (586) of those individuals had experienced a TBI (as opposed to a spinal cord injury); the average age of the applicants was 37 years old; 91% of the total cases were successful (Neal & Fuller, 2014).

### *Conclusion*

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. These five state models 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.



**Virginia's Neurobehavioral Treatment Needs,  
Costs, and Current Services:**

# Virginia's Neuro-behavioral Treatment Needs, Costs, and Current Services:

A study conducted by the Virginia Commonwealth University (Survey and Evaluation of Research Laboratory [SERL], 2014) shows that in Virginia, 86% of brain injury survivors and 94% of their caregivers indicate a prevalence of experienced cognitive disability as a result of brain injury; this was followed closely by behavioral or emotional problems (70% as reported by survivor, 74% as reported by the caregiver) and physical disabilities (69% as reported by survivor, 74% as reported by the caregiver). These data (see Table 3) were collected through two surveys: one given to survivors of brain injury and the other to their caregivers.

**Table 3 Brain Injury Survivor and Caregiver Reported Experiences**

Reported Experience	Brain Injury Survivor	Brain Injury Caregiver
Cognitive Disability	86%	94%
Behavioral Emotional Problems	70%	74%
Physical Disabilities	69%	74%

Interestingly, over half of those surveyed (53% survivor, 61% caregiver) reported that they had not been provided information or advice regarding neurobehavioral services immediately following the injury. And, of those who had been given information or advice, a third were unsatisfied with what they received (SERL, 2014).

In order to gain a better understanding of the neurobehavioral services currently offered in Virginia as well as the extent of needs for providers, a survey of providers was conducted. [A summary of the data is provided in Appendix C].

# A Description of Public and Private Funding for In- and Out-of-State Neurobehavioral Treatment and Services

Table 4 summarizes neurobehavioral treatment and services funding history, beginning with a legislatively mandated action plan (S.J.R. 158, 1998) regarding appropriate treatment for individuals with brain injury who receive services via the state mental health system. This report (Department of Mental Health, 1999) described the need for treatment of individuals along the full spectrum of brain injury severity and identified "long-term supported living options with intensive behavioral supports" (p. 1) as the greatest unmet need. The authors acknowledged, however, that there was "no system of care in the community for people with brain injuries and no mental illness" (pp. 1-2), regardless of injury severity. The Commonwealth has never offered a Home and Community-Based Services (HCBS) waiver for adult Virginians with brain injury, but the possibility has been suggested in numerous reports and policy papers for at least the last 16 years.

**Table 4 Timeline: Reports, Legislation, and Legal Actions Relevant to HCBS Brain Injury in Virginia**

Year	Agency	Report	Action	Reference
1999	DMHMRS, DRS	<i>Action Plan for the Appropriate Treatment of Persons with Brain Injuries in the Mental Health System (report to the General Assembly)</i>	Recommended funding a variety of services for individuals with brain injury via an HCBS waiver as part of a larger strategy to "divert people from entering the state mental health system and to assist individuals in transitioning from state mental health facilities to their communities." (p. 18)	The Commonwealth of Virginia, The Department of Mental Health, Mental Retardation and Substance Abuse Services, 1999
2003	Virginia Olmstead Task Force	<i>One Community: Final Report of the Task Force to Develop an Olmstead Plan for Virginia</i>	Recommended development and implementation of a brain injury waiver "...to include specialized long-term placements for people with significant behavioral issues...specialized programs for both emergency and short-term treatment of people with behavioral issues... and the development of a network or team of brain injury specialists available to provide training and consultations to service providers in the community and in institutions interested in or currently trying to serve people with behavioral issues as the result of brain injury" (p. 28) to address the need of individuals with brain injury to access community services in order to avoid institutionalization and for Virginia to comply with Olmstead ruling.	Task Force to Develop an Olmstead Plan for Virginia, 2003

Table 4 *Timeline: Reports, Legislation, and Legal Actions Relevant to HCBS Brain Injury in Virginia*  
*Continued*

Year	Agency	Report	Action	Reference
2005	General Assembly	<i>Code of Virginia § 37.1-179 (Chapters 718, 725, 2005 Acts of Assembly), subsequently incorporated into Code of Virginia § 37.2-403, 37.2-404, 37.2-406</i>	Anticipating a Medicaid waiver for brain injury, authorized DMHMRSAS to license service providers (including residential) for individuals with brain injury. Required DRS to collaborate with DMHMRSAS on licensing-related activities. Defined "brain injury" for licensing purposes.	Va. Code § 37.1-179; Va. Code § 37.2-403, 37.2-404, 37.2-406
2007	JLARC	<i>Access to State-Funded Brain Injury Services in Virginia</i>	Identified Medicaid HCBS waiver for brain injury survivors as one option for funding needed services for Virginians with brain injury (p. 88). Highlighted several advantages of an HCBS waiver to the state: can offer services to "a larger segment of the population with brain injury," the ability to control costs and access federal funding, can decide what population it wants to target and tailor services to that population's needs (p. 91). Indicated primary challenge of an HCBS waiver is the potential cost to the state (p. 91).	JLARC, 2007
2009	BIAV, VBIC, DARS	<i>Brain Injury in Virginia: State Action Plan 2009-2013</i>	Included goal to "increase funding for brain injury programs and services to address gaps in service delivery system." An objective identified for meeting this goal was, "Secure passage of Medicaid Brain Injury Waiver" (p. 14).	BIAV, 2010; VBIC, 2010; VDARS, 2010
2010	VBIC	<i>Neurobehavioral Treatment for Virginians with Brain Injury</i>	Recommended implementation of a "demonstration program" to provide support for the behavioral needs of Virginians with brain injury. Indicated possible funding methods for such a program could be: 1) an HCBS waiver that specifically included neurobehavioral services, 2) an HCBS waiver for individuals not served by existing pediatric or geriatric HCBS waivers, 3) and/or a "money-follows-the-person" demonstration grant from the Olmstead Office of Community Integration for People with Disabilities (pp. 24-25).	VBIC, 2010

*Note.* HCBS: Home and Community-Based Services; BIAV: Brain Injury Association of Virginia; DARS: Department for Aging and Rehabilitative Services; DBHDS: Department of Behavioral Health and Developmental Services (formerly DMHMRSAS); DMHMRSAS: Department of Mental Health, Mental Retardation, and Substance Abuse Services (now DBHDS); DRS: Department of Rehabilitative Services (in 2012 joined with the Department for Aging to become DARS); JLARC: Joint Legislative Audit and Review Commission; VBIC: Virginia Brain Injury Council

The impact of the U.S. Supreme Court's 1999 decision in *Olmstead vs. L.C.* on the provision of services to Virginians with disabilities, including individuals with brain injury, merits further discussion given its imperative for person-centered, community-based services and supports. The court ruled that:

...the proscription of discrimination [in Title II of the Americans with Disabilities Act of 1990 (ADA)] may require placement of persons with mental disabilities in community settings rather than in institutions.... when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. (*Olmstead v. L.C.*, 1999, p. 587)

Table 5 provides a timeline of events relating to Olmstead compliance in Virginia.

**Table 5** Timeline: Action Relevant to Olmstead Compliance in Virginia

Year	Agent	Description	Citation
2002	Gov. Mark Warner, Virginia General Assembly	Convened task force (comprised of individuals with disabilities; family members; advocates; providers; representatives from 15 state agencies, local government; other stakeholders; five legislators) to make recommendations regarding implementation of <i>Olmstead</i> decision in Virginia	"Olmstead;" <i>Task Force to Develop an Olmstead Plan for Virginia</i> , 2003
2002-2003	Task Force to Develop an Olmstead Plan for Virginia	Surveyed consumers, family members, facilities, and programs; solicited reports from six state agencies regarding major populations of individuals with disabilities.  Issued final report containing 102 recommendations.	<i>Task Force to Develop an Olmstead Plan for Virginia</i> , 2003
2004	Gov. Mark Warner	Issued Executive Order 61, creating Director of Community Integration for People with Disabilities, Olmstead Community Integration Implementation Team, and stakeholder Oversight Advisory Committee.	"Olmstead;" The Olmstead Initiative
2005	Gov. Mark Warner	Issued Executive Order 84 to continue implementation of Olmstead decision in Virginia	"Olmstead"
2006	Gov. Tim Kaine	Issued Executive Order 2, directing Implementation Team and stakeholder groups to continue collaborative work developing cross-governmental strategic plan for community integration.	"Olmstead"
2006	Virginia General Assembly	Codified stakeholder advisory group into Community Integration Advisory Commission	"Olmstead"
2007	Gov. Tim Kaine	Issued Executive Directive 6, requesting multiple state agencies to "complete and annually update a comprehensive, cross-governmental strategic plan designed to assure continued community integration of Virginians with disabilities" (p. 1).  Also requests submission for the governor's approval of the initial plan and updates	"Olmstead;" Community Integration Team
2011	U.S. Department of Justice	Issued findings against Virginia for non-compliance with ADA as interpreted by <i>Olmstead</i> , including: "failure to develop a sufficient quantity" of community-based services to provide alternatives for individuals currently residing in or at risk of entering state institutions	"Olmstead;" U.S. Department of Justice, Civil Rights Division, 2011
2012	United States and Commonwealth of Virginia	Settlement agreement	

*Note.* "Olmstead" refers to [OlmsteadVA.com](http://OlmsteadVA.com)

The research team activated a Freedom of Information Act (FOIA) request for data that would account for the number and cost of Virginians who receive neurobehavioral treatment and services in- and out-of-state. For comparative purposes, data were also requested regarding services for minors.

### In-State

Table 6 details findings reported by the Virginia Department of Medical Assistance Services (DMAS). Provider types represented in this dataset are as follows: skilled nursing facilities (non-mental health and non-mental retardation [MH/MR]), long-term inpatient hospitals, rehabilitation hospitals, and intermediate care facilities. In 2011 through 2014, the average number persons with brain injury served annually in Virginia was 615. The percentage increase from 2011 to 2014 is 394%. The total cost of treatment and services per day averaged \$133.83.

Table 6 In-State Skilled Nursing Facility Care for Adults in Virginia by State Fiscal Year

State Fiscal Year	Unique Number of Recipients	Average Length Of Stay (Days)	Average Cost of Stay (Per Day)
2011	268	175.56	\$148.65
2012	426	148.53	\$130.76
2013	710	141.45	\$127.47
2014	1,057	136.17	\$128.44

Note. "Adults" refers to persons age 22 years and older.

### Out-of-State

Between 2010 and 2014, 54 to 66 persons were served in out-of-state facilities (i.e., hospitals, rehabilitation hospitals, intermediate care facilities, or skilled care facilities) annually, with a yearly average of 58 persons served. Total cost per day was the sum of *cost per services* and *peripheral expenses*, averaging \$594.42 per day, with a range of \$447.84 to \$691.98 daily. Notably, 2010 and 2011 were likely to have been years with high acuity patients, with 15% (2010) and 11% (2011) mortality rates.

Data were also reported for 2006 through 2010; number of recipients averaged 40, but total cost per day averaged \$1,180. Strikingly, the cost per day in 2008 was reported to have been \$2,780.60.

Comparably, out-of-state costs per day are about four times the cost of in-state costs, though this may be partially attributed to differential acuity tiers (i.e., level of severity; see Table 2).

### Treatment of Minors

Data were also requested on in-patient treatment of minors (persons 17 years of age or younger), both in- and out-of-state. From 2011 to 2014, in-state costs averaged \$947.80 per day; out-of-state costs averaged \$1,701.08 (nearly double that of in-state).

The background features a complex geometric pattern of overlapping triangles. The top and middle sections are filled with various shades of brown, from light tan to dark chocolate, creating a textured, crystalline appearance. In the bottom right corner, there is a distinct white wireframe structure composed of interconnected lines forming a network of irregular polygons, set against a solid blue background that also occupies the bottom left corner.

**Updated Research and  
Recommendation Process:**

# Updated Research and Recommendation Process:

## Survey Methodology, Results, and Interpretation

### Neurobehavioral Treatment and Services, Improving Access to Neurobehavioral Care for Virginians with Brain Injury

#### Methodology

The purpose of the study was to survey brain injury service providers/organizations and state-funded agencies in order to provide a comprehensive, updated report on the scope of neurobehavioral needs in the Commonwealth of Virginia. Potential benefits to respondents from participation in this study included an assessment of service needs that will lead to an informed recommendation for service development, policy decisions, and funding mechanisms.

Given the study's focus on *access to neurobehavioral services*, responding providers, organizations, and agencies were provided with the following definitions, which arose from an empirical review of medical, psychological, and rehabilitative literature. Please note, since the survey was administered, the provided definitions of neurobehavioral and neurobehavioral needs have changed slightly.

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

**Neurobehavioral needs:** Neurobehavioral needs refer to the compromising cognitive, behavioral, and/or social changes that result from an acquired brain injury (ABI). Although these needs and their duration vary depending on the severity of the injury, individuals with both mild and severe brain trauma may experience changes in their personalities, find problem solving difficult, experience a lack of motivation, or act impulsively. Neurobehavioral needs for individuals with persistent neurobehavioral issues often stem from compromised functional abilities that limit an individual's ability to engage in professional, social, and educational activities. Additionally, co-morbid psychiatric and mental health diagnoses are not uncommon while persistent neurological disabilities may lead to under-employment and increased rates of government financial assistance and incarceration (Baddeley, 1986; DeGuise et al., 2008; Evans, 2001; Johnstone, Mount, & Schopp, 2003; Wood, 2001; Zasler, Martelli, & Jacobs, 2013).

