Neurobehavioral Treatment for Virginians with Brain Injury

A Virginia Brain Injury Council Position Paper
Written by the Ad Hoc Neurobehavioral Committee
In Response to the Commissioner of the
Virginia Department of Rehabilitative Services

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DRS
DEPARTMENT OF
REHABILITATIVE SERVICES

May 4, 2010

Mr. James A. Rothrock
Commissioner
Department of Rehabilitative Services
8004 Franklin Farms Drive
Richmond, VA 23229

Commissioner Rothrock:

The Virginia Brain Injury Council is pleased to submit the following position paper written by its Ad Hoc Neurobehavioral Committee. This position paper was written in response to your challenge to:

> "…develop a 'white paper' on neurobehavioral treatment options in Virginia as a basis for discussion/action between the commissioners of Department of Rehabilitative Services and the Department of Mental Health, Mental Retardation and Substance Abuse Services." (Virginia Brain Injury Council Minutes, 7/30/04).

The members of the Ad Hoc Neurobehavioral Committee were brain injury experts from around the State. Their names and affiliations are listed at the end of this document.

This effort is the result of a systematic, data-driven process that:

- Identifies the unmet neurobehavioral needs of Virginians with acquired brain injury;
- In collaboration with the Virginia Department of Behavioral Health and Developmental Services, and the Department of Medical Assistance Services, proposes the development of a 3-level system of care demonstration program to address the unmet needs; and
- Provides cost estimates for the implementation of this demonstration program.

Please note that this position paper was developed and authored in May of 2009 before the official name change went into effect for the "Department of Mental Health, Mental Retardation and Substance Abuse Services," now called the "Department of Behavioral Health and Developmental Services." Therefore, there are references to *both* official agency names based on when the timing of the referenced action occurred.

We are proud of this effort and hope that it serves as a strategic plan to address a significant unmet need that affects tens of thousands of Virginians. Thank you for your vision and leadership in making this charge to the Council. And thank you for your outstanding record of service to Virginians with disabilities.

Sincerely,

Carole Norton, Ph.D.
Chair, Virginia Brain Injury Council

Table of Contents

Executive Summary
Neurobehavioral Treatment for Virginians with Brain Injury
Position Paper, Virginia Brain Injury Council, 2008

- More than 250,000 Virginians 18 years and older are estimated to have brain injury related complications.
- There are only 20 neurobehavioral treatment beds available in Virginia; these are privately owned and not reimbursed by Medicaid or most private insurance.
- The behavioral and psychiatric complications of brain injury are woefully under addressed in the Commonwealth, with a significant unmet need for specialized assessment/treatment programs.
- Families are suffering as Virginians with brain injury are sent out of state for costly, extended stays to receive treatment for neurobehavioral complications.
- Problems range from a small percentage of severe, complicated cases that require intensive treatment, to those that can be addressed in community settings.
- Persons with brain injury related neurobehavioral problems in acute psychiatric hospitals, state mental health institutions, skilled nursing facilities, and adult and juvenile correctional systems often can be more effectively treated through community-integrated neurobehavioral programs and services.
- There is a clear need to expand the continuum of services for people with neurobehavioral problems to foster community re-integration.
- Education on evidence-based best practices for current and future providers of neurobehavioral treatment programs must occur across the continuum of care.
- The development of standards, oversight mechanisms, and treatment and outcome accountability are needed to address the neurobehavioral problems of persons with brain injury.
- The unmet behavioral needs of people with brain injury are directly related to mental health reform initiatives currently occurring in Virginia.
- Services occurring within facility-based setting are compromised without community based services to support persons with brain injury after discharge.
- The 2007 Joint Legislative Audit and Review Commission report, *Access to State Funded Brain Injury Services* concluded that:
  - Thousands of survivors suffer from behavioral issues as a result of their injuries;
  - Those with severe behavioral issues often receive treatment out of state, and many more are inappropriately placed in long term care or correctional facilities;
  - An increase in community-based services would reduce the number of survivors who reside in nursing homes and other long term care facilities;
  - Implementing a TBI specific waiver program could provide needed assistance for these individuals.

THE NEED FOR INTERAGENCY COLLABORATION:

- There is a clear and pressing need for a permanent interagency agreement among the Virginia Departments of Rehabilitative Services, Medical Assistance Services, Juvenile Justice, Corrections and Behavioral Health and Developmental Services to address brain injury in a statewide, systematic way.
- The Department of Behavioral Health and Developmental Services - in conjunction with the Departments of Rehabilitative Services and Medical Assistance Services - should review current licensing requirements for non-Medicaid residential facilities to ensure best practices and to develop new regulations across all levels of neurobehavioral care. This includes the use of objective acuity measures for behavioral risk factors to better identify using validated screening tools and increased access to appropriate services, is a priority that should begin in the Executive Branch at the Secretariat level.
- The Departments of Rehabilitative Services, Medical Assistance Services and Behavioral Health and Developmental Services should emphasize the expansion of community-based neurobehavioral treatment services for persons with brain injury as a central component of the Olmstead Community Integration discussions.
- The Department of Medical Assistance Services should aggressively pursue implementation of a Home and Community Based Brain Injury waiver.
- There should be modification of Medicaid policies to cover in-state neurobehavioral programs, including those not designated as skilled nursing programs.

MODELS OF SERVICE DELIVERY REQUIREMENTS:

- A comprehensive, holistic, neuropsychological/neuropsychiatric, system of care approach is the model system of best practices for neurobehavioral care.
- Supported living programs require greater availability, a greater neurobehavioral focus, and better coordination.
- Access to appropriate and necessary services should be a basic human right available to those persons with brain injury who lack coverage through the provisions of the Individuals with Disabilities Education Act, Medicaid, Medicare, private insurance, the Department of Defense or the Department of Veterans Affairs.
- There should be a focus on 3 elements of neurobehavioral care:
  - Residential neurobehavioral programs for people with intense behavioral and support needs;
  - Residential community-integrated neurobehavioral group homes for people with moderate to high needs;
  - Community-based supported living programs and services.
- Neurobehavioral treatment should be incorporated into Virginia's core brain injury services of community based case management, clubhouses/day programs and resource coordination, endorsed by the Virginia Brain Injury Council, the Virginia Alliance of Brain Injury Service Providers & the Brain Injury Association of Virginia.

DEFINITIONS OF LEVELS OF CARE / ESTIMATED COSTS (IN 2007 DOLLARS):

- Intensive residential treatment: *24 hour support and supervision, active neurobehavioral treatment and rehabilitation, and medication trials in a safe environment (excludes 1:1 Supervision):* **$470 per day**
- Community-integrated group homes: *24-hour supervision for those with moderate support needs and risk factors* **$370 per day**
- Supported living programs:
  - *24-hour on-site services* **$250 per day**
  - *Daily, but less than 24-hour supports* **$140 per day**
  - *Supports provided 2-3 times / week* **$ 55 per day**

FUNDING FOR A DEMONSTRATION PROJECT:

- There should be a 3-tiered model of neurobehavioral services and supports: intensive residential treatment, community-integrated group homes, and community based supported living programs and services.
- Some of these needs could be met through reallocation of state funds currently being spent on out of state and inappropriate in-state placements.
- The implementation of a brain injury waiver would enhance the system of care and draw down federal funds currently not available to Virginia.
- The Commonwealth Neurotrauma Initiative should consider developing a request for proposals with input from the Departments of Rehabilitative Services, Medical Assistance Services and Behavioral Health and Developmental Services, and the Virginia Brain Injury Council, the Virginia Alliance of Brain Injury Service Providers, and the Brain Injury Association of Virginia for a small neurobehavioral pilot project to generate outcome data that could serve to drive future neurobehavioral funding decisions.
- If the proposal is fully funded, funds should be distributed across the system of care. If not fully funded, it is recommended that guidance be provided by the Neurobehavioral Committee of the VBIC.
- 100 individuals could be served through a demonstration project; the numbers may be reflected as:
- Intensive residential treatment: *10 people X $470/day x 26 weeks* **$ 855,400**
- Community-integrated group homes: *20 people x $370/day x 365 days* **$2,701,000**
- Community-based supported living programs: *70 people* for 365 days **$4,423,800**
  - 24-hour on-site services:
    35 people x $250/day x 52 weeks=$3,193,750
  - Daily (less than 24-hour) support:
    17 people x $140/day x 52 weeks=$868,700
  - Weekly (2-3 times /week) supports:
    18 people x$55/day x 52 weeks=$361,350

TOTAL COST: $7,980,200

Introduction

This position paper is the response of the Virginia Brain Injury Council to the charge by James A. Rothrock, Commissioner of the Virginia Department of Rehabilitative Services to:

> "…develop a 'white paper' on neurobehavioral treatment options in Virginia as a basis for discussion/action between the commissioners of Department of Rehabilitative Services and the Department of Mental Health, Mental Retardation and Substance Abuse Services." (Virginia Brain Injury Council Minutes, 7/30/04).

