REPORT OF THE
DEPARTMENT OF MENTAL HEALTH, MENTAL
RETARDATION AND SUBSTANCE ABUSE SERVICES

ACTION PLAN FOR THE APPROPRIATE TREATMENT OF PERSONS WITH BRAIN INJURIES IN THE MENTAL HEALTH SYSTEM

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

SENATE DOCUMENT NO. 16

COMMONWEALTH OF VIRGINIA
RICHMOND
1999

COMMONWEALTH of VIRGINIA

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To Governor Gilmore and Members of The General Assembly:

Attached please find the Department of Mental Health, Mental Retardation and Substance Abuse Services' and the Department of Rehabilitative Services' report on an Action Plan for the Appropriate Treatment of Persons with Brain Injuries in the Mental Health System in response to Senate Joint Resolution 158.

We appreciate this opportunity to describe the limitations of existing services and supports for people with brain injuries and serious mental illness and recommend ways in which the Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Rehabilitative Services can work together to better address these needs.

Sincerely,

Richard E. Kellogg, Commissioner
DMHMRSAS

John R. Vaughn, Commissioner
DRS

pc: The Honorable Claude A. Allen
Gayle Vergara

REPORT ON SENATE JOINT RESOLUTION 158

Request for the development of an action plan for the appropriate treatment of persons with brain injuries in the mental health system.

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Report on Senate Joint Resolution No. 158

Request for the development of an action plan for the appropriate treatment of persons with brain injuries in the mental health system.

Preface

SENATE JOINT RESOLUTION NO. 158 requests the Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Rehabilitative Services to develop an action plan for the appropriate treatment of persons with brain injuries in the mental health system. The Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Rehabilitative Services worked together to produce this report. The staff assigned to this study were:

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EXECUTIVE SUMMARY

It is estimated that nearly 2,000 of the 10,000 people reported to the Virginia Brain Injury Central Registry each year will require long-term services and supports due to resulting physical, cognitive, and behavioral impairments. The majority of persons who survive mild to moderate brain injury are able to return to their homes and families with minimal follow-up support. Some people who sustain a brain injury require intensive specialized treatment and long-term intervention and supports to effectively address cognitive and behavioral challenges directly related to the injury. In the absence of appropriate long-term treatment and support, many people with brain injuries, especially those with challenging behaviors caused by the injury, are placed in state psychiatric facilities.

In Fiscal Year 1998, there were 118 individuals with a diagnosis of acquired brain injury, including trauma, dementia, tumor, stroke, and other neurological disease, who resided in Virginia's state psychiatric facilities [this is the unduplicated count of all individuals with this diagnosis who were on inpatient status at any point during that fiscal year]. An analysis of patients with a diagnosis of brain injury at Western State Hospital, where the majority of these patients were treated, revealed that almost 20% had a primary diagnosis of brain injury with no mental illness or mixed diagnoses of mental illness and neurological head injury, the latter of which significantly impacted clinical presentation. This cohort is not appropriate for psychiatric hospitalization and would best be served by programs specifically designed to serve individuals with brain injury.

There is limited state funding for specialized services for individuals with brain injury. While DRS provides and administers several critical services and programs for this population, these services are inadequate to meet demand and do not reflect the full continuum of services and supports required for individuals with brain injury and severely challenging behavior. Long-term residential services represent the area of greatest need in Virginia, specifically long-term supported living options with intensive behavioral supports. Few providers in Virginia offer affordable short-term behavioral treatment and support within a secure environment for people with brain injury, and none offer long-term services that are affordable to the target group as a whole.

Woodrow Wilson Rehabilitation Center's Brain Injury Services Program is not designed to provide a full continuum of behavioral services and current admission criteria exclude individuals with severely challenging behaviors. The absence of an appropriate, secure residential setting for people with brain injuries and severely challenging behavior forces some individuals requiring intensive behavioral and cognitive retraining to seek such services outside Virginia, sometimes paid for with state dollars.

There is currently no system of care in the community for people with brain injuries and

no mental illness. Both short and long-term specialized rehabilitation services for people with brain injuries and severely challenging behavior are needed to divert people from admission to state mental hospitals and to assist individuals in transitioning from state mental health facilities to their communities.

DRS is the designated state agency responsible for coordinating rehabilitative services for persons with functional and central nervous system disabilities. Given the limited available funding for specialized services for individuals with brain injury, there is not a comprehensive service delivery system in the Commonwealth to meet the specialized needs of this population. Federal regulations governing Medicaid, however, contain provisions which allow states to provide certain non-medical services by applying for and implementing a Home and Community Based Services Waiver. Fifteen states have implemented such a waiver under Medicaid for persons with brain injury to cover a range of non-medical services such as case management, structured day programming and supported living services. Such services can assist individuals with brain injury and challenging behavior to avoid institutional care.