#### *Instrumentation*

The study consisted of a survey and needs assessment adapted from the Rutgers Center for State Health Policy (2009) and administered to service providers via *Qualtrics*, a web-based platform. The survey contained quantitative and qualitative items. The Institutional Review Boards affiliated with James Madison University (JMU) and the Virginia Department for Aging and Rehabilitative Services (VDARS) approved the survey. To evaluate average completion time and offer cursory item validation, the survey was piloted to a small sample with an 87.5% response rate. Several items were adjusted for clarity or eliminated to assure an average completion time of 20 minutes.

#### *Participants*

The survey was sent to a comprehensive, non-random population 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.

There was significant overlap between the documents used to compile the participant list, thus every reasonable effort was made to send the survey to one individual at each agency, resulting in a final sample size of 190. Two and a half weeks after opening the survey, the research team called participants for whom phone numbers were acquired, inviting their participation. This increased the response rate from 14% (n=26) to 44% (n=84).

## Results Summary

A comprehensive report of results, including output from statistical tests and descriptive graphs, tables, and figures, is available upon request. More information is provided in Appendix C.

### *Respondent Characteristics*

While 84 of 190 representatives responded, yielding a robust response rate of 44%, response rates for individual questions varied. Data for all respondents are included when descriptive statistics are presented; to compute various inferential tests, missing data were eliminated in order to match sets.

**Types of agencies.** Three “types” of agencies or organizations best typified the respondents: brain injury or disability providers, other public agencies, or other private agencies. Notably, participants also included community services boards, community provider agencies, outpatient therapy organizations, and hospitals.

**Service locations.** 41% (31/76) provide statewide services; 59% (45/76) provide services to regions or municipalities. Responses represented 80 municipalities across the Commonwealth.

**Service venues.** Respondents provide services in many places, with the most frequently delineated venue being the client’s community, followed closely by the client’s home. Services are also provided in outpatient facilities, client’s employment area, day programs, and residential facilities. Notably, some organizations provide services across more than one venue and no one organization reported *only* providing services in the client’s community.

**Neurobehavioral services.** 51% (37/72) indicate that their organization offers programs or services that are specific to individuals with neurobehavioral needs. Twenty-seven respondents provided a text response answer that estimated the number of annual neurobehavioral needs cases for which they provide service. Answers ranged from 4 to 1,200. Some respondents provided a range; others said that they could not estimate the number of cases. Without the three respondents that said that they were unable to estimate, the low average is: 158 cases. The high average is: 161 with the range from 7 to 1,200. The median number of cases for the low range is 45 and the median number of cases for the high range is 50.

**Core services.** 50 of the 84 respondents elected to indicate the one category that best reflects their agency or organization’s core services; 38% provide community living supports; 26% provide medical and therapeutic supports; 18% provide education or employment services; and 18% provide rehabilitative services. Participants then answered a series of questions aligned with the particular category chosen:

**Community living support services.** The most frequently denoted services in this category are: information and referral, advocacy to the individual or family, independent living services and life skills training, recreation/support services, and peer support.

**Medical and therapeutic services.** The most frequently checked services in this category are: individual counseling, mental health, case management, substance use evaluation and treatment, psychiatry, and psychology. Of note, neuropsychiatry and neuropsychology were indicated, but by only 5 respondents, respectively.

*Education or employment services.* There was little variability in the services selected by responses; in order, they include supported employment, career counseling/guidance, work adjustment, information and referral, vocational evaluation, learning supports, among others.

*Rehabilitative services.* Again, little variability existed in participants' selection of services that represented what they provide. Top services were family education, training, and counseling; and cognitive rehabilitation therapy. These were followed by inpatient rehabilitation, case management, post-acute rehabilitation, and neurobehavioral treatment.

*Referral sources.* Designating their top three referral sources, 71 participants responded. Above and beyond all sources was that of "physician" with 45 total cites. Secondary were medical caregivers (14), self-referral (13), family referral (13), and DARS (12).

*Eligibility requirements.* Participants identified any specific *diagnostic* eligibility requirements that individuals with neurobehavioral needs must meet to receive services. Unsurprisingly, the majority (74%) must have *at least* an ABI diagnosis; other diagnoses may include mental health, substance abuse, etc. Three agencies (4%) have no diagnosis requirements.

*Funding requirements.* Participants indicated any funding eligibility requirements that clients must meet to receive services. Twenty (30%) indicated "no payment information considered" whereas all other responses were some combination of Medicaid, Medicare, private insurance, private funding, and/or other funding (e.g., DARS).

*Demographic requirements.* Close to half of the responding agencies and organizations have demographic eligibility requirements, with the most frequent being that of age. Some serve individuals who are homeless, are disabled, or have veteran status.

#### *Indication of Service Needs or Gaps – Quantitative Data*

Participants were asked to indicate the degree (1-5 with 1=strongly disagree and 5=strongly agree) to which certain services constitute a gap or need in (1) their *own* organization and (2) in *other* organizations. As Tables 8 and 9 indicate, results are reported on aggregate, and then subdivided into (a) scores for respondents that *provide neurobehavioral services* and (b) scores for respondents that *do not provide neurobehavioral services*.

Tables 8 and 9 indicate several trends. Generally, the strongest needs and gaps pertain to funding, intensive residential supports, transitional or group living, and neuropsychology. Most respondents perceive gaps or needs to be greater in other organizations or agencies than in one's own; inferential tests reveal some of these differences to be statistically significant. On aggregate, providers that offer neurobehavioral services perceive own and other's gaps and needs to be greater than those providers that do not offer neurobehavioral supports.

*Table 8 Perceived Needs and Services in Own Organization*

	Mean-All (36)	Mean- Neuro (16)	Mean - non Neuro (20)
<b>1=Strongly Disagree, 2=Disagree, 3=Neither Disagree or Agree, 4=Agree, 5=Strongly Agree</b>			
Applied behavioral analysis and positive behavioral supports	3.75	3.86	3.65
Cognitive Therapy	3.56	3.50	3.60
Complementary and alternative medicine (CAM)	3.25	3.38	3.15

*Table 8 continued page 29*

Table 8 *Perceived Needs and Services in Own Organization*  
*Continued*

	Mean-All (36)	Mean- Neuro (16)	Mean - non Neuro (20)
<b>1=Strongly Disagree, 2=Disagree, 3=Neither Disagree or Agree, 4=Agree, 5=Strongly Agree</b>			
Community-based services	3.64	3.75	3.55
Funding Mechanisms	4.38	4.44	4.35
Group homes (community integrated)	3.86	4.19	3.60
Individual counseling	3.36	3.69	3.10
Intensive residential treatment	3.81	3.88	3.75
Interagency collaboration	3.58	3.81	3.40
Medical and therapeutic services	3.42	3.56	3.40
Multidisciplinary patient-centered approach	3.36	3.19	3.50
Neuropsychological and behavioral management	3.67	3.31	3.95
Pharmacological interventions	3.50	3.25	3.70
Skilled nursing	3.36	3.31	3.40
Supported living programs	4.17	4.31	4.05

*Note.* All “missing data” cases were removed (i.e., all respondents in this data set responded to every item: “Applied behavioral analysis and positive behavioral supports,” etc.)

Table 9 *Perceived Needs and Services in Other Organizations*

	Mean-All (36)	Mean- Neuro (16)	Mean - non Neuro (20)
<b>1=Strongly Disagree, 2=Disagree, 3=Neither Disagree or Agree, 4=Agree, 5=Strongly Agree</b>			
Applied behavioral analysis and positive behavioral supports	4.11	4.06	4.15
Cognitive Therapy	4.03	4.13	3.95
Complementary and alternative medicine (CAM)	3.81	3.86	3.75
Community-based services	4.31	4.19	4.40
Funding mechanisms	4.53	4.63	4.55

*Table 9 continued page 30*

Table 9 *Perceived Needs and Services in Other Organizations*  
*Continued*

	Mean-All (36)	Mean- Neuro (16)	Mean - non Neuro (20)
<b>1=Strongly Disagree, 2=Disagree, 3=Neither Disagree or Agree, 4=Agree, 5=Strongly Agree</b>			
Group homes (community integrated)	4.19	4.44	4.00
Individual counseling	3.92	4.06	3.80
Intensive residential treatment	4.00	4.06	3.95
Interagency collaboration	4.14	4.13	4.15
Medical and therapeutic services	3.92	4.06	3.80
Multidisciplinary patient-centered approach	3.92	4.06	3.80
Neuropsychological and behavioral management	4.14	4.25	4.05
Pharmacological interventions	3.83	4.00	3.70
Skilled nursing	3.83	4.06	3.65
Supported living programs	4.33	4.50	4.20

*Note.* All “missing data” cases were removed (i.e., all respondents in this data set responded to every item: “Applied behavioral analysis and positive behavioral supports,” etc.)

Indication of  
Service Needs  
or Gaps –  
Qualitative Data

Three short neurobehavioral cases were created to reflect real cases of neurobehavioral issues reported in the Commonwealth. Respondents were asked to describe their course(s) of action in responding to these cases. In most instances, a singular course of action was identified, though many respondents idealized an interdisciplinary, coordinated, or team-centric approach. Themes were organized through multi-rater qualitative coding with the organizing concept of *referral and assessment*. Respondents indicated that the primary *referral and assessment* actions involved a neuropsychologist or neuropsychiatrist, physician, or other general practitioner. Secondary actions involved referrals or consultations to a brain injury provider for case management, with the client or family, by a mental health professional or agency, or by a behavioral management specialist.

While most survey participants did not designate outcomes in their responses, instead referring to *processes*, a number of responses alluded to an ideal outcome. An organizing concept arose around the notion of *reviewing and adjusting medications* pursuant to referral and assessment by a physician, neuropsychiatrist, or neurologist. This was seconded by *behavioral modification* (e.g., de-escalation or positive behavioral supports).

Several trends are revealed in these data. One is that there is a gap between how respondents would pragmatically versus idealistically deal with neurobehavioral cases. There is a strong adherence to a medical, pharmacologically centric model stressing short-term stabilization versus a continuum of interdisciplinary care and trans-agency supports.

[More detailed analyses of the qualitative data are provided in Appendix C.](#)



# **Conclusion: General Policy Recommendations**

# Conclusion: General Policy Recommendations

Each of the proposed policy recommendations are resultant of a meta-analysis of neurobehavioral literature, model systems, and nationwide waiver programs; a systematic survey and needs assessment; interviews with Virginia-based providers, advocates, and policymakers; and a FOIA request of expenditures for both in- and out-of-state care.

All findings of this study stress a compelling need for multi-agency, interdisciplinary neurobehavioral services provided across a continuum of care *with a responsiveness to individualized needs*. Each aspect of the care continuum should be considered when providing services. For instance, it is unreasonable to develop 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.

## Specific Recommendations Addressing Current and Future Needs

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:

1. Prevention, education, and screening/identification;
2. Crisis stabilization in a 24-hour, secured unit; and
3. Provision of short- and long-term residential and community-based supports.

Of the many programs nationwide that integrate education, crisis stabilization, and provision of supports, the Commonwealth's Department of Behavioral Health and Developmental Services (DBHDS)'s *Regional Education Assessment Crisis Services Habilitation* (REACH) program is a worthy model to emulate for two reasons: (1) its current funding structure and (2) its coordination of services across existing entities and agencies.

To clarify, the primary action outlined in this report is *not* to add a neurobehavioral component to the existing REACH program, but to create a parallel initiative that serves individuals with brain injury and their caregivers. The following set recommendations use the REACH program as a contextual framework for providing services to Virginians with brain injury who require acute, crisis, short-term, and long-term supports residentially and in the community. First, an overview of REACH is provided.

### REACH – An Overview

In its fifth year, the REACH program is an extension of the Commonwealth's community crisis system and is in place "to meet the crisis support needs of adults who have an intellectual and/or developmental disability and are experiencing crisis events which put them at risk for homelessness, incarceration, hospitalization, and/or danger to self or others" (REACH Program Standards, 2015, p. 3). With grounding in the highly researched Systemic Therapeutic Assessment Respite Treatment (START) model, REACH programs are regionally based with several integrative services (personal communication, August 20, 2015):

1. *Prevention and education*. The objective of prevention and education is to "increase the system's capacity to serve the individual" (REACH Program Standards, 2015, p. 4) which is accomplished by providing educational resources and training for families, emergency services personnel, law enforcement, residential and day providers, inpatient and outpatient facilities, psychiatric providers, and others.
2. *Mobile crisis*. Each of the five regional REACH programs has 24/7 crisis phone lines. Within Quarter III of Fiscal Year 2015, roughly 1,000 emergency and non-emergency calls were received; the majority necessitated preventative intervention (~600), followed by information or consultation (~200). Two hundred fifty (250) were crisis calls resulting in 208 onsite responses by mobile team (personal communication, August 20, 2015).

3. *Therapeutic home.* REACH has 5 Crisis Therapeutic Homes (CTHs) within the state, with 6 beds per home. For each CTH, three beds are crisis prevention; the other three are dedicated for crisis stabilization situations (i.e., emergencies) that do not meet Temporary Detention Order (TDO) criteria, yet are serious enough to place current guardians, family members, or the individual at risk of harm. The recommended length of stay for crisis prevention is 3-5 days. Unless an extension applies, lengths of stay for crisis stabilization do not exceed 30 consecutive days (REACH Program Standards, 2015).

Among the many strengths of REACH, is the program's role in mitigating crisis and preventing psychiatric hospitalizations (DBHDS, REACH (Adult ID/DD Crisis Services) [REACH], 2015). Also, REACH uses components of existing crisis support systems (i.e., Community Service Boards and the Behavioral Authority), which allows for cohesion and integration among service providers. Regarding funding, the General Assembly appropriates 2.2 million dollars annually to REACH. Serving Medicaid and non-Medicaid clients, regions are instructed to maximize billing, yielding an additional \$700,000 in revenue annually (personal communication, August 20, 2015).