This paper was written for the Virginia Brain Injury Council by its Ad Hoc Neurobehavioral Committee. It is a consensus statement based on a collaborative statewide effort to deal more effectively with the cognitive and behavioral problems of people with acquired brain injury. The Neurobehavioral Committee was composed of both members and non-members of the Virginia Brain Injury Council. Each committee participant has a documented expertise in the field. The names of all Committee members are listed at the end of this report. The Virginia Brain Injury Council then approved the final version of this response.

This effort builds upon several past efforts:

- Virginia State Senate Joint Resolution Number 158, 1998, requesting that the Department of Mental Health, Mental Retardation and Substance Abuse Services and Department of Rehabilitative Services "develop an action plan for the appropriate treatment of persons with brain injuries in the mental health system."

- Virginia State Senate Document Number 16, 1999, "Action Plan for the Appropriate Treatment of Persons with Brain Injuries in the Mental Health System" for people with brain injuries housed in State psychiatric hospitals with challenging behaviors. It concluded that, "This cohort is not appropriate for psychiatric hospitalization and would best be served by programs specifically designed to serve individuals with brain injury."

- The priorities identified by the Virginia Brain Injury Council in 2000 in response to the findings of Virginia's 1998-2000 federal Traumatic Brain Injury Act grant, which included short- and long-term neurobehavioral residential treatment options.

- Virginia Senate Document Number 15, 2007, by the Joint Legislative Audit and Review Commission to the Governor and the General Assembly, "Access to State-Funded Brain Injury Services in Virginia" which focused specifically on access to community based services for those with traumatic brain injury. It noted that:
  - There are thousands of people suffering from behavioral issues due to brain injury;
  - Those with severe behavioral issues often end up receiving treatment out of state;
  - Many more are inappropriately placed in long-term care or correctional facilities.
  - There is "virtually no system of care in the community for people with behavioral problems who do not have the financial resources to pay for private care" (page 83).
  - An increase in community-based services will reduce the number of people with brain injuries who reside in nursing homes and other long term care facilities.

- Expansion of community-based services can occur by waiving the Medicaid requirement that people with brain injuries live in long-term care facilities by expanding the existing Individual and Family Developmental Disabilities Support waiver program or by developing a specific traumatic brain injury Medicaid waiver program (page viii).
- And, the report stressed that those who should be first served are those "with the most severe functional disabilities" (page viii), including people with severe neurobehavioral problems who are "generally underserved" (page viii), who "may not be receiving the most appropriate care" (page 21), and who represent a "major unmet need" (page 84).

The Joint Legislative Audit and Review Commission utilized information from variety of sources to compile its report, including an earlier draft of the current position paper and interviews with several members of the Ad Hoc Neurobehavioral Committee.

The Executive Summary is a lay-oriented summary for the non-expert. It was approved by the Virginia Brain Injury Council in 2008 in advance of the position paper itself. The position paper is a professional consensus statement for best practices and cost estimates to address this important and unmet need.

Definition and Magnitude of the Problem

This position paper focuses on the unmet cognitive and behavioral treatment needs of people with acquired brain injury. Acquired brain injury is one of several classes of brain injury. Other classes include developmental brain injury such as cerebral palsy and trisomy 21 (Down's syndrome) and degenerative brain injury such as Alzheimer's disease and Parkinson's disease.

Acquired brain injury can be caused by a variety of factors. These include oxygen deficiency (anoxic/hypoxic brain injury) secondary to heart attack or near drowning; infectious diseases such as meningitis that causes inflammation of the layers that surround the brain; toxic chemicals such as lead; toxic metabolites such as those associated with liver and kidney failure; electrical shock; primary brain tumors such as meningiomas and glioblastomas; and secondary brain tumors that come from cancers elsewhere in the body. However, the main causes of acquired brain injury are stroke and trauma.

Traumatic brain injury is produced by forces or objects that injure the brain directly, rupture the arteries that supply the brain, and/or twist the long fiber pathways that project through the brain. Traumatic brain injury is a major cause of mortality killing more than 50,000 Americans annually (5) and accounting for 1/3 of all trauma-related deaths (1). At least 2% of the US population is living with the long-term complications of a traumatic brain injury (5). According to the July 2006 population estimates from the US Census Bureau, there are 7,642,884 people in Virginia. This translates into 152,858 people across all age groups and 116,721 Virginians over the age of 18 living with the complications of traumatic brain injury.

Stroke affects even more people. It is caused by an interruption of blood flow to the brain due to the occlusion of brain arteries (e.g., clots or fatty deposits) or to the rupture of brain arteries (e.g., prolonged hypertension). According to the Centers for Disease Control and Prevention, it is a leading cause of disability and kills over 150,000 Americans annually, making it the third leading cause of death behind heart disease and cancer. According to the Centers for Disease Control and Prevention, 2.7% of Virginians over the age of 18 are living with stroke. Based on 2006 population statistics, this translates into 157,573 Virginians, 90% of whom are living with a long-term disability (10, 11). This means that there are 141,816 Virginians over the age of 18 living

with a stroke-related disability, which is 21% greater than those living with the complications of a traumatic brain injury:

The Neurobehavioral Committee estimates that there are a total of 258,537 people 18 years and older living in Virginia with the complications of traumatic brain injury and stroke. This quarter million figure does not count those 18 years and older living with a traumatic brain injury who are served by the Department of Defense or the Department of Veterans Affairs; it does not count Virginians who fail to be diagnosed with mild traumatic brain injuries; and it does not count the many Virginians living with other forms of acquired brain injury such as anoxia, brain cancers, neurotoxins and infectious diseases. Acquired brain injury is a leading cause of disability in Virginia.

The most prevalent and disabling long-term consequences of acquired brain injury include cognitive and behavioral problems. These problems are called the neurobehavioral cluster. It includes problems with thinking, memory, attention, perception, language, impulse control, insight, mood, social behavior and substance abuse. Because of the widespread anatomical distribution of behavioral and arousal systems in the brain, varying degrees of cognitive and behavioral problems are produced by virtually all brain injuries, including mild traumatic brain injury. However, it is the persistent long-term cognitive and behavioral problems produced by more severe brain injuries that constitute the neurobehavioral focus of this position paper. Unfortunately, given their complexity, such problems are often undiagnosed or incorrectly diagnosed. This difficulty is compounded by numerous factors including pre-injury cognitive and emotional issues, lack of Medicaid support, discrepant insurance reimbursement policies, and ineffective behavioral assessments (8). There is also a lack of adequate supports for individuals in their home and community environments resulting in the loss of social and interpersonal relationships, the inability to participate in personally meaningful and productive activities (work, volunteer, etc.), and the lack of respite and support for caregivers. Despite the importance of this issue, the National Association of State Head Injury Administrators states that people with neurobehavioral problems are frequently “treated by professionals who have not been educated in brain injury and in settings not designed to address brain injury” (6).