Major Findings and Recommendations

There are three distinct groups of head- injured persons in Virginia's state psychiatric facilities. The following is recommended for each group:

- The report proposes that DMHMRSAS continue to admit and treat people with a primary mental illness diagnosis and a co-occurring head injury that presents no significant clinical concerns.

- For people with a primary mental illness diagnosis and a co-occurring head injury that is a significant clinical factor in their treatment, the report proposes that Western State Hospital and Woodrow Wilson Rehabilitation Center's Brain Injury Services Program establish a model pilot program of consultation and staff cross-training to ensure more comprehensive treatment of the co-occurring disorders in the psychiatric setting.

- The report proposes that DMHMRSAS prohibit admissions to state psychiatric facilities of individuals with a primary head-injury diagnosis and no mental illness.

The Department of Rehabilitative Services is the designated state agency for the purpose of coordinating rehabilitative and related services to those with primary brain injuries. The report recommends that the Commonwealth support DRS in pursuing several strategies to promote the development of short and long-term residential alternatives for people with brain injuries who have severely challenging behaviors but no mental illness. Specifically,

- The Commonwealth, through DRS in collaboration with DMHMRSAS, should support the development of community-based models for the provision of services to persons with brain injuries and challenging behaviors.

- The Commonwealth should develop secure residential programs for short-term and long-term treatment and rehabilitation of individuals with the most severely challenging behaviors.

- The Commonwealth should develop long-term supported living options that will assist individuals with brain injuries to live in their own homes.

- DRS and the Department of Medical Assistance Services should pursue financing for the above residential services through a Medicaid waiver for Home and Community-Based Services targeted to Virginians with brain injury.

- DRS, in collaboration with DMAS, should study the use of dedicated brain injury units in nursing facilities, and explore strategies to expand these services where feasible and appropriate.

These recommendations lay the groundwork for achieving statewide implementation of model programs and services for people with brain injuries residing in state mental health facilities.

INTRODUCTION

The National Institute of Health's Institute of Neurological Disorders and Stroke estimates that over 2 million individuals sustain a brain injury each year. Although nearly 95% of people survive a brain injury, between 75,000 to 100,000 persons will die annually from brain injury in the United States, making it the leading cause of death for children and young adults in our society. About half of all brain injuries occur as a result of a motor vehicle crashes, most involving alcohol. Other causes are falls, acts of violence, and sports and recreational accidents.

Increasing numbers of people survive brain injuries today due to advances in emergency medical and acute hospital care for the trauma patient. Approximately 500,000 people require hospitalization for a brain injury and 70,000 to 90,000 will have life-long impairments as a result of the injury. Every five minutes in the United States an individual becomes permanently disabled as a result of a brain injury. Brain injury can affect all aspects of an individual's functioning, including physical, cognitive, emotional, and behavioral. Individuals who sustain a severe brain injury generally have impairments in several areas of functioning.

Brain injury can happen to anyone at any time, but young adult males between the ages of 16 and 30 are at greatest risk. Confronting the challenge of living with multiple functional impairments is difficult enough, but struggling to recover from a brain injury without proper rehabilitation and long-term support is nearly impossible. Unfortunately, for people with severely challenging behavior as a result of a brain injury, lack of understanding and lack of appropriate and timely rehabilitative support contributes to inappropriate placement in state mental health facilities.

Individuals with brain injury enter state mental health facilities for two reasons:

No other residential options - Individuals with severely challenging behaviors caused by a brain injury often reside with families until they are admitted to a psychiatric facility because family members are no longer able to manage ongoing behavioral crises. There are currently no other secure environments in Virginia for people with brain injuries and severely challenging behaviors who present a danger to themselves or others; and

Misdiagnosis - Individuals with severely challenging behaviors caused by a brain injury are sometimes misdiagnosed as having a psychiatric or mental illness, resulting in placement in the state mental health system.

The following cases illustrate typical scenarios involving people with brain injuries for whom admission is sought or gained to state mental health facilities in Virginia:

- FR sustained a moderate to severe brain injury and was treated at a medium sized community hospital. Following acute medical care and inpatient rehabilitation treatment, he was transferred to the hospital's behavioral healthcare unit where he resided for three months.

often physically and/or medically restrained due to extreme agitation, wandering, and a low level of responsiveness. DMHMRSAS and DRS became involved with this case subsequent to extensive efforts on the part of the local hospital to have FR admitted to Western State Hospital. Due to the fact that FR did not have a diagnosis of mental illness, DMHMRSAS requested DRS to identify an appropriate placement for FR. DRS was able to provide funding through the Cognitive Rehabilitation Program for FR to attend a program of comprehensive, residentially-based brain injury medical and rehabilitation services. FR was admitted to Western State Hospital for a five day period while awaiting an opening at the Cognitive Rehabilitation Program. He was discharged to his home and family within six weeks where he remains, requiring minimal follow-up support. It is likely that, without the collaborative efforts of DMHMRSAS and DRS to identify funding for appropriate services, FR would have remained at Western State Hospital at an ongoing cost to the Commonwealth.