#### **Recommendation 1: Prevention, Education, and Screening/Identification**

Drew, once an active college athlete and dedicated student, experienced what he thought was a concussion as a result of tackle during football practice. Although Drew is still living at college and trying to remain a full-time student athlete, he suffers from intense headaches, light sensitivity, irritability, memory loss, and sleeplessness. The cumulative effects of not being able to focus in the classroom or train as an athlete are frustrating and isolating—and Drew's teammates have noticed a change in his once calm and easy-going demeanor. After reluctantly visiting an athletics trainer and medical doctor, Drew was prescribed several medicines to alleviate his headaches and insomnia. Although he has experienced some relief, Drew's inability to focus and erratic behaviors have remained unchanged; his teammates also note a spike in his use and abuse of alcohol.

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 – and can occur in face-to-face settings or virtually. There are numerous mechanisms for virtual collaboration. Telepractice, for instance, is an example of how this can be successfully accomplished.

Recent research on access to crisis intervention services for survivors of brain injury in Virginia concluded that *lack of provider training and education* is among the most critical barriers to individuals seeking appropriate care (Meixner, O'Donoghue, & Witt, 2013). The following steps were previously set forth to address the lack of provider training and education:

1. [Provide] behavioral health providers with appropriate tools to screen for brain injury in individuals seeking services, which may promote early identification, improve rehabilitation outcomes, and mitigate crises.
2. [Recognize] roles of biomechanical and psychosocial causes of psychiatric symptoms following brain injury, which may help reduce stigma, improve provider confidence, and inform providers of alternate approaches to treatment.
3. [Promote] awareness of the prevalence of suicide among persons with brain injury and the important risk assessment role that all providers possess.
4. [Develop] interprofessional teams of providers to maximize access to services, either face-to-face or virtual (i.e., telepractice).
5. [Foster] collaboration and communication through direct education and partnerships among providers, persons with brain injury, and their families.

(p. 383-384)

Screening and identification are linked inextricably 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 REACH. Another evidenced-based interdisciplinary team approach combining intensive case management and behavior supports is CONcEPT (Commonwealth Neurobehavioral Project Team). This project demonstrated success on patient goals; CONcEPT serves as an integrative triage (i.e., identification) team. After receiving referrals from brain injury providers, community services boards, families or others, an inter-professional team assures cases receive the supports and structures necessary for crisis mitigation and stabilization. Of note, a reliable intake system (e.g., telephone, web-based) and deployment of well-trained crisis responders, similar to those involved with REACH, would need to be implemented.

Convenient, accessible, and cost-effective education may be offered through a variety of means. Mobile (i.e., on-site) 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. New Hampshire, for instance, built a statewide mobile (neurobehavioral) dual diagnosis team whose training and education efforts resulted in enhanced collaboration, empowerment, and awareness across providers (Flashman, 2015).

Another CNI grant, the *Community Based Brain Injury Screening Initiative*, may prove instrumental in advancing screening measures within the Commonwealth. Led by Jeffrey Barth, Ph.D., and Donna Broshek, Ph.D., of the Neurocognitive Assessment Laboratory at the University of Virginia, the goal is to “increase the understanding and implementation of brain injury screening among human service professionals statewide resulting in the referral of Virginians with brain injury to more appropriate services, thereby enhancing outcomes for survivors” (J. Barth, personal communication, April 29, 2015). 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 community service sites (i.e., two Community Services Boards, two Centers for Independent Living, two Area Agencies on Aging, and two Free and Charitable Clinics).

Funding considerations:

- 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, as this was how New Hampshire funded their initiative).

#### **Recommendation 2:** Crisis Stabilization in a 24-hour, Secured Unit

Two years ago, Stuart was struck by an SUV while riding his motorcycle to work; he sustained a brain injury to his frontal lobe. Stuart, now unable to work, receives case management services from a local provider. Periodically, Stuart has trouble controlling his emotions and often experiences bouts of inconsolable rage resulting in damage to the home. Often, his periods of anger are followed by depression. Because of Stuart’s unpredictable behaviors, his wife sometimes feels uneasy about her family’s safety and has, on several occasions, taken Stuart to the Emergency Room for further help.

To address the unmet need for intensive neurobehavioral crisis prevention (i.e., mitigation) services for persons with brain injury, particularly those who require 24-hour care, *it is recommended that the Commonwealth pilot a small neurobehavioral crisis prevention 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 could be reevaluated based on more accurate data on bed utilization.* A state psychiatric hospital appears the optimal choice for these individuals at risk of harm to self or others. These 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 level of 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 also need step-down into a crisis stabilization residence or re-entry into the community.

Funding model:

- 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).

### **Recommendation 3: Provision of Short- and Long-Term Residential and Community-Based Supports**

Kendra, a 37-year-old individual who sustained a brain injury as a result of a car accident, was recently released from yet another skilled nursing facility after several episodes of severe agitation and aggression. Safety and wellbeing concerns from Kendra's family grow—and ultimately, they are unable to provide, fund, or find in-state care. Out of local options, Kendra is sent to an out-of-state facility where she has started to receive necessary, multidisciplinary care. However, the financial burden placed on Kendra's family is cumbersome and threatening—even the travel costs to visit Kendra are unsustainable.

Model states employ a robust system of care for persons with brain injury that offer an array of residential (i.e., long-term and crisis stabilization) 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 meet varied neurobehavioral presentations.

#### *Long-Term Structured Residential Care*

While return to the community and home is ideal – and congruent with federal legislation – some persons with neurobehavioral needs exist in a state of persistent crisis that necessitates long-term residential stabilization and care. The current in-state options for long-term residential care, for those high-risk Virginians who can pay independent of insurance, are NeuroRestorative in Blacksburg or Tree of Life in Richmond. However, such financial circumstances are the exception and seldom the rule. The cost of long-term care for those who *initially* have access to funds is adequate; over time, most persons must seek or apply for public funding (i.e., Medicaid).

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 care providers educated in the nuances of traumatic brain injury. More often than not, persons with more severe neurobehavioral presentations are moved through skilled care facilities like “hot potatoes” – ultimately facing discharge without adequate support services or potential placement in out-of-state-facilities.

Given the FOIA data regarding out-of-state care, it is projected that a minimum of 25 neurobehavioral cases annually will require more long-term specialized care. This specialized care likely encompasses 24/7 supervision for safety, intervention by professionals or paraprofessionals for medications and therapies, and supervision to mitigate flight risks. This is a perplexing dilemma in light of Virginia's settlement with the Department of Justice (DOJ), and the ongoing efforts to transition residents of statewide facilities

## Specific Recommendations Addressing Current and Future Needs *Continued*

(e.g., training centers) back into their communities. Optimally, if the efforts in home and community-based integration could accommodate these individuals, issues of institutionalization may be circumvented. Presently, the Commonwealth sends such high-risk cases out of state; Brain Tree Manor in Massachusetts is an example of the entities with which a DMAS partnership exists. Regardless of venue, this care is costly, with high ancillary costs. Further, geographical distance from out of state providers limits the involvement of Virginia families in the recovery process.

Many complex, chronic neurobehavioral cases are managed in other states through contractual agreements with private providers. For example, in Maryland (an ABI waiver state) the state contracts with programs such as Mary T Maryland and NeuroRestorative to meet these needs. Actual costs associated with these arrangements are challenging to quantify. Feedback from interviewees representing various states and models indicate the negotiated payments range from \$600 to \$1200 per day. In Massachusetts, another waiver state (the ABI Waiver with Residential Habilitation [ABI-RH]), there is a designated neurobehavioral unit. The estimated cost is no less than \$700 per day with a cap limit of \$194,486 per year as stipulated in the ABI-RH waiver. In Iowa there is a community-based waiver, however, Iowa utilizes an exception to policy (ETP) approach to outsource the neurobehavioral care. Although each state has different methods to address the NB care issue, there appear to be alternative means that could be further explored and financially analyzed relative to neurobehavioral care in Virginia thus, curtailing the need to transfer residents to other states.

### *Community-Based Supports*

At the age of 44, Emily – a long-time equestrian, college professor, and mother of three teenagers – suffered a brain injury and severe back trauma after falling from her horse. Her family exhausted their savings on an expensive out-of-state program, which provided Emily with supports aiding her physical rehabilitation and early cognitive recovery. Now back at home and unable to return to work, Emily is inattentive and impulsive – two characteristics that are contrary to her pre-accident disposition. Engagement in a clubhouse program did not prove fruitful, as Emily was often verbally abusive and unaware of her behavior toward other clients and staff members. While her husband and children do not feel Emily is at risk of harming herself or others, they are ill equipped to offer Emily the long-term supports she needs to be a productive member of the community.

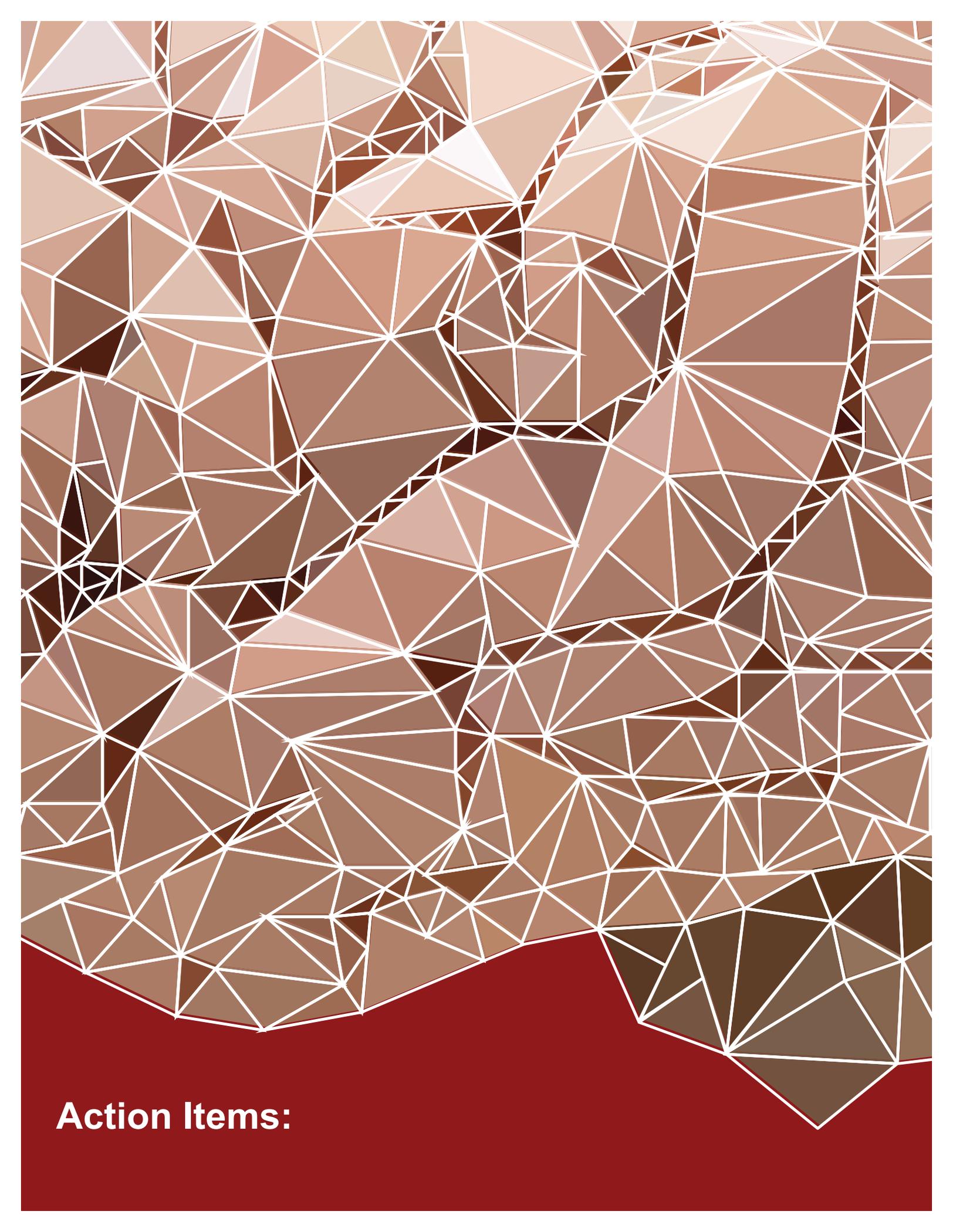
Persons with neurobehavioral issues may require supports beyond what is offered through case management and clubhouse programs, especially as they transition to the home from residential treatment. Likewise, their caregivers may need respite and in-home assistance services. As indicated in the literature, 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 an 1915c Home and Community-Based Services–Brain Injury waiver, which offer preventative care for persons with brain injury who are *at risk* for crisis and assures 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:

- 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.



**Action Items:**

## Action Items:

The following action steps are advised in order to meet the needs of persons in the Commonwealth of Virginia with neurobehavioral needs.