A similar problem occurs with the other forms of acquired brain injury. For instance, while as many as 30% of people living with stroke suffer from depression, it is significantly under diagnosed and under treated (12). This means that upwards of 42,545 Virginians over the age of 18 may have stroke-related depression. Upwards of 31% of people with stroke also have persistent and disabling cognitive problems (13). This translates into 43,963 Virginians over the age of 18 living with stroke-related cognitive problems. As with traumatic brain injury, the risk of developing dementia over time is markedly increased after stroke (14). The Centers for Disease Control and Prevention further estimate that less than 1/3 of stroke survivors between the ages of 18 and 64 receive appropriate rehabilitative care following hospital discharge (11). Not surprisingly, the stroke medical literature---like the traumatic brain injury literature---is replete with statements such as: “relatively little work has been directed toward identifying and treating the common neuropsychiatric disorders occurring after stroke” (15). Difficulties in treating the behavioral and psychiatric problems of acquired brain injury are further compounded by what has been called a “mindless neurology and a brainless psychiatry” (16) whereby the neurologist sees these problems as psychiatric and the psychiatrist sees them as neurologic. Ultimately, people with neurobehavioral problems are at risk for treatment by specialists who lack sufficient expertise. Case studies presented below highlight this unmet need.

The Neurobehavioral Committee concludes that the neurobehavioral problems of acquired brain injury are woefully under addressed in Virginia and that there is a significant unmet need for specialized assessment and treatment programs. Similar conclusions were made in Virginia Senate Document No. 16, 1999, "Action Plan for the Appropriate Treatment of Persons with Brain Injuries in the Mental Health System" and by Virginia Senate Document No 15, 2007, "Access to State-Funded Brain Injury Services in Virginia" by the Joint Legislative and Audit Review Commission. Those who are least likely to receive adequate services include people without personal advocates (8), those who exhibit challenging behaviors without obvious physical problems (8), those who lack private insurance, and those who are supported by Medicaid.

Case Studies

Eric Fletcher **"…exhausted from an exhausted system"**

The Virginian-Pilot newspaper in Norfolk published the case of Mr. Eric Fletcher in its August 5, 2007 editions (available on the World Wide Web at PilotOnline.com http://hamptonroads.com/node/306091). This information is, therefore, part of the public record. Mr. Fletcher suffered a traumatic brain injury two years earlier and made an excellent physical recovery. Unfortunately, he has challenging neurobehavioral problems, tried to kill himself three times, and is a significant danger to others, including his spouse, Mrs. Kathleen Fletcher. The couple's life savings have been nearly exhausted due to the high cost of care. Without his spouse, Mr. Fletcher would be destined for a Medicaid-funded program out of State because of the lack of Medicaid-supported neurobehavioral programs in Virginia. Mrs. Fletcher is quoted as saying, "I'm exhausted from an exhausted system." She is also quoted as saying that at the time of the injury she was thankful that her husband survived but that now, "I don't know that he was lucky….I don't know." When people like Mr. Fletcher are a threat to self or others they are placed in acute facilities that are not specifically designed to treat their neurobehavioral problems. Since there is no system of neurobehavioral transitional care, the person is then typically discharged back to the home environment. A spouse who fears bodily harm from her loved one then faces two difficult choices: accept him back into the home and be assaulted yet again or place him in a shelter. It is clear that there is a significant unmet need for the neurobehavioral problems of acquired brain injury in Virginia.

Michael Leary **Families are being torn apart.**

Mr. Michael Leary's case was described in another Virginian-Pilot article on September 17, 2007 (available on the World Wide Web at PilotOnline.com http://hamptonroads.com/node/328611) and is also part of the public record. He suffered a traumatic brain injury more than 10 years ago and made an impressive physical recovery. Unfortunately, he has persistent and challenging behavioral problems and is a threat to himself and others, which caused him to be, among other things, incarcerated. His sister, Ms. Cathy Turpin, tried to find a neurobehavioral residential facility for him. Due to the lack of Medicaid-funded neurobehavioral programs in Virginia she eventually found a placement in another state. However, before this out-of-state placement, Virginia Department of Medical Assistance Services' policy required that he first be rejected by all

250 or so nursing homes in the State---none of which is a dedicated neurobehavioral treatment facility. Mr. Leary's case demonstrates two problems: 1) Families are suffering from the lack of Medicaid-supported neurobehavioral programs in Virginia; and 2) Increased Medicaid costs are associated with out-of-state placements due to the lack of in-state Medicaid-supported neurobehavioral programs.

Summary of Case Studies

These cases demonstrate that the unmet neurobehavioral needs of people with brain injury have significant financial and personal consequences, including the separation of families, the loss of life savings, higher Medicaid costs for out-of-state placements, and recurring placements in psychiatric, long-term care and prison facilities (5,8) that are not designed to meet their needs. The cost of neurobehavioral problems to the prison system is particularly instructive in this regard: It is estimated that as many as 87% of incarcerated people have sustained a brain injury (5). Based on the Virginia Department of Corrections fiscal year 2005 estimate of 29,706 people over the age of 25 who are incarcerated in state and local facilities, 25,844 adult prisoners have brain injuries. If it is assumed that just 5% of these prisoners have severe neurobehavioral problems that contributed to their crimes, and that the annual fiscal-year 2005 prisoner cost in Virginia is $21,248, then the cost to the Commonwealth simply due to placement in Department of Corrections' facilities for adults with severe neurobehavioral problems is at least $27,452,416 per year not counting management issues thereafter.

The Neurobehavioral Committee concludes that the severity of the unmet behavioral needs of people with acquired brain injury in general, as well as the unmet behavioral needs of a small percentage who are a threat to self and to others, should be directly related to the mental health reform effort currently occurring in the State. Better systems of care are needed to address this important and pressing problem so that those who are "exhausted from an exhausted system" can finally get the help they need.

The Neurobehavioral Committee also concludes that there is a clear and pressing need for a permanent interagency agreement between the Department of Rehabilitative Services and the Department of Behavioral Health and Developmental Services to address this neurobehavioral problem in a statewide, systematic way. A statewide systematic approach also requires the participation of the Department of Medical Assistance Services, the Department of Corrections, and the Department of Juvenile Justice. Given the current positive environment for interagency collaboration, this is an opportune time to forge these partnerships.

The Population of Focus

This position paper is focused on the post-acute neurobehavioral disorders of adults with acquired brain injury. Adults were selected since children from birth to age 21 are mandated to have state and public services by the federal Individuals with Disabilities Education Act (IDEA), and since Medicare provides coverage for older people with acquired brain injury. Also excluded from this position paper are adults receiving financial support from the Department of Defense or the Department of Veterans Affairs.

The Neurobehavioral Committee concludes that the population of greatest risk for under treatment is adults with post-acute neurobehavioral problems who otherwise lack coverage by the provisions of the Individuals with Disabilities Education Act, Medicare, the Department of Defense and the Department of Veterans Affairs.

While this paper is restricted to persons with acquired brain injury, it is recognized that behavioral and psychiatric problems are not unique to this form of brain injury, and also occur with neurodegenerative and developmental brain injuries. It is also recognized that there are overlapping needs across these disability groups, including Medicaid waivers and additional community-based services. In some states, adults with acquired brain injury are covered under age-related or developmental disability programs by way of Medicaid waivers. Medicaid waivers allow public money to fund treatment in institutional settings and can follow people from institutional settings into community-based settings.

While there are overlapping needs with other classes of brain injury, the Neurobehavioral Committee concludes that the focus of attention for this position paper should be acquired brain injury.