- JJ is a 21-year-old woman who suffered a stroke during childbirth. She sustained severe brain damage and was admitted to Western State Hospital from a university teaching hospital. JJ is extremely agitated with marked cognitive impairment, as evidenced by extreme memory deficits, aphasia (language disturbance), and inability to recognize or identify objects. She requires constant supervision in a secure environment to manage and control her behavior. Nursing home placement has been explored, however the extreme level of agitation and potential risk to the frail elderly population have precluded this as a placement option. She will likely remain at Western State Hospital apart from her loving parents and infant daughter, until an appropriate long-term residential program is available.

- DJ is a 40-year-old male who sustained a severe brain injury in a motorcycle accident and who is otherwise physically healthy. Since the injury nearly a year ago, DJ has remained extremely agitated and aggressive. DJ was transferred to a Virginia university teaching hospital where, due to the severity of his agitation and aggression, he was placed in four-point restraints. DJ is now in a nursing home. However, the nursing facility and the family have requested placement in a state psychiatric facility due to severely impaired short term memory, aggression, and his need for maximum assistance in all activities of daily living. In addition to paying privately for nursing home care, the family is also paying for the rental of a special containment bed and a private attendant services to supplement nursing home staff during the day. DJ remains at the nursing facility, where the outcome is uncertain.

These cases represent the multiple issues faced by Virginians with brain injuries and challenging behaviors who are often admitted to state psychiatric hospitals. It is these ongoing issues and concerns that provided the impetus for this joint resolution.

In preparing this document, the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) and the Department of Rehabilitative Services (DRS) included:

(i) a review of past legislative studies and recommendations involving individuals with brain injury and co-occurring mental illness;

(ii) an overview of existing services and supports for this population in Virginia, as well as a brief description of service needs and gaps; (Note: In 1998-1999, the Department of Rehabilitative Services will conduct a statewide assessment of the comprehensive service needs of individuals with brain injuries through a grant award under the federal Brain Injury Act. This assessment will provide needed data to assist state agencies in planning for and providing appropriate services to individuals with brain injury.)

(iii) an overview of the Medicaid Home and Community-Based Services (HCBS) Waiver for individuals with brain injury; and

(iv) the development of service options for individuals with brain injury currently in the mental health system.

LEGISLATIVE BACKGROUND

The 1997 Virginia General Assembly passed Senate Joint Resolution (SJR) 158 requesting that the Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Rehabilitative Services "develop an action plan for the appropriate treatment of individuals with brain injuries in the mental health system."

The General Assembly recognized that

- approximately 10,000 Virginians are reported each year to the Brain Injury Central Registry;
- that in fiscal year 1996, the number of individuals with brain injury in Virginia's public mental health facilities totaled 163;
- that individuals with brain injury have disrupted cognitive functioning, resulting in diminished ability to understand and control behavior;
- that medications prescribed for traditional psychiatric diagnoses may not be appropriate for individuals with brain injury, but neuropharmacologic applications may be effective, if appropriately prescribed and supported; and
- that an array of services could allow individuals with concomitant brain injury and mental illness to return to the community.

A number of recommendations forwarded in earlier legislative studies have resulted in legislation enacted by the General Assembly and are pertinent to this current examination of services to individuals with brain injury in the mental health system. The work of the Joint Subcommittee Studying the Needs of Head and Spinal Cord Injured Citizens (House Joint Resulution 267,

1989) and The Need for Research on the Needs of All Physically Handicapped Persons (House Joint Resolution 135, 1988) produced two formal reports and a series of recommendations leading to the following legislative actions:

- Designation of the Department of Rehabilitative Services as the state agency responsible for coordinating rehabilitative services for persons with functional and central nervous system disabilities (individuals with brain injury are a subset of this population);

- Funding to develop and establish a Long Term Rehabilitation Case Management program for people with physical and sensory disabilities;

- Funding to develop and establish a Personal Assistance Services program;

- Funding to support development of a state/local partnership addressing the needs of persons with traumatic brain injury in Northern Virginia through the creation of a non-profit organization; and

- Legislation to create a "Commission on the Coordination of the Delivery of Services to Facilitate the Self-Sufficiency and Support for Persons with Physical and Sensory Disabilities in the Commonwealth" (House Joint Resolution 45, 1990).