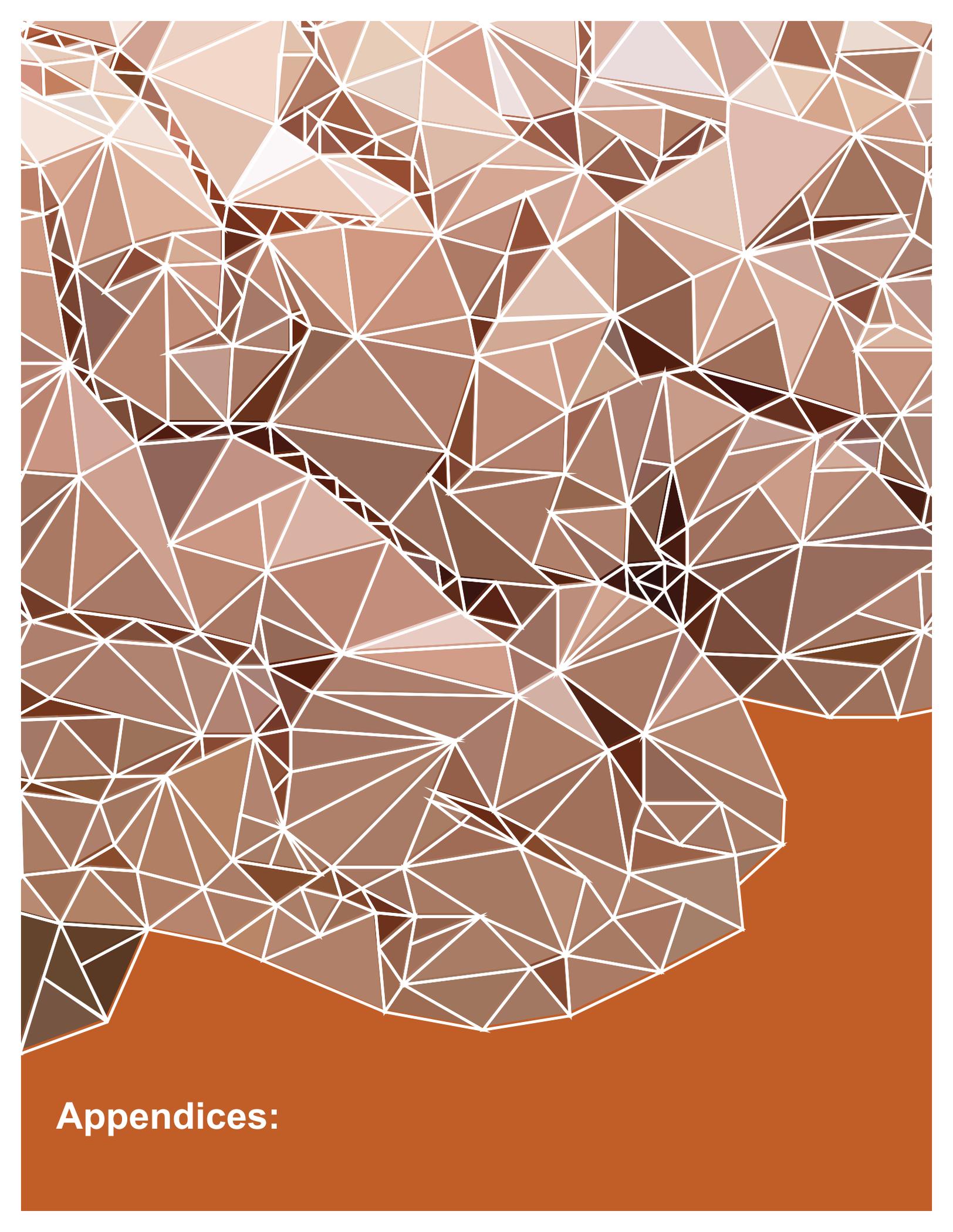
1. Prioritize a Medicaid waiver that would provide residential and community-based habilitation for persons with neurobehavioral issues.
2. Pilot 5-8 beds in a public adult acute psychiatric facility in order to meet the needs of persons with severe neurobehavioral issues (i.e., unsafe to self or others).
3. Create a multiagency initiative (DARS and DBHDS) similar to REACH that creates efficiencies (e.g., cost effectiveness), networks agencies, and empowers providers to optimize care for persons with neurobehavioral issues.

To affect a systems change, no one action or priority item will accomplish that goal. The Commonwealth is advised to work at multiple levels of scale, recognizing that the overall success of change is interdependent across steps.

Appropriately serving individuals like Drew, Stuart, Kendra, and Emily 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.

- With prevention, education, and screening/identification, Drew would have access to appropriate screening for his brain injury and attention to his neurobehavioral presentation by professionals across agencies and fields (e.g., medical, rehabilitative, mental health).
- With crisis stabilization in an adult care inpatient psychiatric hospital, Stuart and his family might circumvent the revolving door of ER visits – especially when he is at greatest risk of harming self or others.
- With structured, long-term residential care, Kendra would receive integrated supports well beyond those offered in a skilled nursing facility – and because she is able to remain in state, her family can remain vested locally in her care.
- With community-based supports, Emily might recover a sense of purpose, discovering compensatory strategies through therapies and applied behavioral analysis. While her neurobehavioral issues present challenges from time to time, Emily's family is versed in ways to provide support.

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.**



**Appendices:**

## Appendices:

### Appendix A: References [Bibliography]

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## Waivers and Other Medicaid Funding Mechanisms

Section 1115 authorizes *research and demonstration* waivers that enable states to utilize federal funding in order to investigate and test novel service delivery, coverage, and reimbursement approaches at various levels of scale and breadth of scope (Schneider, 1997). Generally, a 1115 waiver addresses service needs that cannot be met with an existing 1915 waiver or a Medicaid State Plan Amendment (SPA). Section 1915(b) *managed care* waivers permit states to provide Medicaid services through managed care programs. Section 1915(c) HCBS waivers, most commonly used for brain injury, allow states to help individuals avoid institutionalization through the provision of services offered in the home and/or community.

States must submit an application requesting approval from the Centers for Medicare and Medicaid Services (CMS) to fund services via any waiver type. Among other components, the application must include a demonstration that the waiver will be *cost neutral*; a legislative mandate aimed at making HCBS waivers part of the solution for managing rising Medicaid costs. Cost neutrality is measured in one of two ways:

1. The average per-person cost of HCBS waiver benefits will not exceed the average per-person cost of institutional (e.g., hospital or nursing facility) or other standard Medicaid plan benefits to others with similar care needs.
2. The overall spending via an HCBS waiver will not exceed the total projected spending of institutional care or other standard Medicaid plan benefits for individuals with similar care needs.

Also motivated by the goal of cost-containment, states may make HCBS waiver benefits available only to individuals who are at risk of institutionalization (JLARC, 2007).

Created by the 2005 Deficit Reduction Act (DRA) and reformed under the Patient Protection and Affordable Care Act (ACA) of 2010, the 1915(i) state plan amendment option parallels 1915(c) with several exceptions, outlined in the *Exceptions to the Parallelism between 1915(i) and 1915(c)* table.

### *Exceptions to the Parallelism between 1915(i) and 1915(c)*

Characteristic	Medicaid Waivers	1915(i) State Plan Amendment
Must demonstrate cost neutrality to federal government	Yes	No
Individual must require institutional-level of care to be eligible for HCBS	Yes	No
State may set a cap on the number of individuals enrolled or create waiting lists for an eligible population	Yes	No
States may limit eligibility based on geographic area	Yes	No
State may offer services and supports before an individual needs institutional level-care	No	Yes
Enables states to offer services to individuals with mental health and substance abuse disorders	No	Yes

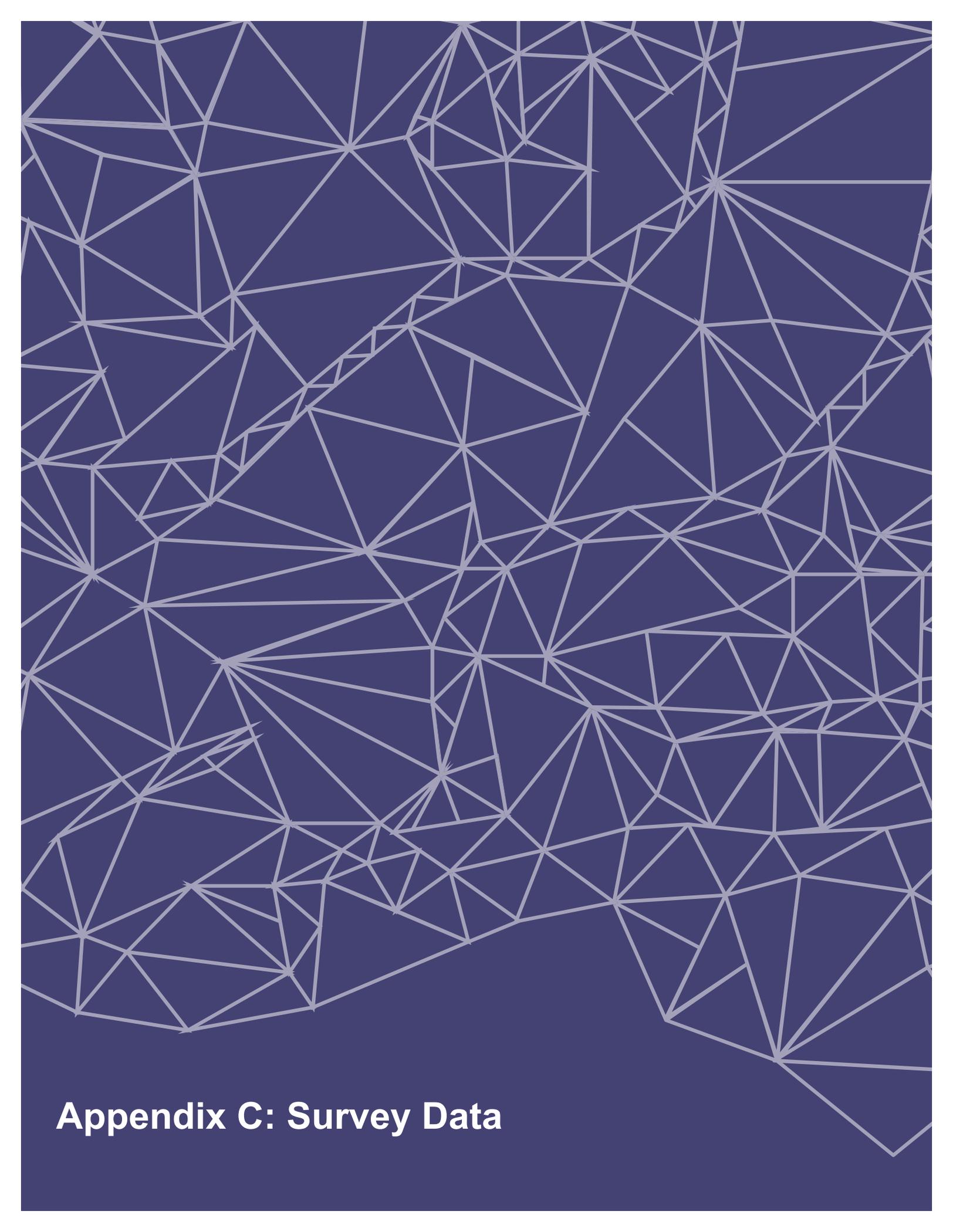
*Note.* Table is based on information provided by the Corporation for Supportive Housing (2010).

## Appendix B: Waiver Explanation *Continued*

Additionally, Section 1915(i) provides a mechanism for states to draw down federal funds in order to offer HCBS as part of their Medicaid plan; whereas, previously states could only receive federal matching dollars for HCBS via a Medicaid waiver. Ultimately, Section 1915(i) state plan amendments provide a robust mechanism for states to serve their residents with disabilities in a manner that complies with the Americans with Disabilities Act and the *Olmstead* decision regarding its implementation (Corporation for Supportive Housing, 2010).

On January 14, 2014, the Centers for Medicare and Medicaid Services (CMS) issued a final rule designed “to enhance quality in HCBS programs and to add protections for individuals receiving services” (NASHIA, 2014b, p. 3). The final rule makes certain that persons receiving services under 1915(c), 1915(i), and 1915(k) waivers are self-directed (i.e., person-centered planning) and offered the fullest range of supports in accord with their goals and preferences. Further, the rule specifies heightened compliance for HCBS settings.

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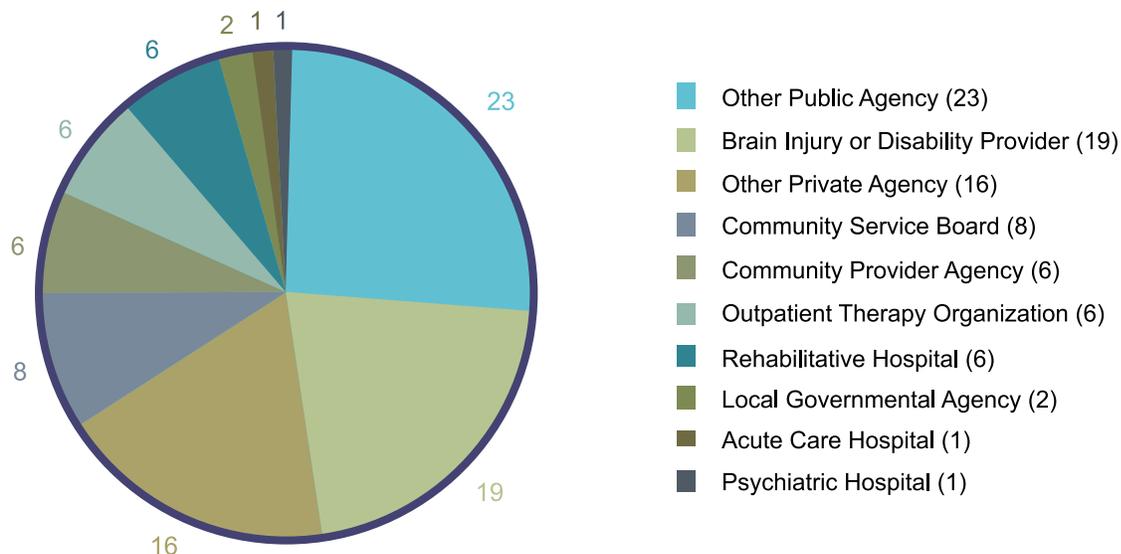
## **Appendix C: Survey Data**

# Appendix C: Survey Data

## Survey Data

Eighty-four representatives from a variety of public and private agencies and organizations in Virginia participated in our survey of current neurobehavioral services and needs. This constituted a 44% response rate. Please note, however, that response rates for individual questions vary. Because few questions were *forced*, or mandatory, some participants chose not to answer every question. The number of respondents for each particular question is written (n=x) where “x” is the number of respondents for that particular question. Percentages are also reported by the number of *individual question* respondents.