An effort was made to estimate the number of adults with brain injury related complications in Virginia. According to the 2006 population estimates of the US Census Bureau, there are 4,043,217 adults between the ages of 25 and 65 in Virginia. While at least 2% of the US population is living with the long-term consequences of a traumatic brain injury (5), pediatric and geriatric traumatic brain injury rates are higher than adult injury rates. The overall estimate of the number of adults between the ages of 25-65 who are living with a traumatic brain injury is consequently assumed to be less than 2% and arbitrarily assigned a conservative value of 1%. Based on this assumption, there are a minimum of 40,433 adults between the ages of 25 and 65 living in Virginia with the long-term complications of a traumatic brain injury who are not covered by the provisions of the Individuals with Disability Education Act or Medicare. Most of these people can be assumed to have cognitive and behavioral problems. This estimate does not count those living with other forms of acquired brain injuries, such as brain tumors, brain injury from poisoning or loss of oxygen, and surgical complications. It also does not count those with stroke. The final estimate of adult Virginians living with the complications of acquired brain injury is therefore assumed to be twice the traumatic brain injury value, or 80,000 people.

The Neurobehavioral Committee estimates that there are tens of thousands of adults living in Virginia with the neurobehavioral consequences of acquired brain injury who lack coverage under the provisions of the Individuals with Disabilities Education Act, Medicare, the Department of Defense or the Department of Veterans Affairs. Their problems range in severity from those that can be addressed in community settings all the way to the small percentage of cases that are highly involved and require very intensive care and treatment.

Previous Department of Rehabilitative Services Neurobehavioral Proposals

The need for dedicated neurobehavioral treatment programs and interagency collaboration between the Virginia Department of Rehabilitative Services and the Department of Behavioral Health and Developmental Services was recognized long before publication of the 2006 National Association of State Head Injury Administrators position paper on the topic (8). Unfortunately, these proposals were never funded and/or interagency collaborations were terminated.

In 1993, the Department of Rehabilitative Services proposed a neurobehavioral unit at Woodrow Wilson Rehabilitation Center using various best practices. The unit was one part of a larger more comprehensive proposal, which was in response to a request from the Commonwealth's 1992 Disability Commission. In addition to the neurobehavioral unit, a comprehensive array of services was proposed, including life skills and inpatient medical rehabilitation services. Of the $8 million requested, only $150 thousand was obtained. Consequently, it was determined that the neurobehavioral unit would not be funded. Instead, the limited allocation was used to expand community transitional services.

In 1998, the Department of Rehabilitative Services and the Department of Mental Health, Mental Retardation and Substance Abuse Services collectively proposed the establishment of a dedicated neurobehavioral unit at Western State Psychiatric Hospital for people with developmental, acquired and degenerative brain injuries. The purpose of the unit was to go beyond standard psychiatric care and include best neurobehavioral practices such as positive behavioral controls, professionals trained in the unique needs of brain injury, and a holistic team approach. It also emphasized specialized discharge planning to promote community transitions in collaboration with Woodrow Wilson Rehabilitation Center and the establishment of a community-based group home. Importantly, the proposal stressed the need for community services boards to play a more active role in the identification of brain injuries using validated and simple screening/identification tools, as is currently done in, e.g., Alaska (8). A resource manual for community-based services was also proposed.

The Neurobehavioral Committee recommends that 1) the Department of Behavioral Health and Developmental Services play a more active role in the identification of brain injury using validated screening tools and, 2) that the Brain Injury Association of Virginia's acquired brain injury resource manual be updated to address all forms of acquired brain injury and be distributed to all community service boards.

Virginia has relatively few programs specifically designed to address the neurobehavioral complications of brain injury. Most of these programs are private residential programs that do not generally accept Medicaid. Also, it is Department of Medical Assistance Services' policy not to fund residential programs for brain injury that are outside of skilled nursing facilities. This precludes treatment for people who do not have other funding supports (e.g., personal injury insurance, worker's compensation, legal settlements, other personal resources) and has caused numerous families in Virginia to lose everything they own. Lastly, and very importantly, until recently there were no statewide standards to insure appropriate residential neurobehavioral care by non-Medicaid service providers. A licensing mechanism developed by the Department of Behavioral Health and Developmental Services in conjunction with the Department of Rehabilitative Services is now established for such facilities. However, the extent to which these

standards insure best practices for neurobehavioral training, expertise and/or content in neurobehavioral residential services remains to be determined.

The Neurobehavioral Committee recommends that the Department of Behavioral Health and Developmental Services in conjunction with the Department of Rehabilitative Services---review the current licensing requirements for non-Medicaid neurobehavioral residential facilities to ensure best practices and to develop new regulations across all levels of neurobehavioral care. This includes behavioral risk factor measures to better identify least restrictive environments and to measure progress and outcomes. Simply housing people with challenging behaviors together does not necessarily constitute effective neurobehavioral care. Guidelines should be updated still further if/when an acquired brain injury Medicaid waiver is passed.

The Neurobehavioral Committee attempted to determine the number of neurobehavioral residential programs in Virginia in 2006 (some programs may have been inadvertently omitted). The identified programs were Head and Heart at Virginia Beach Healthcare and Rehabilitation, Tree of Life in Glen Allen, Lakeview Blue Ridge in Blacksburg, Lakeview Virginia NeuroCare in Charlottesville, Lakeview Shenandoah in Weyers Cave and the Neurological Rehabilitation Living Center in Virginia Beach.

All of these programs admit people with acquired brain injury, except for Heart and Head, which was restricted to traumatic brain injury and, as a skilled nursing facility, was the only Medicaid supported not-for-profit program in Virginia. It was originally funded to support 34 neurobehavioral beds. That number declined to about 20 by September 2007, at which time the program announced its closure. Attempts were then made to place these clients in other programs. Unfortunately, most skilled nursing facilities will not accept people with neurobehavioral issues and, if accepted, current Department of Medical Assistance Services' policy restricts Medicaid funding to these facilities. As noted in the earlier case study of Michael Leary, when placements cannot be found in a skilled nursing facility in Virginia, Virginians with brain injury are sent to out-of-state programs, sometimes at a higher cost than neurorehabilitation/neurobehavioral care here in Virginia. Most individuals with brain injury do not need hospital or skilled nursing level care, nor do they benefit from such care once they are medically stable.

The Neurobehavioral Committee believes that a change in Department of Medical Assistance Services' policy to cover in-State neurobehavioral programs that are not skilled nursing programs should provide a savings to State Medicaid funds together with much needed services to Virginia residents with brain injury.

Based on the statewide assessment, the Neurobehavioral Committee concluded there are approximately 20 specialized neurobehavioral beds in the Commonwealth as of January 2008. There are another 55 residential neurorehabilitation or limited acuity neurobehavioral beds that will accept individuals with brain injury. Many Virginians with brain injury need these programs. However, because of the lack of public funding mechanisms, most are not admitted to these services, and a number of these beds remain vacant because of this funding problem. There is a clear and pressing need for a formalized interagency partnership between the Department of Rehabilitative Services, the Department of Behavioral Health and Developmental Services and the Department of Medical Assistance Services to address this problem in a statewide, systematic way.

Review of Neurobehavioral Systems of Care

The proper implementation of statewide neurobehavioral programs must involve research-based best practices. A recent review of the traumatic brain injury rehabilitation literature notes that this is a relatively new field, and that "studies examining the efficacy of interventions are quite limited" (3). Similar statements can be made for the behavioral and psychiatric treatments for other kinds of acquired brain injury (15). Nonetheless, there are data and an emerging professional consensus that best neurobehavioral practices include the following: A) A comprehensive, holistic, rehabilitative neuropsychological and behavioral management approach; B) validated pharmacological interventions; C) applied behavioral analyses; and D) an emphasis on positive behavioral supports (3, 7). There are also data supporting the benefits of a multidisciplinary, patient-centered approach for the use of environmental, diagnostic, case management, social support and educational tools (3). And there is professional consensus that the most successful neurobehavioral programs have a strong focus on community integration and least restrictive procedures.

The Neurobehavioral Committee concludes that a comprehensive, holistic rehabilitative neuropsychological and behavioral management approach is the model system of best practices.

Based on this assumption, the Committee evaluated various state programs across the country including those that provide a "systems of care" approach. The concept of systems of care is different from the continuum of care approach that has been discussed in Virginia since at least 1989: continuum of care implies a linear treatment approach whereas systems of care relates to a more dynamic, non-linear approach such that people can enter and exit at any level.