A subsequent legislative study focused on the continued development of interagency coordination between DRS and DMHMRSAS. House Joint Resolution 167, 1990 requested an interagency plan for coordinated services for persons with neurological or head injury. The interagency response, prepared by DRS with assistance from DMHMRSAS, defined the target population of persons with neurological or head injury, described the service system relationships with DRS and DMHMRSAS, described existing specialized local, intra- and inter-agency programs and services for the population, and, lastly, presented action steps to begin addressing immediate service needs with current resources and programs. The initial action steps that were identified included:

- Agency support for cooperative case management between the two agencies at the local level;

- Formation of an interagency State Liaison Team for policy development;

- Cooperative resolution of extraordinary cases;

- Appropriate use of agency resources on behalf of mutual clients; and

- Training and technical assistance for agency personnel.

A more recent legislative study, House Joint Resolution 573, 1995 was one of three recommendations made by the Cognitive Rehabilitation Task Force of the Commission on the

Coordination of the Delivery of Services to Facilitate the Self Sufficiency and support of Persons with Physical and Sensory Disabilities (Disability Commission). The Disability Commission appointed the Cognitive Rehabilitation Task Force in recognition that although cognitive rehabilitation is a necessary rehabilitation intervention for persons with acquired cognitive impairments, adequate funding for cognitive rehabilitation services is not available.

The HJR 573 study group was charged with exploring public sources of funding as a way of expanding available dollars for this rehabilitation service. HJR 573 requested five state agencies to determine the feasibility of recognizing and/or paying for cognitive rehabilitation services for constituents with brain injury. The five agencies involved in the resolution were the Department of Rehabilitative Services (DRS), the Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS), the Department for the Visually Handicapped (DVH), the Department of Education (DOE), and the Department of Medical Assistance Services (DMAS).

Information requested from the involved agencies included current status of cognitive rehabilitation services and the future role of each agency in providing and/or paying for cognitive rehabilitation services. Agency findings for DRS and DMHMRSAS were as follows:

- DRS will continue to recognize, provide, and financially sponsor cognitive rehabilitation as an acceptable pre-vocational training modality for individuals with brain injury who require such services. The Department will increase the number of individuals with access to this service through:

    1. continued staff training and education;

    2. program modification based on the results of the agency's Cognitive Rehabilitation Program;

    3. establishment of agency criteria and procedures related to the provision of cognitive rehabilitation services; and

    4. development of a statewide Medicaid waiver proposal for traumatic brain injury.

- DMHMRSAS recognizes that there are consumers within the service system who have a dual diagnosis of traumatic brain injury and mental retardation, mental illness, or substance abuse. In keeping with its established mission, DMHRMSAS will not directly provide cognitive rehabilitation services but will work collaboratively with other agencies to refer consumers and their families to appropriate services. This includes:

    1. identifying individuals with traumatic brain injury during intake at both the Community Services Boards and state hospital;

2. ensuring that case managers understand this disability and initiate appropriate referrals; and

3. better integrating current DMHMRSAS services to ensure holistic treatment.

Lastly, the HJR 573 Study recommendations noted that DMHMRSAS was also willing to advise DRS in its efforts to develop a statewide Medicaid waiver proposal for community services for individuals with brain injury similar to the current waiver program for persons with mental retardation.

EXISTING SERVICES AND SUPPORTS

The Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Rehabilitative Services each have a different primary mission and must adhere to requirements of different funding sources.

Department of Mental Health, Mental Retardation and Substance Abuse Services

The Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) is the state authority for alcoholism, drug abuse, mental health, and mental retardation services. As the state authority, DMHMRSAS assures that efficient, accountable, and effective services are available for citizens with the most serious mental disabilities.

As articulated in the Department's Comprehensive State Plan 1998-2004, mental health service development priorities for state-controlled funds continues to focus on the needs of adults and children with the most serious mental illness, mental retardation and substance abuse disorders. State Board Policy 1029(SYS) 90-2 defines priority populations for mental health service development as adults with serious mental illness, children and adolescents with serious emotional disturbance, and young children at risk of developing serious emotional disturbance.

In addition to these larger population groupings, there are certain subpopulations with mental disabilities or substance abuse problems that require highly specialized services and initiatives to address their needs. Such special needs populations include, but are not limited to people who are deaf, hard of hearing or deafblind and mentally ill; people with drug abuse problems who are HIV positive or who have AIDS; people who are mentally ill and homeless; people who are mentally ill and chemically addicted; people with mental disabilities who are involved in the criminal justice system; and people with mental illness who also have sustained a brain injury.