*Note:* The quantitative survey was condensed into 9 Questions for this Appendix. This was done for clarity.



**Question 1:** Which agency or organization types best defines yours? Check all that apply. (n=77).

*Note.* Other Public Agencies include: Health Departments, State Vocational Rehabilitation Centers, Centers for Independent Living, Virginia Department for Aging and Rehabilitative Services (DARS), Grant Funded Case Management Departments, Public Health Departments, Residential Programs, State Governmental Agencies, State Hospital, Substance Abuse Treatment Centers, and Transitional and Long Term Care Organizations. Other Private Agencies include: Centers for Independent Living, Employment Services Organizations, Private Practices, Advocacy Organizations, Brain Injury Medicine Clinics, Cognitive Training Centers, In-Patient Residential Brain Injury Programs, and Training Facilities.

**Question 2:** Does your organization provide services state-wide (i.e., across all counties and municipalities?) (n=76) *If no is selected, Please check up to the top 5 service areas that your agency or organization serves.*

**Yes: 31;** Thirty-one of the 76 question respondents provide services state-wide. Thirty-one is 41% of 76.

**No: 45;** Forty-five of the 76 question respondents do not provide services state-wide. Forty-five is 59% of 76.

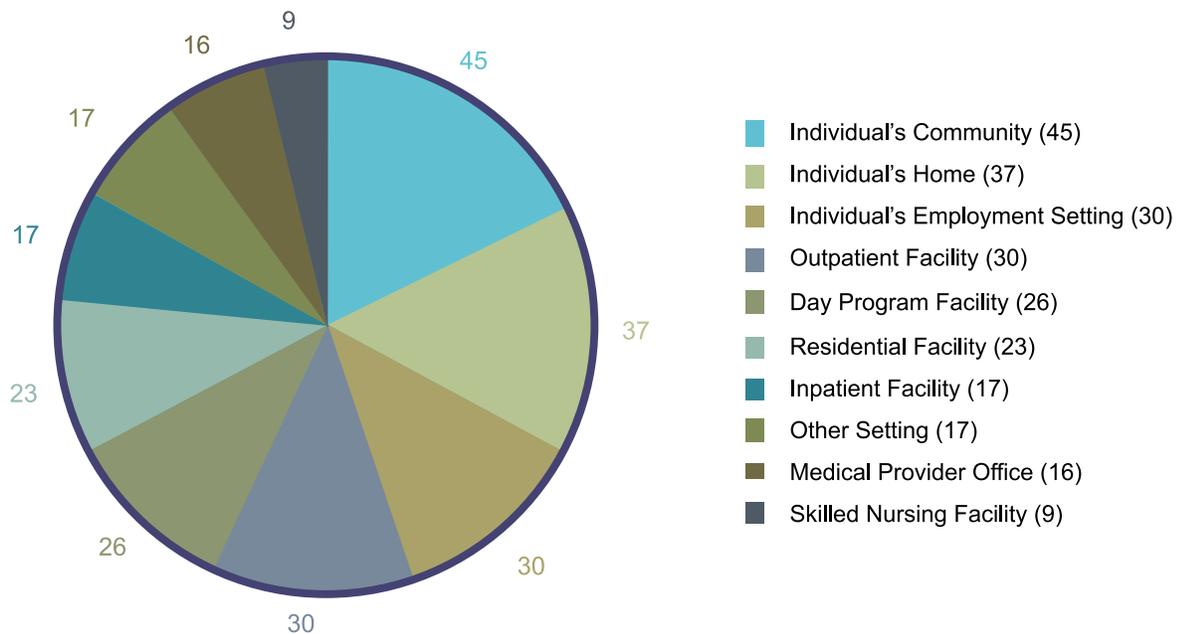
The 45 respondents who *do not* provide state-wide services selected their top five most-served localities in Virginia. Out of the 80 municipalities, Augusta (n=7) the City of Staunton (n=7), Montgomery (n=6), the City of Richmond (n=6) and the City of Waynesboro (n=6) are the most served.

## Appendix C: Survey Data *Continued*

Municipalities in Virginia in which *no services* were provided by the 45 locality-specific agencies: Alleghany, Amelia, Bath, Bedford (city), Bland, Botetourt, Bristol (city), Brunswick, Buchanan, Buena Vista (city), Carroll, Charles City, Charlotte, Colonial Heights (city), Covington (city), Craig, Cumberland, Dickenson, Dinwiddie, Emporia (city), Franklin (city), Galax (city), Grayson, Greene, Greensville, Halifax, Hopewell (city), Isle of Wight, James City, Lee, Lexington (city), Lunenburg, Mathews, Mecklenberg, Middlesex, Nelson, New Kent, Northumberland, Nottoway, Pittsylvania, Poquoson (city), Powhatan, Prince Edward, Prince George, Russell, Scott, Smyth, Southampton, Surry, Sussex, Tazewell, Westmoreland, Williamsburg (city), York.

### Question 3: Where does your agency or organization provide services? Check all that apply. (n=75)

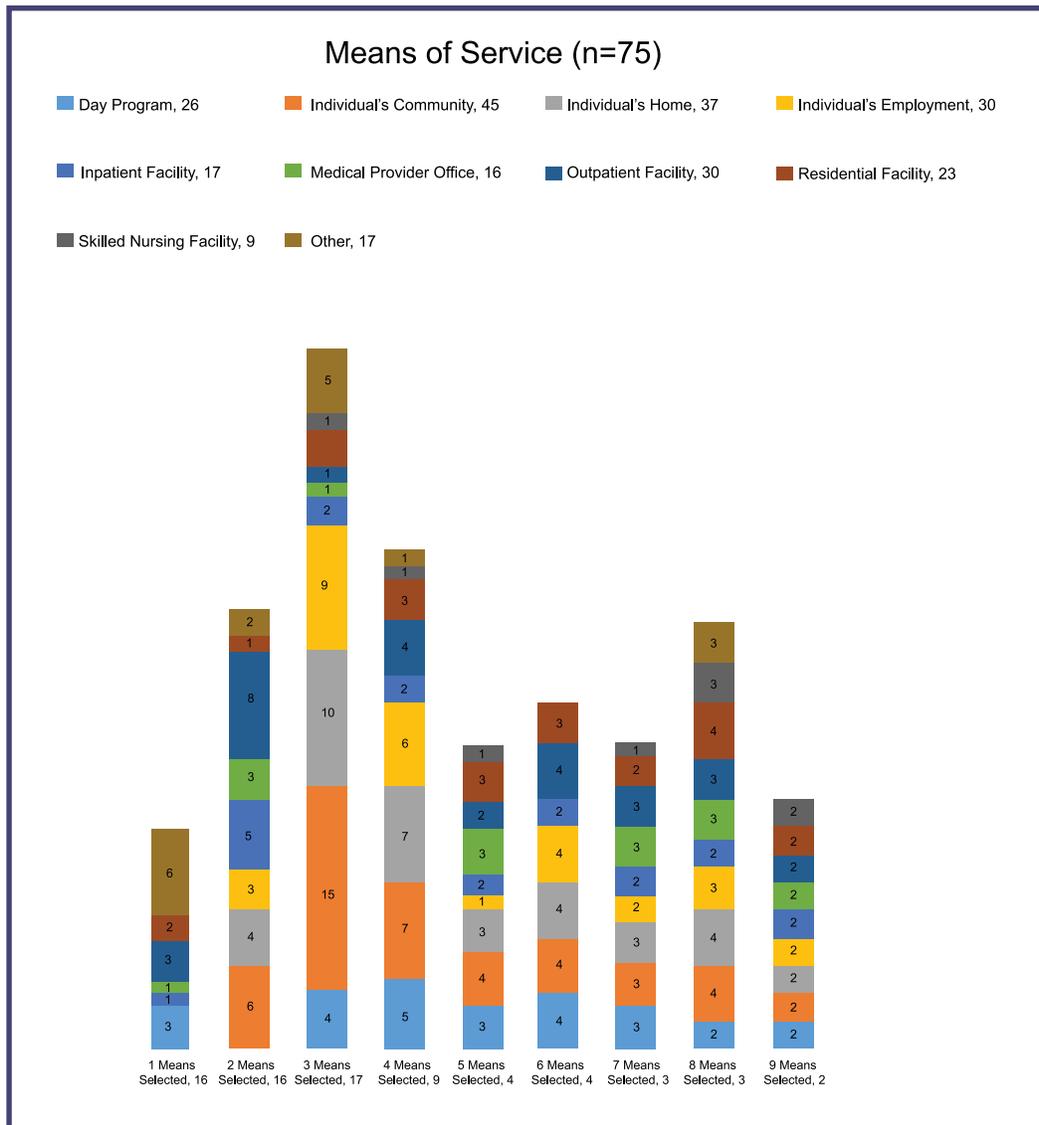
Forty-five representatives indicate that their agency and organization provides services in an individual's community; 37 indicate that they provide services in the individual's home; 30 indicate that they provide services in an employment setting and/or outpatient facility; 26 indicate services are provided in a day program facility; followed by residential facility (23), inpatient facility and/or other setting (17), medical office (16), and skilled nursing facility (9).



### Question 3: Means of Services, *Continued* (n=75)

Forty-five (60%) of the 75 question respondents provide services in an individual's community. Interestingly, no agency representative selected the individual's community as the sole means of service. Seventeen of the 75 question respondents selected 3 means of service while 2 selected all. Given the inclusive nature of the question, services may also be provided through other means. Seventeen of the 75 question respondents stated that they provide services by other means: the represented agency or organization's office, departments of social services, field offices, production facilities, group meetings, the library, Marine Corps Command offices, health departments, camps, facilities and settings that request education, and assisted living facilities.

# Appendix C: Survey Data Continued



Note. Organizations and agencies were able to select all means or settings in which they provide services.

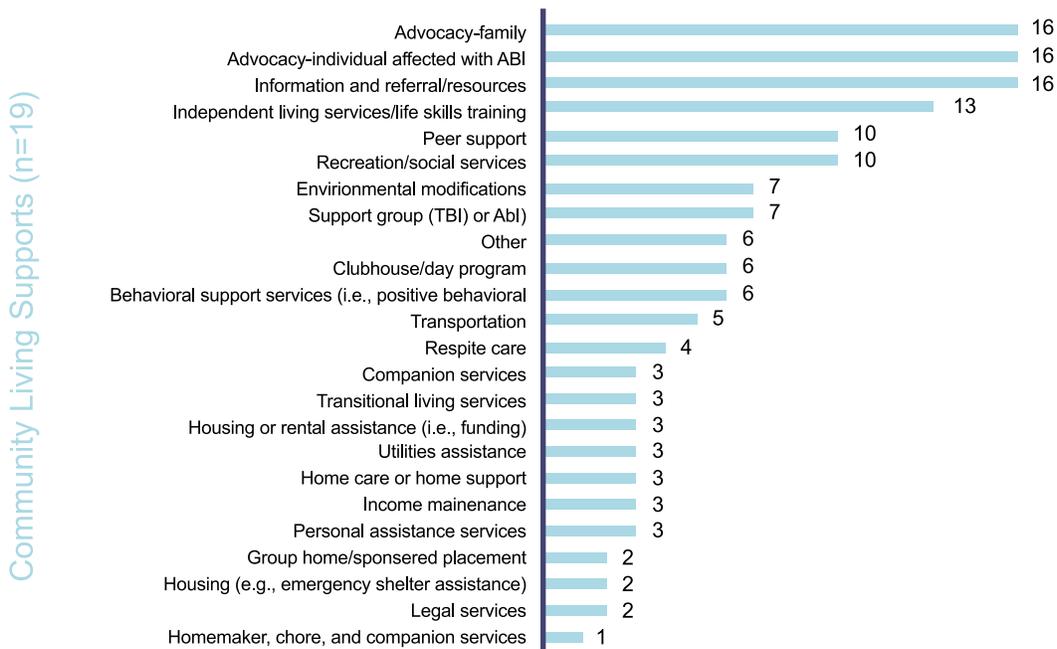
**Question 4:** Select the category that *best reflects* your agency or organization's core services. (n=50).

Core Services	Response	%
Community living supports: (e.g., clubhouse, life skills training, peer supports, etc.)	19	38%
Medical and/or therapeutic services: (e.g., medical case management, OT/PT/SLP, mental health, etc.)	13	26%
Education or employment services: (e.g., job accommodation, supported employment, etc.)	9	18%
Rehabilitative services: (e.g., acute and post-acute, OT/PT/SLP-rehab, cognitive, etc.)	9	18%
<b>Total</b>	<b>50</b>	<b>100%</b>

## Appendix C: Survey Data Continued

### Community Living Supports (n=19)

Nineteen of 50 respondents reported that their organization's core services are community living supports (information and referral, advocacy, independent living services, etc.) Agency representatives were only allowed to select one set of core services, so the response number is low (n=19) because we included a skip logic function (i.e.: respondents who did not select Community Living Supports as their core service were not asked the specific type of community living support services provided by their organization).



*Note.* Other: prevocational/vocational; employment services; waiver service facilitation, DD Waiver Case management, recreation and social; case management; family-like living in residential program.