The Neurobehavioral Committee concludes that a "systems of care" approach is the best approach to address the neurobehavioral problems of acquired brain injury.

An example of a state that has had difficulty with fully implementing a systems of care approach is New York, which utilizes large neurobehavioral nursing homes with limited community-based programs. This approach is good for cost containment because it clusters the most challenging people, but other services are severely lacking. It is important to note that, "Discharge into a questionable setting, with insufficient services, is not a cost-effective investment…as it is likely to fail" (8). This type of approach is also associated with a lack of enduring outcomes and violation of the Olmstead law for least restrictive environments. Ultimately, keeping people in facilities for many years ends up costing more than a validated systems approach, especially for the majority of people who can eventually (after initial intensive treatment) be supported in the community.

By contrast, Rhode Island uses an integrated 4-level systems of care approach. While this approach has less cost containment, the Neurobehavioral Committee determined that it is the model system that can be best adapted to Virginia. The four levels of care range from acute care to community-based services. The Neurobehavioral Committee believes that this systems of care approach will provide Virginians who have neurobehavioral problems:

- A comprehensive delivery of services and supports in a variety of therapeutic and personally relevant living environments;
- Options to meet the diverse needs of individuals across the recovery continuum and with various neurobehavioral challenges;
- Support and training for family members and other caregivers; and

- Entry at any point with movement to any other point in the system.

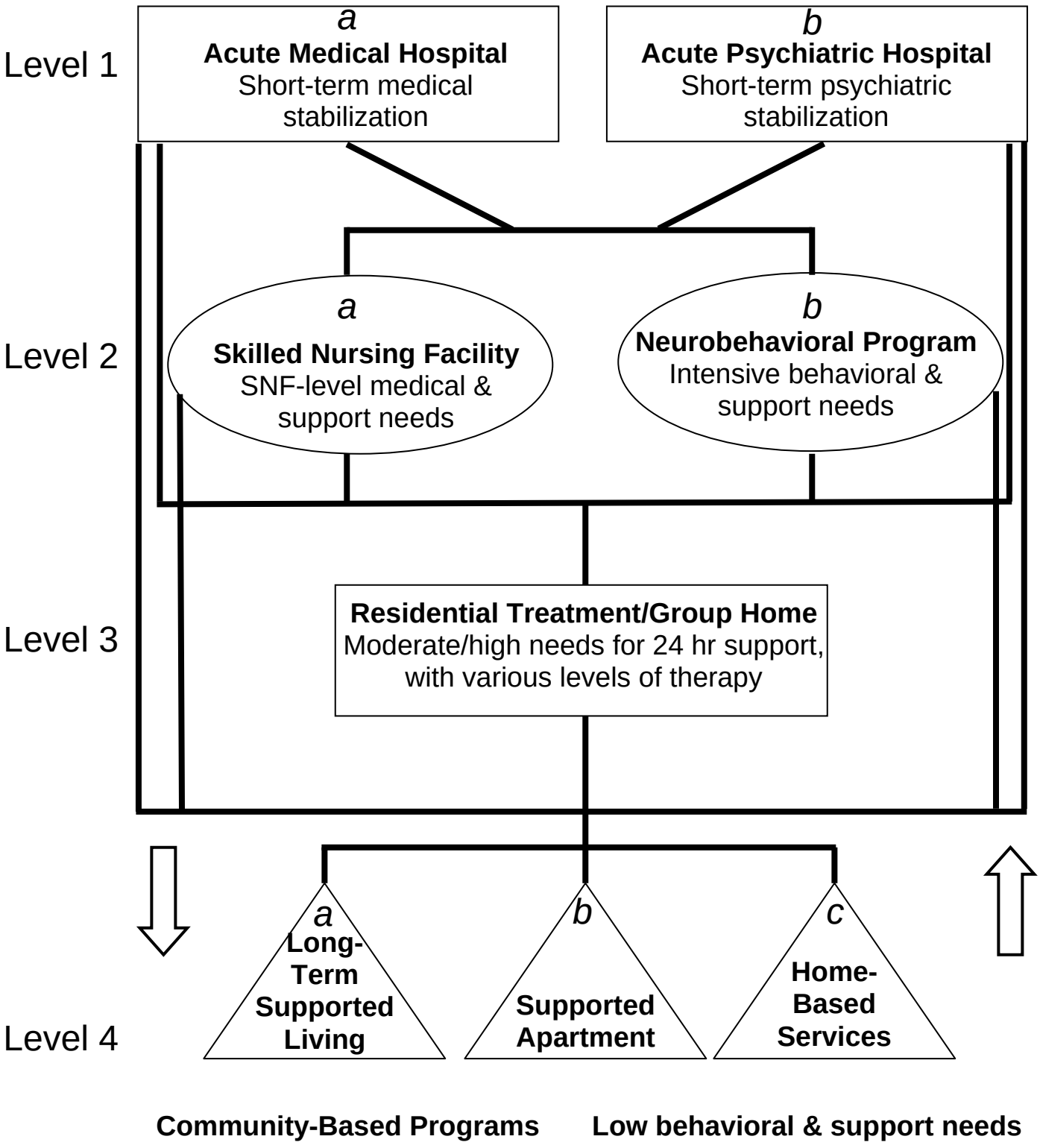
The types of levels of care are summarized here and in the following chart.

- Level 1 for acute, intensive behavioral and support needs:
  - (a) Acute Medical care or
  - (b) Acute Psychiatric care;
- Level 2 for intensive behavioral and support needs:
  - (a) Skilled Nursing Facility or
  - (b) Residential Neurobehavioral Program
- Level 3 for moderate to high behavioral and support needs:
  - Residential Community-Integrated Neurobehavioral Group Homes; and
- Level 4 for community-based low behavioral and support needs:
  - (a) Long-Term Supported Living,
  - (b) Supported Apartment, and
  - (c) Home-Based Services.

The Neurobehavioral Committee evaluated the strengths and weaknesses of each element in this system of care.

The Neurobehavioral Committee recommends a <u>focus on 3 elements of this system of care</u>: residential neurobehavioral programs for people with intense behavioral and support needs (Level 2b); residential community-integrated neurobehavioral group homes for people with moderate to high behavioral and support needs (Level 3); and community-based programs for those with low behavioral and support needs (Level 4) including long-term supported living, supported apartment living and home-based services.

Neurobehavioral Systems of Care: Summary Chart



It is important to note that the various levels of care refer to acuity levels and do not in any way imply a required path or series of steps. For instance, some individuals may be discharged from acute settings directly to home; others may not be successful in an apartment program and require more intense support and supervision in a community-integrated residential treatment home; and still others may transition across the continuum from time of brain injury to eventual independent living.

The neurobehavioral systems of care approach proposed here is consistent with the goals for neurobehavioral services as stated by the National Association of State Head Injury Administrators (8) since it includes services that:

- Change as people's needs change;
- Are responsive to the individuals unique needs;
- Are available and adequate; and
- Are based on best practices.

Proper implementation of these systems of care with state-of-the-art neurobehavioral intervention strategies is also consistent with several other best practices, including:

- Serving the individual in the least restrictive environment;
- Ensuring inclusion and person-centered planning in all phases of care;
- Utilizing medical, rehabilitative, cognitive, behavioral and pharmacological interventions in a holistic, complementary and comprehensive manner;
- Approaching behavior change through positive behavioral support strategies characterized by positive reinforcement, environmental modification, education and self-management, thereby promoting lasting outcomes;
- Facilitating skill development to maximize functional independence, productivity and social participation;
- Emphasizing community access, integration and self-advocacy;
- Utilizing interdisciplinary teams;
- Collaborating between all constituents, including family members, caregivers and other people who are part of the individual's life;
- Providing access to leisure, educational, avocational, pre-vocational and vocational pursuits; and
- Preserving human rights and dignity.