Virginia's publicly supported service system includes fifteen state facilities and 40 community

services boards. State mental health and mental retardation facilities provide highly structured intensive care, inpatient treatment and training services. The nine state mental health facilities, which are the primary focus of service provision for this study, provide a range of psychiatric, psychological, nursing, support, and ancillary services. Specialized programs are provided for geriatric, child and adolescent, and forensic patients.

For persons with brain injury who also experience mental health problems, Virginia's state psychiatric facilities offer the standard range of services as are available for the general psychiatric population, as well as limited neuropsychological evaluation and occupational and speech therapy services. Western State Hospital also offers case-specific consultation with Woodrow Wilson Rehabilitation Center between neuropsychology and speech therapy staff of the two institutions. Additionally, Western State Hospital has recently implemented a "treatment mall" model that includes a variety of groups designed to address such issues as anger and stress management, social skills, etc.

In order to capture information relative to the numbers of individuals with a diagnosis of brain injury being served in the state mental health facilities, data from the three previous fiscal years (FYs 1996, 1997 and 1998) were gathered from the Department's Patient/Resident Automated Information System (PRAIS). As indicated previously, the inpatient numbers represent an unduplicated count of all individuals with a diagnosis of brain injury who were on inpatient status at any point during the previous three fiscal years.

State Fiscal Year	State In-Patients with Brain Injury	Average Total Length of Stay in Days
1996	163	688
1997	136	700
1998	118	716

Using the average daily cost per bed day of $304.99 in FY98, it currently costs the Commonwealth approximately $13.1 million per year to provide inpatient services to this population.

Among all of DMHMRSAS' facilities, Western State Hospital has had, for the previous three fiscal years, the largest numbers of individuals with brain injury. For that reason, Western State Hospital staff were asked to identify and examine all patients with a diagnosis of brain injury in regard to the following questions:

a. Is there clear evidence of a brain injury?

b. Did the brain injury precede the mental illness and evoke the behavior problem or did the brain injury come after the onset of mental illness?

c. If there is an injury, at what age did the injury occur? What is the severity of the

injury?

d. Are there significant numbers of individuals with brain injury who are not receiving appropriate services at WSH and who could potentially benefit from collaboration between WSH and WWRC?

The essential findings of this December, 1997 analysis revealed the identification of 78 patients with a brain injury, including those with head trauma, dementia, tumor, stroke or other neurological disease. Patients were categorized into five groups as follows:

1. Sixteen patients (19%) had a diagnosis of mental retardation, cerebral palsy, head injury in early childhood, or other developmental delay;

2. Twelve patients (14%) were diagnosed with some form of dementia, either degenerative dementia, such as Alzheimer's Disease, or Alcohol-Induced Dementia, neurosyphilis, or vascular dementia;

3. Thirty-four patients (40%) had a primary psychiatric diagnosis with a history of head injury which does not remarkably influence the psychiatric presentation or course;

4. Ten patients (12%) had mixed diagnoses of mental illness and neurological head injury, the latter of which significantly impacted clinical presentation; and

5. Six patients (7%) had a primary diagnosis of brain injury.

In examining the treatment and rehabilitative needs of the patients in these categories, Western State Hospital staff determined that the sixteen (16) patients who comprised categories #4 and #5 (ie. almost 20% of the hospital's brain-injured population) would benefit from services specifically designed to serve individuals with brain injuries. While there is, at present, no such program available at Western State Hospital, many of these residents have benefitted from consultation between the neuropsychology staff of Woodrow Wilson Rehabilitation Center and Western State Hospital. The remaining sixty-two (62) patients comprising categories #1-#3 are receiving services on hospital wards designed to meet their needs. Western State Hospital has a dual-diagnosis (MI/MR) Unit with specialized programming and the extended care and the Geriatric Admissions Units have programs in place to meet the needs of those with dementia. The patients comprising category #3 do not require specialized programming and are scattered throughout the hospital where they participate in the traditional range of services provided at the hospital.

Department of Rehabilitative Services

The Department of Rehabilitative Services (DRS) provides vocational rehabilitation and related services to individuals with physical and sensory disabilities through a statewide system of 42

local offices staffed by vocational rehabilitation counselors and other vocational specialists. In addition, DRS operates Woodrow Wilson Rehabilitation Center, a state-funded facility offering an array of vocationally-related services on a residential and outpatient basis. Individuals with brain injuries receive services at Woodrow Wilson Rehabilitation Center through two channels: the Brain Injury Services Program or directly through WWRC's medical or vocational services programs.

The WWRC Brain Injury Services (BIS) Program serves individuals with acquired brain injuries (i.e., from trauma, tumors, cerebral hemorrhages and strokes, or infections). BIS staff also provide consultant services to persons with an acquired brain injury who may be receiving services through another WWRC program.