*Question 4 Community Living Supports: Of the Community Living Supports that you just checked, what percentage would you estimate address neurobehavioral needs for persons with ABI? (n=18)*

Minimum % of Neurobehavioral Needs for Persons with ABI	Maximum of Neurobehavioral Needs for Persons with ABI	Average of Neurobehavioral Needs for Persons with ABI	Mode	Median
2%	80%	35.11%	80%	22%

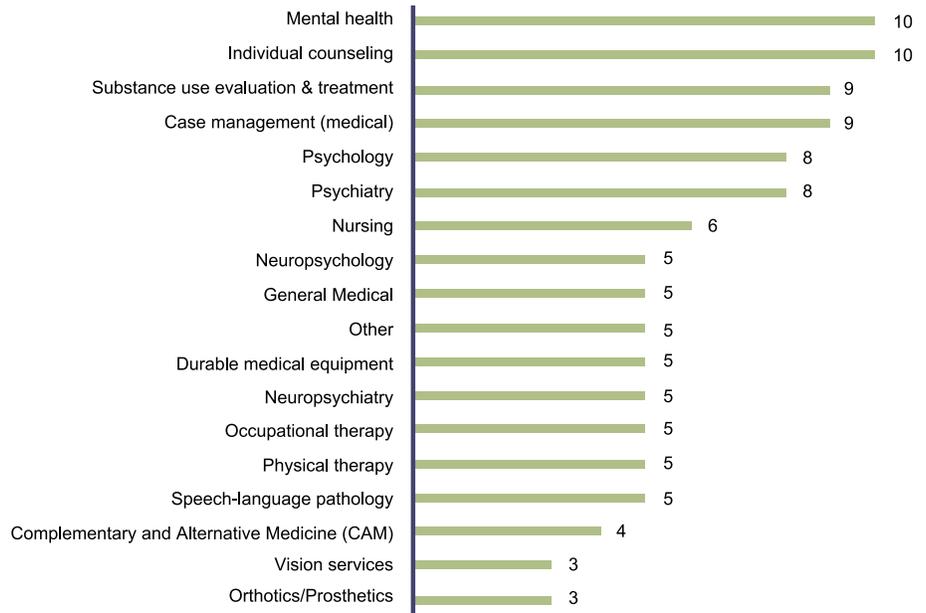
*Note.* One organization representative that selected Community Living Support Services did not estimate the percentage of support services provided that address the neurobehavioral needs for persons with ABI.

### Medical and/or Therapeutic Services (n=13)

Thirteen of the 50 respondents of the Core Services question reported that their organization's core services are medical and therapeutic services (individual counseling, mental health services, case management, etc.) Agency representatives were only allowed to select one set of core services, so the response number is low (n=13) because we included a skip logic function (i.e.: respondents who did not select medical and therapeutic services as their core service were not asked the specific type of medical and therapeutic services provided by their organization).

# Appendix C: Survey Data Continued

## Medical and/or Therapeutic Services (n=13)



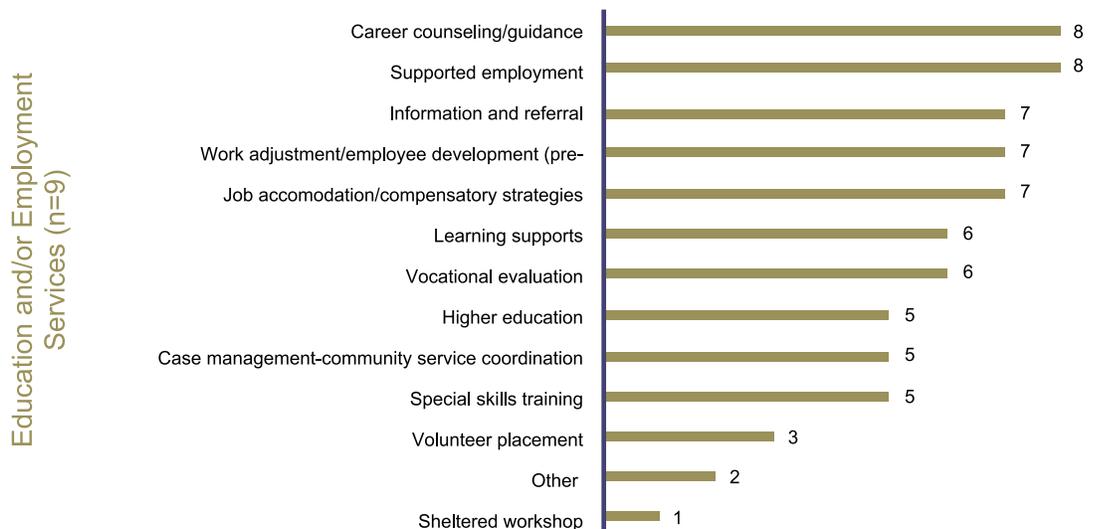
*Note.* Other: Case management services for SMI (serious mental illness) and SA (substance abuse); mental health skill building; crisis intervention and crisis stabilization, CIT, medication management, emergency services, peer support services, residential services; prenatal care, STD, immunization, consultation for difficult diagnoses and resource identification; limited, immunizations and screening for care; acute Inpatient Rehab Services; dietary and TR.

*Question 4 Medical and/or Therapeutic Services: Of the Medical and/or Therapeutic Services that you just checked, what percentage would you estimate address neurobehavioral needs for persons with ABI? (n=13)*

Minimum % of Neurobehavioral Needs for Persons with ABI	Maximum of Neurobehavioral Needs for Persons with ABI	Average of Neurobehavioral Needs for Persons with ABI	Mode	Median
1%	100%	30.08%	10%	10%

## Education or Employment (n=9)

Nine of 50 respondents reported that their organization's core services are education or employment services (supported employment, career counseling/guidance, job accommodation/compensatory strategies, etc.) Agency representatives were only allowed to select one set of core services, so the response number is low (n=9) because we included a skip logic function (i.e.: respondents who did not select education or employment services as their core service were not asked the specific type of education or employment services provided by their organization).



*Note.* Other: Medicaid waiver prevocational; Educational and clinical neuropsychological assessments.

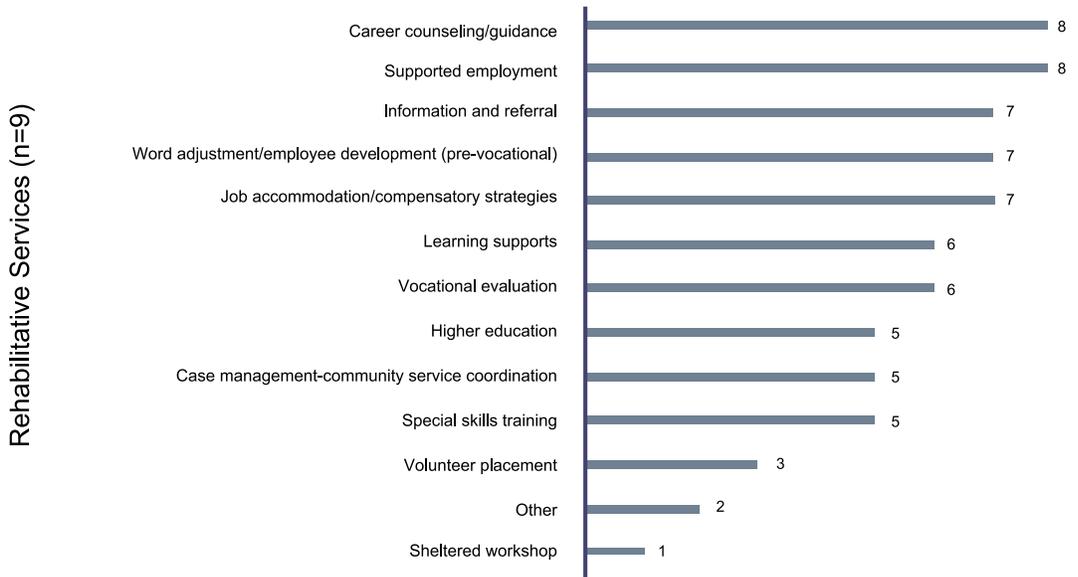
# Appendix C: Survey Data Continued

*Question 4 Education or Employment: Of the Education and/or Employment services that you just checked, what percentage would you estimate address neurobehavioral needs for persons with ABI? (n=9)*

Minimum % of Neurobehavioral Needs for Persons with ABI	Maximum of Neurobehavioral Needs for Persons with ABI	Average of Neurobehavioral Needs for Persons with ABI	Mode	Median
2%	61%	29.33%	n/a	25%

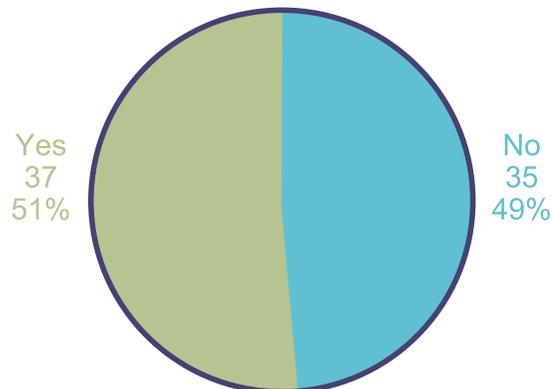
## Rehabilitative Services (n=9)

Nine of 50 respondents reported that their organization’s core services are rehabilitative services (family education, training, counseling; cognitive rehabilitative therapy, inpatient rehabilitation, etc.) Agency representatives were only allowed to select one set of core services, so the response number is low (n=13) because we included a skip logic function (i.e.: respondents who did not select rehabilitative services as their core service were not asked the specific type of rehabilitative services provided by their organization).



*Question 4 Rehabilitative Services: Of the Rehabilitative Services that you just checked, what percentage would you estimate address neurobehavioral needs for persons with ABI? (n=9)*

Minimum % of Neurobehavioral Needs for Persons with ABI	Maximum of Neurobehavioral Needs for Persons with ABI	Average of Neurobehavioral Needs for Persons with ABI	Mode	Median
9%	90%	59.22%	65%   70%	85%



## Appendix C: Survey Data Continued

**Question 5:** Does your organization offer programs or services that are **specific** to individuals with neurobehavioral needs? (n=72).

**Question 6:** How are referrals for acquired brain injury (ABI) services received by your organization? List your top three sources of referrals (e.g., physician, caregiver, etc.) (n=71)

Seventy-one participants provided at least one of the top three referral sources of acquired brain injury services; roughly 50 unique referral sources were listed. The most frequently listed are:

Physicians (n=45)	Self and/or Family Referral (listed together as one referral source) (n=6)
Caregivers (Non-Emergency) (n=14)	Department for Aging and Rehabilitative Services (DARS) (n=12)
Self-Referral (n=13)	Community agencies, partners, or providers (non-CSB) and case managers (n=6)
Family Referral (n=13)	

*Note:* Fewer than six agency or organization representatives listed any other referral source in their top three.

**Question 7:** Please identify specific eligibility requirements that **individuals with neurobehavioral needs** must meet to receive services from your organization. Within each category, **check all that apply.** (n=68)

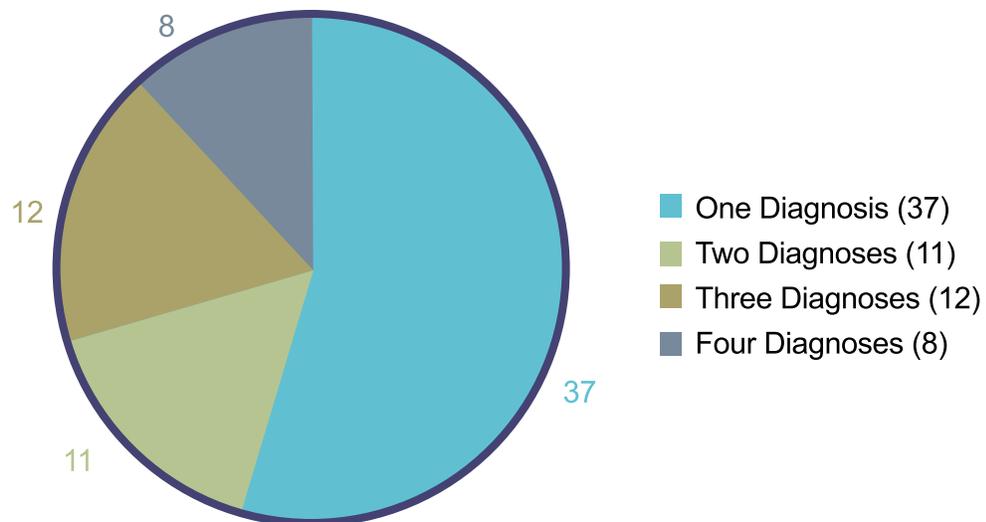
Eligibility Requirement Category	Options (Check All That Apply)	Frequency of Responses (n=68)	"Other" (most frequent responses)
Diagnoses	Acquired Brain Injury (ABI)	50 (74%)	Documental intellectual (ID/DD) developmental, physical, or learning disability; barriers to employment: medical, mental health, domestic violence, learning needs, housing and family needs, etc.; traumatic brain injury; behavioral diagnoses; spinal cord injury, arthritis, ms, cp, lupus; or learning disabilities, ADD, OCD, ODD, ED; or cerebral palsy, CVA, congenital brain injury
	Mental Illness (MI)	26 (38%)	
	Substance Abuse (SA)	22 (32%)	
	Fill-in-the-Blank (Other)	30 (44%)	
	No Specific Diagnoses Requirements	3 (4%)	
Eligibility Requirement Category	Options (Check All That Apply)	Number of Responses (n=68)	"Other" (most frequent responses)
Funding	Medicaid Eligibility	29 (43%)	Department of Aging and Rehabilitative Services (sponsorship); negotiated; sliding fee schedule; state general funds; grants.
	Private Insurance Coverage	29 (43%)	
	Private Funding (Cash Only-No Insurances Billed)	29 (43%)	
	Medicare/Medicaid Coverage	27 (40%)	
	Fill-in-the-Blank (Other)	26 (38%)	
	No Payment Information Considered	24 (35%)	