The strengths and weaknesses of the 4-levels of care are described as follows:

Level 1 (a). Acute Medical Hospital and Level 1 (b). Acute Psychiatric Hospital

At present, Medicaid and other funding mechanisms provide coverage for acute medical and acute psychiatric care in the Commonwealth. Unfortunately, commercial insurances traditionally pay for short-term acute care and not for the other levels of care. Individuals with acute medical needs are routinely served in hospitals, and those with acute psychiatric needs (e.g., suicidality, homicidality, active psychosis or other behavioral manifestations related to imminent risk to self or to others) are routinely served in psychiatric hospitals with secure units. People with post-acute neurobehavioral problems are sometimes placed in medical facilities after admissions to emergency rooms or due to the lack of beds in state psychiatric facilities. Acute care settings would clearly benefit from additional training and resources to support individuals with the neurobehavioral sequelae of brain injury. However, there is a reluctance to admit such individuals because of regulatory and liability issues. There are also problems identifying suitable discharge sites and other placement-appropriateness issues. Most importantly, the research literature suggests that such traditional acute medical and psychiatric hospital settings

are not the optimal treatment settings for the neurobehavioral population. For instance, individuals with neurobehavioral challenges may have chronic, problematic and high risk behavior, but may only manifest traditional acute psychiatric symptoms intermittently, and therefore may not meet admission criteria. Additionally, due to limited discharge options, length of stay in acute care settings is often extended well beyond the acute period for individuals with neurobehavioral challenges, resulting in unnecessary restriction, inappropriate treatment, and excessive costs to the funding source. Further, inappropriate staff training and treatment related to psychoactive medications and environmental designs can actually exacerbate rather than mitigate the behavioral problems.

The Neurobehavioral Committee concludes that acute medical and psychiatric hospital care is not the most effective placement for post-acute neurobehavioral treatment.

The Neurobehavioral Committee recommends more neurobehavioral training and resources for acute care programs

Level 2 (a). Skilled Nursing Facility

The Commonwealth currently funds care in skilled nursing facilities, and through Medicaid, provides a payment for skilled nursing programs serving the neurobehavioral population. Individuals with neurobehavioral challenges in skilled nursing facilities need a 24-hour care environment that cannot be met in a community setting. Typically these settings are designed for persons with high physical and medical support needs. While they can occasionally manage some degree of aggressive or other risk behavior, and can provide various degrees of active neurobehavioral treatment and rehabilitation, neurobehavioral treatment is not their focus of care.

Further complicating matters is the fact that the skilled nursing facility program evolved from the elder care model and is often staffed and run accordingly. Skilled nursing facilities with mixed populations also must manage the risk posed to older persons by younger persons with brain injuries and behavioral challenges. This model is not optimal for persons with brain injuries, and consumer feedback suggests that rehabilitation and neurobehavioral services in skilled nursing facilities are quite limited. In fact, many such facilities will not admit such cases when they are able to and often seek to discharge such individuals to other settings when possible. Unfortunately, such alternative settings rarely exist, thereby entrapping both the individual and the program. Individuals in these settings have minimal access to the community, meaningful day activities, or medical, rehabilitative and therapeutic services designed to address their behavioral challenges. It is clear, therefore, that skilled nursing facilities have difficulty providing the elements of best practices as described above for neurobehavioral care. Hence, it is important to distinguish skilled nursing facilities from intensive neurobehavioral treatment programs.

The Neurobehavioral Committee concludes that there are a number of persons with neurobehavioral challenges who are presently placed in skilled nursing facilities who could be better served in less restrictive, more appropriate settings if such were available through their funding mechanism, typically Medicaid.

Level 2 (b). Residential Neurobehavioral Programs for Intensive Support

Unlike skilled nursing facilities, residential neurobehavioral programs for intensive support are treatment environments designed specifically for individuals with severe neurobehavioral challenges who require 24 hour, high level support and supervision, active neurobehavioral treatment and rehabilitation, and behavioral intervention and medication trials in a safe environment. Staff training and environmental/therapeutic interventions are specifically designed to manage aggressive and other high risk behaviors. In most cases, acute psychiatric facilities

and skilled nursing facilities are rarely needed for this population if such intensive residential neurobehavioral programs are in place.

The Neurobehavioral Committee concludes that residential <u>neurobehavioral programs for intensive support are typically a more therapeutically appropriate alternative</u> than skilled nursing facilities and acute psychiatric hospitals for individuals with more chronic neurobehavioral issues or for those in the earlier stages of brain injury recovery who need more sustained, intensive and comprehensive treatment. Unfortunately, current Department of Medical Assistance Services' policy does not allow this therapeutic setting to be an option.

An important feature of intensive residential neurobehavioral programs is the provision of intensive treatment by licensed professionals with specific training and experience in acquired brain injury across a variety of disciplines. These programs: A) are well-suited to implement best practices; B) have low staff-to-client ratios; C) facilitate community access, self-care, behavioral data collection, and leisure and productive skill development; D) provide individualization of treatment as the norm with person-centered planning; and E) focus on the specific needs and goals of each person to develop the skills and supports necessary to live in the least restrictive, community inclusive environment. An intensive neurobehavioral treatment program differs from less progressive approaches that seek to reduce or stop behavioral symptoms without addressing their underlying causes or their long-term management. Unfortunately, as noted earlier, there is a scarcity of these intensive neurobehavioral programs in the Commonwealth with only 20 dedicated beds, all of which are funded through private sources. While there are some public funding mechanisms on a case by case basis, there is no dedicated Medicaid funding stream. Consequently, many families without worker's compensation or long-term care insurance become impoverished within a relatively short period of time due to the cost of care. Many families ultimately---and unfortunately---rely on the safety net provided by acute psychiatric facilities when behavioral problems become so dangerous as to require highly intensive and invasive procedures such as seclusion and restraint. It is clear, therefore, that a number of persons with neurobehavioral challenges who are presently being served in acute psychiatric hospitals and in skilled nursing facilities could be better served in intensive residential neurobehavioral programs if such settings were available through their funding mechanisms.

<u>Level 3. Residential Treatment via Community-Integrated Neurobehavioral Group Homes</u>

Residential community-integrated neurobehavioral group homes serve individuals who require 24-hour supervision, have moderate support needs and risk factors, and pose less risk to themselves or others than persons served in Level 1 or Level 2 above. These settings may be viewed as a 'step-down' from more restrictive settings, be they acute hospitalization, skilled nursing or intensive residential neurobehavioral programs. Community-integrated residential treatment programs focus on rehabilitation and re-entry with an emphasis on functional rehabilitation, social integration, leisure development and vocational opportunities. These programs also provide a comprehensive interdisciplinary rehabilitation team, though there is typically less focus on active licensed therapist treatment and more of a focus on community-based activities and natural supports with licensed therapists providing evaluation, care plan input and supervisory oversight. The treatment team may utilize multiple sites or be accessed through existing community agencies or organizations. Transitional, peer or 'life coach' services are often provided in these programs to facilitate vocational, social and recreational success. Community-integrated residential treatment settings are typically based in residential 'group' homes, allowing for economies of scale, community integration, social networking and home-like settings. Residential treatment group home programs exist in the Commonwealth and are funded through private sources and by some public funding on a case by case basis, largely to facilitate discharge from acute psychiatric hospitals. Unfortunately, there is no dedicated

Medicaid funding stream for persons with acquired brain injury making it a significant family burden for those who do not have private insurance or other private resources.

The Neurobehavioral Committee concludes that there are a number of persons with neurobehavioral challenges presently served in acute psychiatric hospitals or skilled nursing facilities that could be diverted to community-integrated neurobehavioral group home services if such settings were available through their funding mechanisms.

Level 4. Long-Term Supported Living Program, Supported Apartment Program and Home-Based Services Program

This community-based level of care varies depending upon the needs of the person. It ranges from 24-hour on site services to living at home. While each type of service has merits, one universal concern is the lack of awareness in community-based programs on best practices for the behavioral, medical and pharmacological treatment of neurobehavioral issues.