Specialized BIS services include cognitive rehabilitation, neuropsychological evaluation and treatment, behavior management, community re-entry and independent living skills training, employment counseling and interdisciplinary transition services to the community. Psychological counseling to manage depression and adjustment to disability is also available.

Cognitive rehabilitation refers to therapeutic activities designed to assist an individual in developing and using strategies to enhance thinking abilities and compensate for cognitive deficits associated with brain injury, such as impairments in memory, attention, planning, and problem-solving. Unfortunately, WWRC in general, and BIS specifically, are neither designed nor equipped to provide comprehensive behavioral services to people with brain injuries who have severely challenging behavior. Since people with brain injuries and severely challenging behavior cannot be served effectively within the current programs, services, or environment of WWRC, they do not meet admission criteria.

As mentioned previously, approximately 10,000 individuals with brain injury are reported to the Virginia Brain Injury Central Registry each year. Of that number, about 20% or 2,000 individuals will require life-long services and care.

Some individuals remain in "low responsive" coma-like states and typically require nursing care. Many, however, have the potential to return successfully to their communities if they had access to intensive, specialized brain injury rehabilitation services. There is limited state funding of specialized services for people with brain injuries in Virginia. While the mission of DRS is to provide primarily vocational rehabilitation services to people with disabilities, DRS has been designated to administer several programs funded by the General Assembly for people with physical and sensory disabilities, including brain injuries. These programs and services provided and administered by DRS, along with FY 1999 funding allocations, are briefly described below:

Case Management

State General Funds:
Long Term Rehabilitation Case Management Program: $388,000 (150 people per year)
Brain Injury Services, Inc., a private, nonprofit in Fairfax: $309,247 (175 people per year)

There are two state-funded programs offering long-term case management services statewide: Brain Injury Services, Inc. in Fairfax County receives state funding to provide case management services to 175 people with brain injuries in Northern Virginia every year, while the Department of Rehabilitative Services (DRS) offers long-term case management services to approximately 150 people with physical and sensory disabilities in all other areas of the state (85% of whom have impairments resulting from a brain injury).

There is a waiting list for all state-funded case management services. Services include individual and systems advocacy and coordination of services to assist an individual in meeting personal goals. Participation in case management is voluntary and may be life-long. Long-term case management is cost-effective and reduces the risk of institutionalization by providing community-based support.

Community Living Services
(Life skills training, neurobehavioral intervention, and community transition services)

State General Funds:
DRS Cognitive Rehabilitation Program: $200,000 (10-15 people/year)
WWRC Brain Injury Services Program: $150,000 (approximately 75 people/year)
Brain Injury Services, Inc., a private nonprofit in Fairfax: $100,000 (approximately 75 people/year).

DRS administers the Cognitive Rehabilitation Program, a state-funded program of "last resort" targeting individuals with brain injury who are likely to benefit from a program of cognitive rehabilitation services and who reside in, or are at risk of placement in, an institutional setting (state mental health facility, nursing home, jail).

Services may include a short-term, residential program of specialized rehabilitation services followed by transitional life skills training in the community or a program of community-based life skills training only. Since its 1992 inception, funding levels have been stable although insufficient to meet demand. Life skills training services provided through the Cognitive Rehabilitation Program and through the WWRC Brain Injury Services Program include specialized intervention techniques and strategies focusing on improving the ability to function more effectively on a daily basis despite underlying cognitive deficits using a compensatory versus restorative approach.

Services are typically provided in a community-based environment when the individual is medically stable (i.e. following hospital or acute rehabilitation discharge). Non-state funding for cognitive rehabilitation services (e.g. life skills

training and neurobehavioral treatment) is not generally available unless an individual requires two or more medical rehabilitation services, such as physical, occupational or speech therapy. Since 1992, the DRS-administered Cognitive Rehabilitation Program (CRP) has provided intensive, specialized rehabilitation services to sixty (60) individuals with significant impairments and challenges due to brain injury. To date, CRP funds have helped to prevent or reduce the risk of institutionalization of approximately forty-five (45) people; eight (8) individuals were moved out of state mental health facilities into less restrictive settings. Unfortunately, due to extremely challenging behavior and lack of appropriate community-based supports, including secure residential options, three (3) individuals returned to the state facilities.

Day Rehabilitation Program Services

State General Funds:
DRS Administration of Contracts: $100,000 each for programs in Fredericksburg and Virginia Beach (approx. 20 people per year in each program)
Brain Injury Services, Inc., a private, nonprofit in Fairfax: $283,335 (approximately 60 people per year)

Structured day programs provide activities focused on helping participants attain individual goals to increase their level of independent living, social, and vocational skills. The overall goal of the day program is to assist individuals in transitioning from post-injury to community living and employment.