## Appendix C: Survey Data Continued

Eligibility Requirement Category	Options (Check All That Apply)	Number of Responses (n=67)	"Other" (most frequent responses)
Demographic Criteria	Age Limitations	33 (49%)	Disability status; legal status; county resident status; must have a child in the home; must have significant disability, want to work, & live/work/or go to school in VA; all demographics; wide range of demographics
	Homelessness	11 (16%)	
	Veteran Status	11 (16%)	
	Fill-in-the-Blank (Other)	7 (10%)	
	Does Not Apply	29 (43%)	

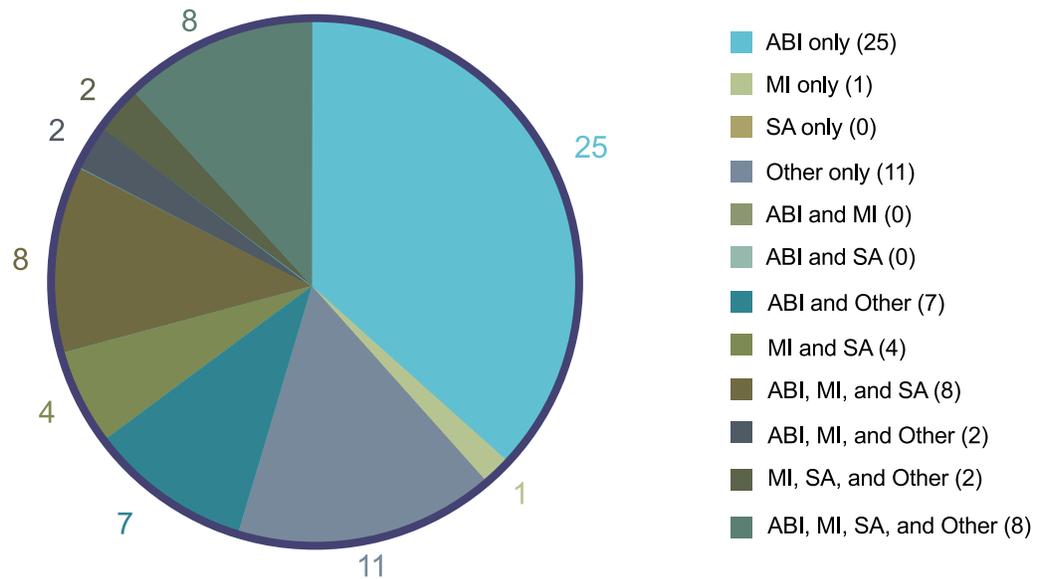
*Note.* The *check all that apply* feature of this question could lead to a misinterpretation of the data. For example, a survey respondent may select four diagnoses as specific eligibility requirements that an individual with neurobehavioral needs must meet before receiving services; this response is traditionally interpreted as *an individual with neurobehavioral needs must have all four diagnoses before receiving services*. However, the response may also be interpreted as *an individual with neurobehavioral needs must have any one of the four selected diagnoses before receiving services*. The following tables have been included to better explain the nature of the survey responses.

Number of Diagnoses as Service Eligibility Requirements Selected (n=68)



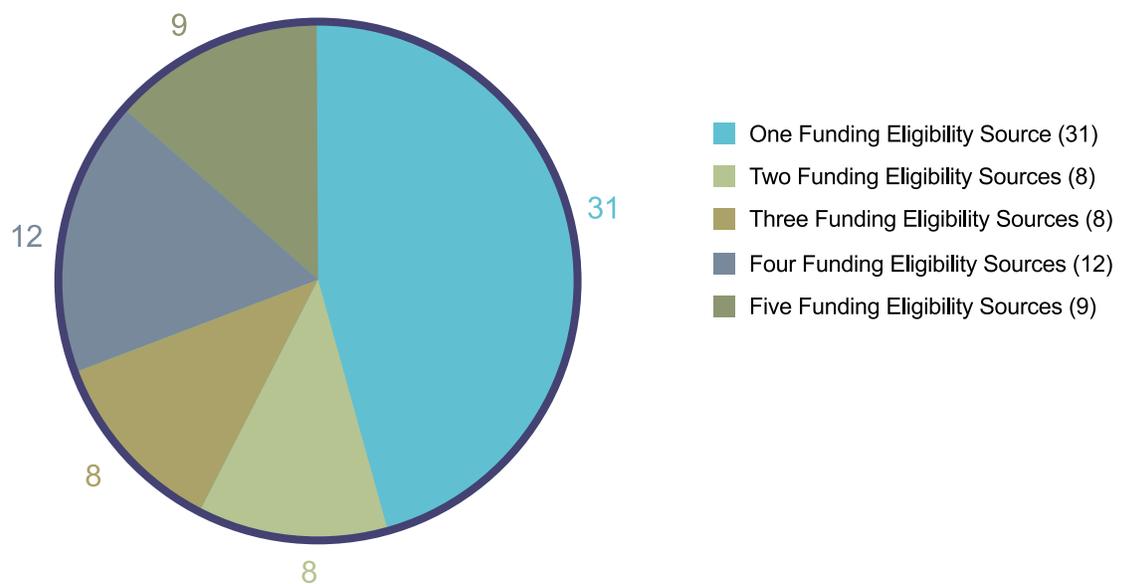
# Appendix C: Survey Data Continued

Diagnoses as Service Eligibility Combinations  
(n=68)



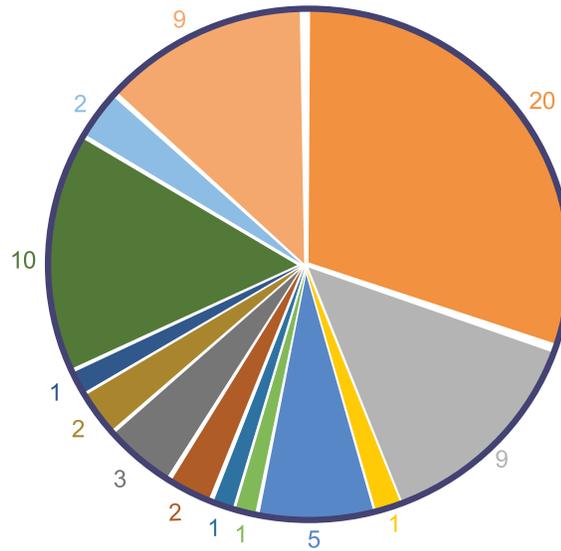
Note. ABI: Acquired Brain Injury; MI: Mental Illness; SA: Substance Abuse.

Number of Funding Eligibility Requirements Selected  
(n=68)



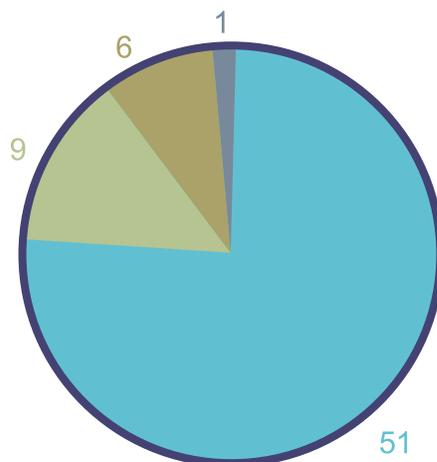
# Appendix C: Survey Data Continued

### Funding Eligibility Requirements Combinations (n=68)



- Only Medicaid Eligible (1)
- Only No Payment Information Considered (20)
- Only Other (9)
- Medicare/Medicaid Coverage and Other (1)
- Private Funding and Other (5)
- Medicaid Eligible and Private Insurance (1)
- Private Insurance and Private Funding (1)
- Private Insurance and Private Funding and Other (2)
- Medicaid Eligible, Medicare/Medicaid Coverage, Private Insurance Coverage (3)
- Medicaid Eligible, Medicare/Medicaid Coverage, and Other (2)
- Medicaid Eligible, Private Insurance, Private Coverage (1)
- Medicaid Eligible, Medicare/Medicaid Coverage, Private Insurance Coverage, Private Funding (10)
- Medicaid Eligible, Medicare/Medicaid Coverage, Private Insurance Coverage, Other (2)
- Medicaid Eligible, Medicare/Medicaid Coverage, Private Insurance Coverage, Private Funding, Other (9)

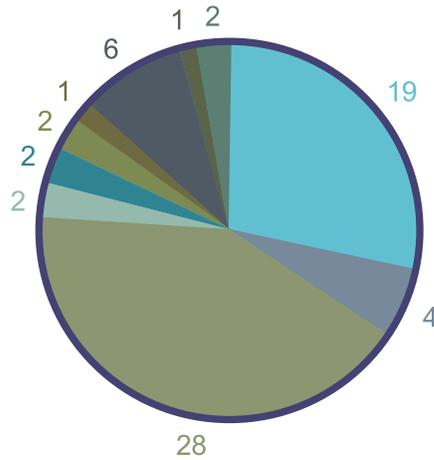
### Number of Demographic Criteria as Service Eligibility Requirements Selected (n=67)



- One Demographic Criterion (51)
- Two Demographic Criteria (9)
- Three Demographic Criteria (6)
- Four Demographic Criteria (1)

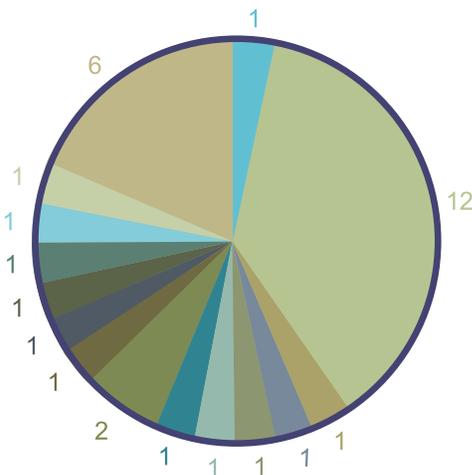
# Appendix C: Survey Data Continued

Demographic Criteria as Service Eligibility Requirements Combinations (n=67)



- Only Age Limitations (19)
- Only Vetern Status (0)
- Only Dues Not Apply (28)
- Age Limitations and Vetern Status (2)
- Age Limitations and Does Not Apply (1)
- Age Limitations, Homelessness, Vetern Status, and Other (1)
- Homelessness and Other (0)
- Vetern Status and Other (0)
- Only Homelessness (0)
- Only Other Status (4)
- Age Limitations and Homelessness (2)
- Age Limitations and Other (2)
- Age Limitations, Homelessness, and Vetern Status (6)
- Homelessness and Vetern Status (2)
- Homelessness and Does Not Apply (0)
- Vetern Status and Does Not Apply (0)

Age Limitations as Eligibility Requirements (n=33)



- 21 years or older (1)
- 18 years or older (12)
- 18 years or older (women) (1)
- 18 years (1)
- 18 years to 60 years (with incapacity/disabled and over 60) (1)
- 18 years to 65 years (1)
- 17 years or younger (eligible age for military commitment) (1)
- 15 years or older (adult size); 15 years or older (2)
- 6 years to 100 years (1)
- 5 years or older (1)
- 5 years to 105 years (1)
- 5 years to 95 years (1)
- 4 years to 90 years (1)
- 3 years or older (1)
- Other/Unspecified (6)

## Appendix C: Survey Data Continued

### Question 8: Please Estimate of the Number of Persons with Neurobehavioral Needs Served by Your Agency/Organization Annually (n=27).

Twenty-seven respondents provided a text response answer that estimated the number of annual neurobehavioral needs cases for which they provide service. Answers ranged from 4 to 1,200. Some respondents provided a range; others said that they could not estimate the number of cases.

Without the three respondents that said that they were unable to provide an estimate, the low average is: 158 cases. The high average is: 161 with the range from 7 to 1,200. The median number of cases for the low range is 45 and the median number of cases for the high range is 50.

### Question 9a: Rate the Degree to Which You Believe Each Item is a Service Gap or Need (Own Agency or Organization- All Providers) (n=36)

We asked participants to indicate on Likert scale (1=Strongly Disagree and 5=Strongly Agree) their perceived service needs and gaps in their own organization (Question 9a1-3) and in other organizations (Question 9b1-3). To understand more about agency service gaps and needs for individuals with neurobehavioral needs, we separated the data from respondents who stated that they provide services specifically to individuals with neurobehavioral needs (16 of the 36 question respondents are “neuro-specific providers”) from those who stated that they do not provide services specifically to individuals with neurobehavioral needs (20 of the 36 question respondents are “non-neuro providers”). Tables are provided for more information and clarification.