The Neurobehavioral Committee concludes that better statewide standards, education, and treatment/outcome accountability are needed to address the neurobehavioral problems of persons with acquired brain injury receiving community-based services.

Long-Term Supported Living Program. This system of community-based care is a lower cost extension of a Level 3, community-integrated residential group home program. It targets people with lower needs and risk factors who require long-term 24-hour on-site services. These programs have a community-living focus and are managed by healthcare extenders such as nurse's aides, life skills aides and personal care attendants with oversight by licensed personnel. There is minimal formal rehabilitation. Actual living situations vary greatly and include programs already available in many areas of the State through assisted living settings, half-way houses and congregate living facilities.

The Neurobehavioral Committee believes that there is a need to expand long-term supported living programs for people with neurobehavioral problems.

Supported Apartment Program. Supported apartment programs are similar to long-term supported living programs but target individuals with neurobehavioral challenges who require less than 24-hour support and have low needs and risk factors. Again, the focus is on community living. In-home support staff may be present for a few hours a week up to many hours per week based on individualized needs.

The Neurobehavioral Committee believes that supported apartment programs are an effective, community-based approach to manage neurobehavioral problems in people with low needs and risk factors.

Home-Based Services Program. The third type of community-based program within Level 4 is for persons with neurobehavioral challenges who reside at home independently or with the support of family or significant others. They have a low need for supervision and services and low risk factors. For those who meet eligibility criteria, Medicaid waivers may fund medical services, home health services, allied health services, counseling, and psychological services to persons residing within their own home or apartment. The complexity and time-consuming nature of providing these services is often a disincentive for provider participation under Medicaid, as levels of reimbursement are low.

The Neurobehavioral Committee concludes that home-based services require greater availability, a greater neurobehavioral focus, and better coordination. The Neurobehavioral Committee also concludes that a home-based neurobehavioral emphasis should be formerly incorporated into the so-called "foot print" of basic core services promoted by the Virginia Brain Injury Council for regional resource coordinators, case managers and day programs.

Proposal for a Demonstration Program and its Associated Costs

According to the Joint Legislative Audit and Review Commission (Senate Document No. 15, 2007), Virginia allocated $5.3 million for brain injury services and research in fiscal year 2007. Despite that, the Commission concluded that neurobehavioral programs are severely lacking. To address this unmet need, the Neurobehavioral Committee recommends a demonstration program.

The Neurobehavioral Committee proposes a 3-tiered demonstration program for 100 adults requiring post-acute neurobehavioral care in Virginia as a first step to address the specialized behavioral care of people with brain injuries. The care levels should be: Level 2(b)-Intensive Residential Neurobehavioral programs, Level 3-Community-Integrated Residential Treatment/Group Home programs, and Level 4-Long-Term Supported Living, Supported Apartment, and Home-Based Services programs.

The cost estimates for each of the 3 levels of care was estimated by the Neurobehavioral Committee based on 2007 information. Given the paucity of published data on this topic, rate estimates were based on the experience of one corporation providing such services nationally, combined with the best professional judgment of the Neurobehavioral Committee. Based on these considerations, it was assumed that, of 100 adults with post-acute acquired brain injuries:

- 10% (10 people) will require access to a Level 2(b)-Intensive Residential Neurobehavioral Program for stabilization because of high support needs and severe risk factors to self or others;
- 20% (20 people) will require access to a Level 3-Residential Treatment Group Home because of moderate support needs and moderate risk factors to self/others; and
- 70% (70) people will require access to a Level 4-Community-based Long-term Supported Living, Supported Apartment or Home-based Services program.

Cost estimates for these programs were then determined based on a systematic assessment across various states and the inclusion of realistic, evidence-based treatment options, including occupational, physical and behavioral therapies. Consequently, the cost estimates are more than so-called bed-rate estimates. One-to-one care, physician treatment, and laboratory measures were not considered. The costs for commercial facilities were also not determined. The Neurobehavioral Committee made the following cost estimates:

- **Estimated demonstration program costs for Level 2(b)-Residential Neurobehavioral Program services**: The estimated cost for one person with an acquired brain injury in this

kind of program was **$470 per day in 2007 dollars**. The total estimated cost for 10% of the 100 people (i.e., 10 people) to receive this care **for 6 months was $855,400**. Twelve months of care equals twice that amount, or $1,710,800.

- **Estimated demonstration program costs for Level 3- Residential Community-Integrated Neurobehavioral Group Home care**: The estimated cost for one person in this type of program was **$370 per day in 2007 dollars**. The total estimated cost for 20% of the 100 people (i.e., 20 people) to receive this care **for 12 months was $2,701,000**.

- **Grand total estimated costs** for Level 2(b) and Level 3 demonstration programs serving a total 30 people with acquired brain injury:

  - **$ 855,400** 10 people in a Level 2(b)-Neurobehavioral Program for 6 months.
  - **$2,701,000** 20 people in a Level 3-Residential Treatment/Group Home annually
    $3,556,400 Sum in 2007 dollars.

- **Estimated costs for Level 4-Community-Based Long-term Supported Living, Supported Apartment and Home-Based Services**: The Neurobehavioral Committee estimated the total daily costs in 2007 dollars for the various types of Level 4 care as follows in 2007 dollars:

  - **$250 per day:** Long-Term Supported Living;
  - **$140 per day:** Supported Apartment; and
  - **$ 55 per day:** Home-based Services.

  Assuming that 70% of 100 people need Level 4 care (70 people), it was the professional consensus of the Neurobehavioral Committee that the percentages of those needing specific types of Level 4 community-based services care were as follows:

  - 50% (35 people): Long-Term Supported Living;
  - 25% (17 people): Supported Apartment; and
  - 25% (18 people): Home-based Services.

  Based on these data, the **total costs in 2007 dollars to support 70 people with Level 4 care for 12 months** was:

  - **$3,193,750**: 50% (35 people) in Long-Term Supported Living;
  - **$ 868,700**: 25% (17) people in Supported Apartment; and
  - **$ 361,350**: 25% (18) people in Home-based Services:
    $4,423,800: Sum in 2007 dollars

- **Annual Grand totals** for the three levels of care for this 100 person demonstration program (Level 2(b), plus Level 3, plus Level 4):

  - **$ 855,400**: Level 2(b)-Neurobehavioral Program: 10 people for 6 months.
  - **$2,701,000**: Level 3-Residential Treatment: 20 people for 1 year.
  - **$4,423,800**: Level 4: 70 people, for 1 year
    $7,980,200: Grand Total

If the proposed demonstration program is fully funded the Neurobehavioral Committee recommends that the funding should be distributed across the system of care. If not fully funded, it is recommended that guidance be sought by the Neurobehavioral Committee.

The Neurobehavioral Committee recommends that the Commonwealth Neurotrauma Initiative should develop a request for proposals (RFP) with input from the Department of Behavioral Health and Developmental Services, the Department of Rehabilitative Services and the Virginia Brain Injury Council for a small neurobehavioral pilot project to generate outcome data to drive later neurobehavioral funding decisions. The Neurobehavioral Committee does not recommend that the mission of the Commonwealth Neurotrauma Initiative be otherwise redefined.