Participation in the program is voluntary and may be time-limited or ongoing. Programs are typically open to eligible individuals on a set or sliding scale fee. Participants and paid professional staff operate the program collaboratively. Two new day programs for people with brain injuries in the Richmond area are being planned: Sheltering Arms will operate a privately-funded, low-cost day program focusing on social and recreational activities, while DRS plans to issue an RFP for a model clubhouse program for persons with brain injury using "seed" money as start-up funding . The clubhouse is based on the Fountain House psychosocial rehabilitation model.

Personal Assistance Services

State General Funds:
DRS Administration of Program: $80,000 (approximately 10 people/year)

The DRS Personal Assistance Services for People with Brain Injuries (PAS/BI) Program is a consumer-directed program providing personal care and supervision in an individual's home. Participants in the PAS/BI program may direct their own care

and supervise their attendants, or they may choose a surrogate to assist them. Services are cost-effective and reduce institutional placement by supporting individuals in the residential setting of their choice.

Supported Employment

State General Funds:
DRS Supported Employment for Persons with Physical Disabilities: a portion of $163,000 is used for individuals with brain injuries
DRS Long Term Employment Support Services: a portion of $ 1,875,000 is used for individuals with brain injuries

DRS counselors purchase supported employment (SE) services from vendors across the state who provide intensive, one-to-one support in job development, job placement, and job site training, as well as follow-along support for as long as the individual is employed. The federal/state vocational rehabilitation system, administered in Virginia by the Department of Rehabilitative Services, does not have funding for federally mandated long-term follow-along support for people receiving SE services. Funding for follow-along support is available through the local community services boards for people with mental retardation, but this is not available for individuals with acquired brain injuries. SEPD and LTESS state funds can be used for follow-along services for people with physical disabilities, including people with brain injuries. These two sources of SE follow-along funds supplement DRS' federal/state vocational rehabilitation (VR) funding for the purchase of initial supported employment services and other vocationally related services for VR customers. SEPD and LTESS funds are limited and do not meet the current demand for SE long-term follow-along support.

Supported Living Services

State General Funds:
Brain Injury Services, Inc., a private nonprofit in Fairfax: $203,000 (11 people/year)

Public funding for supported living for people with brain injuries is limited. Supported living services, or supervised residential services, include various options such as individual, shared, and group residences. Specialized residential services for people with brain injuries reduce institutionalization when family members can no longer be caretakers.

Other Services

Additional services in Virginia for persons with brain injury are provided by private nonprofit or "for profit" organizations. Sheltering Arms Hospital has a residential and outpatient Transitional Rehabilitation Services program that offers short-term, post-acute rehabilitation services. Long-

term residential programs for people with brain injuries are provided through Learning Services in Northern Virginia and Tree of Life in Central Virginia. These programs are privately run and are cost prohibitive for most families. Further, as already noted, behavior deficits disqualify individuals from the limited number of community-based brain injury rehabilitation programs.

There are significant service gaps, particularly in the post-acute phases of treatment (i.e., following acute medical and rehabilitative care) since funding for acute services is typically available through private insurance or Medicaid. However, when individuals become medically stable, post-acute services are inaccessible, either due to lack of funding or lack of service availability. There is currently no system of care in the community for people with brain injuries and no mental illness. Community living support services, including life skills training, neurobehavioral intervention, and community transition skills training are needed, as well as long-term supported living services. Enhanced access to these two essential service components would result in reduced numbers of admissions of individuals with brain injury to state psychiatric facilities and increased numbers of discharges of individuals who could be successfully transitioned to the community.

MEDICAID WAIVER FOR HOME AND COMMUNITY BASED SERVICES FOR PEOPLE WITH BRAIN INJURIES

Individuals with brain injury and their families are often faced with a critical dilemma: Either send their loved one to a nursing home or a hospital based setting, or provide home care at a prohibitive cost that depletes the families' savings and sometimes their well-being. More importantly, individuals with brain injury do not want to live the remaining 30 to 40 years of their life in a nursing home or hospital.

Medicaid will fund the cost of care in a nursing home or chronic disease hospital, but will not fund community-based services, many of which are non-medical in nature, which allow persons with acquired brain injury to return to or remain in their homes. However, federal regulations governing Medicaid contain provisions allowing states to provide these non-medical services, by applying for and implementing a Home and Community Based Services Waiver.

A Home and Community Based Services Waiver allows a state to provide, to a selected target population, services under Medicaid which the program does not customarily cover. Under a Waiver, the federal government waives the requirement that all Medicaid recipients must receive the same services (known as comparability of services).

It provides the individual with the ability to choose between institutional care or living in their home community. In 1988, the federal government recognized that the Medicaid program had a bias toward funding institutional care, such as nursing homes. Authority for the U.S. Health Care Financing Administration (HCFA) to approve HCBS waivers was developed as a means to counter that bias, with the stipulation that the cost of community supports be less than or equal to the cost of care within the appropriate institutional setting (cost neutral).