(SD=Strongly Disagree, D=Disagree, N=Neither Agree nor Disagree, A=Agree, SA=Strongly Agree)						
	1-SD	2-D	3-N	4-A	5-SA	Mean(M)
Applied Behavioral Analysis and Positive Behavioral Supports	1 (3%)	3 (8%)	9 (25%)	14 (39%)	9 (25%)	3.75
Cognitive Therapy	2 (6%)	4 (11%)	8 (22%)	16 (44%)	6 (17%)	3.56
Complementary and Alternative Medicine (CAM)	5 (14%)	1 (3%)	14 (39%)	12 (33%)	4 (11%)	3.25
Community-Based Services	4 (11%)	5 (14%)	2 (6%)	14 (39%)	11 (31%)	3.64
Funding Mechanisms	1 (3%)	0 (0%)	2 (6%)	14 (39%)	19 (53%)	4.38
Group Homes (Community Integrated)	3 (8%)	1 (3%)	8 (22%)	10 (28%)	14 (39%)	3.86
Individual Counseling	3 (8%)	8 (22%)	5 (14%)	11 (31%)	7 (19%)	3.36
Intensive Residential Treatment	2 (6%)	3 (8%)	8 (22%)	13 (36%)	13 (36%)	3.81
Interagency Collaboration	4 (11%)	6 (17%)	3 (8%)	12 (33%)	12 (33%)	3.58
Medical and Therapeutic Services	2 (6%)	6 (17%)	8 (22%)	14 (39%)	7 (19%)	3.42
Multidisciplinary Patient-Centered Approach	6 (17%)	5 (14%)	4 (11%)	12 (33%)	9 (25%)	3.36
Neuropsychological and Behavioral Management	3 (8%)	4 (11%)	5 (14%)	14 (39%)	10 (28%)	3.67
Pharmacological Interventions	2 (6%)	4 (11%)	11 (31%)	12 (33%)	7 (19%)	3.5
Skilled Nursing	3 (8%)	4 (11%)	13 (36%)	9 (25%)	7 (19%)	3.36
Supported Living Programs	1 (3%)	1 (3%)	4 (11%)	15 (42%)	15 (42%)	4.17

Note. Frequencies are reported with percentages in parentheses. All “missing data” cases were removed (i.e., all respondents in this data set responded to every item: “Applied behavioral analysis and positive behavioral supports,” etc.)

# Appendix C: Survey Data Continued

**Question 9a1:** Rate the Degree to Which You Believe Each Item is a Service Gap or Need (Own Agency or Organization- Neuro-Specific Providers) (n=16)

(SD=Strongly Disagree, D=Disagree, N=Neither Agree nor Disagree, A=Agree, SA=Strongly Agree)

	1-SD	2-D	3-N	4-A	5-SA	Mean(M)
Applied Behavioral Analysis and Positive Behavioral Supports	0 (0%)	2 (13%)	3 (19%)	6 (38%)	5 (31%)	3.86
Cognitive Therapy	1 (6%)	3 (19%)	2 (19%)	7 (44%)	3 (19%)	3.50
Complementary and Alternative Medicine (CAM)	2 (13%)	1 (6%)	4 (25%)	7 (44%)	2 (13%)	3.38
Community-Based Services	2 (13%)	2 (13%)	0 (0%)	6 (38%)	6 (38%)	3.75
Funding Mechanisms	1 (6%)	0 (0%)	0 (0%)	5 (31%)	10 (63%)	4.44
Group Homes (Community Integrated)	0 (0%)	1 (6%)	3 (19%)	4 (25%)	8 (50%)	4.19
Individual Counseling	0 (0%)	4 (25%)	1 (4%)	7 (44%)	4 (25%)	3.69
Intensive Residential Treatment	0 (0%)	2 (13%)	4 (25%)	4 (25%)	6 (38%)	3.88
Interagency Collaboration	2 (13%)	2 (13%)	0 (0%)	5 (31%)	7 (44%)	3.81
Medical and Therapeutic Services	1 (6%)	2 (13%)	2 (13%)	9 (56%)	2 (13%)	3.56
Multidisciplinary Patient-Centered Approach	3 (19%)	3 (19%)	2 (13%)	4 (25%)	4 (25%)	3.19
Neuropsychological and Behavioral Management	1 (6%)	4 (25%)	2 (13%)	7 (44%)	2 (13%)	3.31
Pharmacological Interventions	1 (6%)	3 (19%)	4 (25%)	7 (44%)	1 (6%)	3.25
Skilled Nursing	1 (6%)	9 (56%)	5 (31%)	4 (25%)	3 (19%)	3.31
Supported Living Programs	0 (0%)	1 (6%)	0 (0%)	8 (50%)	7 (44%)	4.31

Note. Frequencies are reported with percentages in parentheses. All "missing data" cases were removed (i.e., all respondents in this data set responded to every item: "Applied behavioral analysis and positive behavioral supports," etc.)

**Question 9a2:** Rate the Degree to Which You Believe Each Item is a Service Gap or Need (Own Agency or Organization- Non-Neuro Providers) (n=20)

(SD=Strongly Disagree, D=Disagree, N=Neither Agree nor Disagree, A=Agree, SA=Strongly Agree)

	1-SD	2-D	3-N	4-A	5-SA	Mean(M)
Applied Behavioral Analysis and Positive Behavioral Supports	1 (5%)	1 (5%)	6 (30%)	8 (40%)	4 (20%)	3.65
Cognitive Therapy	1 (5%)	1 (5%)	6 (30%)	9 (45%)	3 (15%)	3.60
Complementary and Alternative Medicine (CAM)	3 (15%)	0 (0%)	10 (50%)	5 (25%)	2 (10%)	3.15
Community-Based Services	2 (10%)	3 (15%)	2 (10%)	8 (40%)	5 (25%)	3.55
Funding Mechanisms	0 (0%)	0 (0%)	2 (10%)	9 (45%)	9 (45%)	4.35
Group Homes (Community Integrated)	3 (15%)	0 (0%)	5 (25%)	6 (30%)	6 (30%)	3.60
Individual Counseling	3 (15%)	4 (20%)	4 (20%)	6 (30%)	3 (15%)	3.10
Intensive Residential Treatment	2 (10%)	1 (5%)	4 (20%)	6 (30%)	7 (35%)	3.75
Interagency Collaboration	2 (10%)	4 (20%)	3 (15%)	6 (30%)	5 (25%)	3.40
Medical and Therapeutic Services	1 (5%)	4 (20%)	6 (30%)	4 (20%)	5 (25%)	3.40
Multidisciplinary Patient-Centered Approach	3 (15%)	2 (10%)	2 (10%)	8 (40%)	5 (25%)	3.50
Neuropsychological and Behavioral Management	2 (10%)	0 (0%)	3 (15%)	7 (35%)	8 (40%)	3.95
Pharmacological Interventions	1 (5%)	1 (5%)	7 (35%)	5 (25%)	6 (30%)	3.70
Skilled Nursing	2 (10%)	1 (5%)	8 (40%)	5 (25%)	4 (20%)	3.40
Supported Living Programs	1 (5%)	0 (0%)	4 (20%)	7 (35%)	8 (40%)	4.05

Note. Frequencies are reported with percentages in parentheses. All "missing data" cases were removed (i.e., all respondents in this data set responded to every item for both own organization and other organization services gaps and needs: "Applied behavioral analysis and positive behavioral supports," etc.)

# Appendix C: Survey Data Continued

## Question 9a: Rate the Degree to Which You Believe Each Item is a Service Gap or Need (Other Agency or Organization- All Providers) (n=36)

(SD=Strongly Disagree, D=Disagree, N=Neither Agree nor Disagree, A=Agree, SA=Strongly Agree)						
	1-SD	2-D	3-N	4-A	5-SA	Mean(M)
Applied Behavioral Analysis and Positive Behavioral Supports	1 (3%)	0 (0%)	5 (14%)	18 (50%)	12 (33%)	4.11
Cognitive Therapy	0 (0%)	2 (6%)	6 (17%)	17 (47%)	11 (31%)	4.03
Complementary and Alternative Medicine (CAM)	0 (0%)	2 (6%)	10 (28%)	17 (47%)	7 (19%)	3.81
Community-Based Services	0 (0%)	1 (3%)	2 (6%)	18 (50%)	15 (42%)	4.31
Funding Mechanisms	0 (0%)	0 (0%)	3 (8%)	9 (25%)	24 (67%)	4.53
Group Homes (Community Integrated)	0 (0%)	1 (3%)	7 (19%)	12 (33%)	16 (44%)	4.19
Individual Counseling	0 (0%)	4 (11%)	3 (8%)	21 (58%)	8 (22%)	3.92
Intensive Residential Treatment	1 (3%)	3 (8%)	5 (14%)	13 (36%)	14 (39%)	4.00
Interagency Collaboration	0 (0%)	2 (6%)	4 (11%)	17 (47%)	13 (36%)	4.14
Medical and Therapeutic Services	0 (0%)	2 (6%)	8 (22%)	17 (47%)	9 (25%)	3.92
Multidisciplinary Patient-Centered Approach	0 (0%)	6 (17%)	5 (14%)	11 (31%)	14 (39%)	3.92
Neuropsychological and Behavioral Management	0 (0%)	1 (3%)	6 (17%)	16 (44%)	13 (36%)	4.14
Pharmacological Interventions	0 (0%)	4 (11%)	8 (22%)	14 (39%)	10 (28%)	3.83
Skilled Nursing	0 (0%)	4 (11%)	10 (28%)	10 (28%)	12 (33%)	3.83
Supported Living Programs	0 (0%)	2 (6%)	2 (6%)	14 (39%)	18 (50%)	4.33

*Note.* Frequencies are reported with percentages in parentheses. All "missing data" cases were removed (i.e., all respondents in this data set responded to every item : "Applied behavioral analysis and positive behavioral supports," etc.)

## Question 9a1: Rate the Degree to Which You Believe Each Item is a Service Gap or Need (Other Agency or Organization- Neuro-Specific Providers) (n=16)

(SD=Strongly Disagree, D=Disagree, N=Neither Agree nor Disagree, A=Agree, SA=Strongly Agree)						
	1-SD	2-D	3-N	4-A	5-SA	Mean(M)
Applied Behavioral Analysis and Positive Behavioral Supports	1 (6%)	0 (0%)	1 (6%)	9 (56%)	5 (31%)	4.06
Cognitive Therapy	0 (0%)	1 (6%)	1 (6%)	9 (56%)	5 (31%)	4.13
Complementary and Alternative Medicine (CAM)	0 (0%)	1 (6%)	4 (25%)	7 (44%)	4 (25%)	3.86
Community-Based Services	0 (0%)	1 (6%)	0 (0%)	10 (63%)	5 (31%)	4.19
Funding Mechanisms	0 (0%)	0 (0%)	1 (6%)	4 (25%)	11 (69%)	4.63
Group Homes (Community Integrated)	0 (0%)	0 (0%)	2 (13%)	5 (31%)	9 (56%)	4.44
Individual Counseling	0 (0%)	1 (6%)	0 (0%)	12 (75%)	3 (19%)	4.06
Intensive Residential Treatment	0 (0%)	1 (6%)	3 (19%)	6 (38%)	6 (38%)	4.06
Interagency Collaboration	0 (0%)	2 (13%)	0 (0%)	8 (50%)	6 (38%)	4.13
Medical and Therapeutic Services	0 (0%)	1 (6%)	1 (6%)	10 (63%)	4 (25%)	4.06
Multidisciplinary Patient-Centered Approach	0 (0%)	3 (19%)	0 (0%)	6 (38%)	7 (44%)	4.06
Neuropsychological and Behavioral Management	0 (0%)	1 (6%)	0 (0%)	9 (56%)	8 (38%)	4.25
Pharmacological Interventions	0 (0%)	2 (13%)	1 (6%)	8 (50%)	5 (31%)	4.00
Skilled Nursing	0 (0%)	1 (6%)	4 (25%)	4 (25%)	7 (44%)	4.06
Supported Living Programs	0 (0%)	0 (0%)	1 (6%)	6 (38%)	9 (56%)	4.50

*Note.* Frequencies are reported with percentages in parentheses. All "missing data" cases were removed (i.e., all respondents in this data set responded to every item : "Applied behavioral analysis and positive behavioral supports," etc.)

# Appendix C: Survey Data Continued

**Question 9a2:** Rate the Degree to Which You Believe Each Item is a Service Gap or Need (Other Agency or Organization- Non-Neuro Providers) (n=20)

(SD=Strongly Disagree, D=Disagree, N=Neither Agree nor Disagree, A=Agree, SA=Strongly Agree)

	1-SD	2-D	3-N	4-A	5-SA	Mean(M)
Applied Behavioral Analysis and Positive Behavioral Supports	0 (0%)	0 (0%)	4 (20%)	9 (45%)	7 (35%)	4.15
Cognitive Therapy	0 (0%)	1 (5%)	5 (25%)	8 (40%)	6 (30%)	3.95
Complementary and Alternative Medicine (CAM)	0 (0%)	1 (5%)	6 (30%)	10 (50%)	3 (15%)	3.75
Community-Based Services	0 (0%)	0 (0%)	2 (10%)	8 (40%)	10 (50%)	4.40
Funding Mechanisms	0 (0%)	0 (0%)	2 (10%)	5 (25%)	13 (65%)	4.55
Group Homes (Community Integrated)	0 (0%)	1 (5%)	5 (25%)	7 (35%)	7 (35%)	4.00
Individual Counseling	0 (0%)	3 (15%)	3 (15%)	9 (45%)	5 (25%)	3.80
Intensive Residential Treatment	1 (5%)	2 (10%)	2 (10%)	7 (35%)	8 (40%)	3.95
Interagency Collaboration	0 (0%)	0 (0%)	4 (20%)	9 (45%)	7 (35%)	4.15
Medical and Therapeutic Services	0 (0%)	1 (5%)	7 (35%)	7 (35%)	5 (25%)	3.80
Multidisciplinary Patient-Centered Approach	0 (0%)	3 (15%)	5 (25%)	5 (25%)	7 (35%)	3.80
Neuropsychological and Behavioral Management	0 (0%)	0 (0%)	6 (30%)	7 (35%)	7 (35%)	4.05
Pharmacological Interventions	0 (0%)	2 (10%)	7 (35%)	6 (30%)	5 (25%)	3.70
Skilled Nursing	0 (0%)	3 (15%)	6 (30%)	6 (30%)	5 (25%)	3.65
Supported Living Programs	0 (0%)	2 (10%)	1 (5%)	8 (40%)	9 (45%)	4.20

*Note.* Frequencies are reported with percentages in parentheses. All "missing data" cases were removed (i.e., all respondents in this data set responded to every item : "Applied behavioral analysis and positive behavioral supports," etc.)



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