Overall Costs to Treat Adult Virginians with Significant Neurobehavioral Problems

These funding estimates are restricted to 100 people and do not address the entire spectrum of neurobehavioral needs in the Commonwealth. The Neurobehavioral Committee estimated that, relative to these 100 people, there are at least 20 times as many (2000 persons) with significant behavioral needs not receiving adequate treatment. If it is assumed that there are 40,433 adults between the ages of 25 and 65 in Virginia with traumatic brain injury disabilities alone---most with neurobehavioral problems---then 2000 people represents 5% of that population. This does not count those living with other forms of acquired brain injury with significant neurobehavioral issues. The actual need may therefore be much higher. Nonetheless, based on the 2000 person estimate, the total annual cost to address Levels 2, 3 and 4 systems of care in Virginia is at least 20 times greater than the proposed demonstration program or **$159.7 million**, broken down across program levels as follows:

- **$16.9 million**: Level-2b Neurobehavioral Program for intensive support
- **$54.0 million**: Level-3 Residential Treatment/Group Home for moderate/high support
- **$63.9 million**: Level-4 Long-Term Supported Living
- **$17.9 million**: Level-4 Supported Apartment
- **$7.0 million**: Level-4 Home-based Services

Potential Funding Considerations for the Demonstration Program

The Neurobehavioral Committee identified the following funding possibilities for the proposed demonstration program, several of which were also noted by the Joint Legislative Audit and Review Commission 2007 report:

1. A specific Medicaid brain injury waiver that includes neurobehavioral services as described in this report.
2. Home and Community-Based Services (HCBS) Medicaid waivers that accept non-pediatric and non-geriatric populations; an example is an Independent Care type waiver that supports, among others, those with brain injuries. (available on the World Wide Web at http://www.nashia.org/issues/medicaid.html)

3. Utilization of Medicaid waivers related to the "Money Follows the Person" 4 year demonstration program of the Olmstead Office of Community Integration for People with Disabilities. Funding is blended with the EDCD (Elderly or Disabled with Consumer Direction) waiver to support the individuals moving from the long-term care facility to the home. It is applicable to all disabilities, including brain injury.

To better address the neurobehavioral needs of people with acquired brain injury, the Neurobehavioral Committee recommends that the Department of Rehabilitative Services and the Department of Behavioral Health and Developmental Disabilities emphasize the need to expand community-based neurobehavioral treatment services during the continuing Olmstead Community Integration discussions so that the funding literally "follows the person" as individuals migrate from one level of neurobehavioral care to another.

The Neurobehavioral Committee also recommends that the partnership among the Department of Rehabilitative Services, the Department of Behavioral Health and Developmental Disabilities, and the Office of Community Integration for People with Disabilities be maintained across time.

4. State Discharge Assistance Program (DAP) funding, which is designed to reduce state mental health facility populations by moving people into community settings.
5. State funding for contracts with existing private neurobehavioral facilities. The 2007 Joint Legislative Audit and Review Commission report notes the benefits of building on existing infrastructure.
6. Collaborate with private insurers to expand neurobehavioral coverage.

Summary of Recommendations

The Neurobehavioral Committee recommends:

- a permanent interagency agreement between the Department of Rehabilitative Services and the Department of Behavioral Health and Developmental Disabilities to address this neurobehavioral problem in a statewide, systematic way. A statewide systematic approach should require the participation of the Department of Medical Assistance Services, the Department of Corrections, and the Department of Juvenile Justice.
- that the Department of Behavioral Health and Developmental Disabilities plays a more active role in the identification of brain injury using validated screening tools
- that the Brain Injury Association of Virginia's acquired brain injury resource manual be updated to address all forms of acquired brain injury and be distributed to all community service boards.
- the Department of Behavioral Health and Developmental Disabilities---in conjunction with the Department of Rehabilitative Services---review the current licensing requirements for non-Medicaid neurobehavioral residential facilities to ensure best practices and to develop new regulations across all levels of neurobehavioral care. This includes behavioral risk factor measures to better identify least restrictive environments and to measure progress and outcomes. Guidelines should be updated still further if/when an acquired brain injury Medicaid waiver is passed.

- a change in Department of Medical Assistance Services' policy to cover in-State neurobehavioral programs that are not skilled nursing programs should provide a savings to State Medicaid funds together with much needed services to Virginia residents with brain injury.
- a focus on 3 elements of this system of care: residential neurobehavioral programs for people with intense behavioral and support needs (Level 2b); residential community-integrated neurobehavioral group homes for people with moderate to high behavioral and support needs (Level 3); and community-based programs for those with low behavioral and support needs (Level 4) including long-term supported living, supported apartment living and home-based services.
- more neurobehavioral training and resources for acute care programs
- creating funding mechanisms that would allow a number of persons with neurobehavioral challenges presently served in acute psychiatric hospitals or skilled nursing facilities to be diverted to community-integrated neurobehavioral group home services.
- better statewide standards, education, and treatment/outcome accountability are needed to address the neurobehavioral problems of persons with acquired brain injury receiving community-based services. This is true not only at the community-based level but across the continuum of care.
- the expansion of long-term supported living programs for people with neurobehavioral problems, including supported apartment programs, which are an effective, community-based approach to manage neurobehavioral problems in people with low needs and risk factors.
- Greater availability of home-based services with a greater neurobehavioral focus and better coordination.
- home-based neurobehavioral services be formerly incorporated into the so-called "foot print" of basic core services (e.g. regional resource coordination, case management and transitional day programs) promoted by the Virginia Brain Injury Council for.
- funding of a 3-tiered demonstration program for 100 adults requiring post-acute neurobehavioral care in Virginia as a first step to address the specialized behavioral care of people with brain injuries. The care levels should be: Level 2(b)-Intensive Residential Neurobehavioral programs, Level 3-Community-Integrated Residential Treatment/Group Home programs, and Level 4-Long-Term Supported Living, Supported Apartment, and Home-Based Services programs. (*If the proposed demonstration program is fully funded the Neurobehavioral Committee recommends that the funding should be distributed across the system of care. If not fully funded, it is recommended that guidance be sought by the Neurobehavioral Committee).*
- the Commonwealth Neurotrauma Initiative should develop a request for proposals (RFP) with input from the Department of Behavioral Health and Developmental Disabilities, the Department of Rehabilitative Services and the Virginia Brain Injury Council for a small neurobehavioral pilot project to generate outcome data to drive later neurobehavioral funding decisions. The Neurobehavioral Committee does not recommend that the mission of the Commonwealth Neurotrauma Initiative be otherwise redefined.
- the Department of Rehabilitative Services and the Department of Behavioral Health and Developmental Disabilities emphasize the need to expand community-based neurobehavioral treatment services during the continuing Olmstead Community Integration discussions so that the funding literally "follows the person" as individuals migrate from one level of neurobehavioral care to another.
- the partnership among the Department of Rehabilitative Services, the Department of Behavioral Health and Developmental Disabilities, and the Office of Community Integration for People with Disabilities be maintained across time.

Members of the Ad Hoc Neurobehavioral Committee of the Virginia Brain Injury Council

This position paper was prepared for the Virginia Brain Injury Council by the Ad Hoc Neurobehavioral Committee of the Council. The Neurobehavioral Committee spent countless hours at significant personal cost in a genuine effort to improve the lives of Virginians with neurobehavioral problems and did so in an unbiased, evidence-based way. The Committee was composed of both Council members and non-members. In all cases, they were selected based on their state-wide and/or national expertise. Ideally, consensus panels should be formed by individuals who do not have a major vested interest in the outcome. For instance, the 1998 NIH Consensus Development Panel on Rehabilitation of Persons with Traumatic Brain Injury (9) excluded membership by clinicians/providers with significant traumatic brain injury-related financial income and researchers with significant traumatic brain injury funding. These exclusionary criteria were not applied to the Neurobehavioral Committee, as often such persons are the most knowledgeable and experienced in the field. In the interest of full disclosure, it is acknowledged that some members had research funding and/or salary-related interests relative to post-acute neurobehavioral care.

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The Committee wishes to thank Susan E. White of the Virginian-Pilot for her accurate and moving portrayal of the neurobehavioral problems of Eric Fletcher, his wife and caregiver, Kathleen, as well as of Michael Leary, and his sister and caregiver, Cathy Turpin.

Last, the Neurobehavioral Committee thanks the thousands of Virginians like Mr. Fletcher and Mr. Leary and their families who are living with the devastating neurobehavioral consequences of acquired brain injury: they keep us focused on doing the right thing for the right reason; and they teach us that there but for the grace of God go all of us. Kathleen Fletcher is quoted as saying she is "…exhausted from an exhausted system." It is hoped that this effort will begin the process by which a true system of care for this important problem becomes a reality.

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(Term Ends 1/2011)

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