There are currently fifteen (15) states that have implemented a Home and Community Based Services (HCBS) Waiver under Medicaid for persons with brain injury. The waiver allows states to provide Medicaid approved services, many of them non-medical services not ordinarily covered by Medicaid, to people in a community-based setting as long as the cost is equal to or less costly than services provided in an in institutional setting.

While each of the state waivers is unique, they all provide an array of non-medical services such as case management, behavior intervention, transitional and supported living, independent living skills training, environmental modification and structured day programs to augment more traditional medical services, such as home health and nursing care, physical therapy, and speech therapy. Medicaid waiver services can assist individuals with brain injuries, particularly those with challenging behaviors, to avoid costly, and often inappropriate, institutional care.

CONCLUSIONS AND RECOMMENDATIONS

It is clear that individuals with brain injuries in Virginia who have severely challenging behavior are sometimes admitted to state mental health facilities simply because there are no appropriate, effective alternatives. Often, admission to a state psychiatric facility is a "last resort." It is also clear that there are a small number of patients in Virginia's state psychiatric hospitals with mixed diagnoses of mental illness and brain injury. Given these issues, what specific actions can be taken to provide appropriate services to people with brain injuries in state mental health facilities?

In developing recommendations for the appropriate treatment of people with brain injuries in the state mental health system, the following two primary goals and supporting action plans have been identified:

GOAL 1. Provide effective treatment and services to individuals appropriately residing in state mental health facilities who have a primary mental illness with co-occurring brain injury.

Recommendation 1: Improve services to individuals with co-occurring mental illness and brain injury who are currently residing in the state facilities by developing a model pilot program of consultation and cross training between the staff of Western State Hospital and Woodrow Wilson Rehabilitation Center's Brain Injury Services Program.

> Once a model pilot program has been developed, implemented, and evaluated, similar programs could be established statewide. The pilot program should include the following components: (i) development of a mechanism for the identification of people with brain injuries residing in or entering state mental health facilities; (ii) development of a multidisciplinary Brain Injury Team comprised of staff from WSH and WWRC BIS and/or other local brain injury specialists; (iii) development of a treatment protocol within Western State Hospital for the neuropsychological assessment and service planning for

individuals whose current symptoms are deemed to be due primarily as a result of an acquired brain injury; (iv) ongoing consultation and cross-training of staff from the state mental health hospitals and local brain injury professionals; and (v) centralization of services for people with brain injury and co-occurring mental illness residing in state mental health facilities, as well as centralized, dedicated staff to work with residents with brain injuries.

GOAL 2. Move individuals with a primary diagnosis of brain injury out of the state mental health facilities into appropriate and effective community-based treatment programs and services which would, in turn, prevent future inappropriate admissions of individuals with primary brain injury.

Recommendation 1: The Commonwealth should provide support to the Department of Rehabilitative Services as the designated state agency for the purpose of coordinating rehabilitative services to individuals with functional and central nervous system disorders, including those with primary brain injury.

§51.5-9.1 of the Code of Virginia designates DRS as the state agency for coordinating rehabilitative services to persons with functional and central nervous system disabilities and charges DRS with providing a comprehensive assessment of the need for rehabilitative and support services, identifying gaps in services, promoting interagency coordination, developing models for case management, and advising the Secretary of Health and Human Resources, the Governor and the General Assembly on programmatic and fiscal policies and the delivery of services to such persons. Given the limited state funding for specialized services for individuals with brain injury, DRS is not able to adequately fulfill its mandate to this population by either purchasing, managing, or directly providing the full range of services and supports required to meet the specialized and comprehensive needs of this population.

Recommendation 2: DMHMRSAS should formulate and implement clear admissions protocol prohibiting admissions to state psychiatric facilities of all individuals with a primary brain injury who do not have a documented serious mental illness.

Recommendation 3: DMAS, in partnership with DRS and with consultation from DMHMRSAS, should implement a Medicaid Waiver for Home and Community-Based Services for Persons with Brain Injury.

A Medicaid Home and Community-Based Services waiver program in Virginia could transition a targeted number of people currently in state facilities to more appropriate, and more effective, community-based settings, as well as divert people from entering the state mental health system. The Department of Mental Health, Mental Retardation, and Substance Abuse Services, the Department of Rehabilitative Services, and the Department of Medical Assistance Services should work collaboratively on implementing this waiver.

Recommendation 4: The Commonwealth should develop secure residential programs for short-

term and long-term treatment for individuals with the most severely challenging behaviors.

In 1993, DRS developed a plan to expand WWRC programs for individuals with brain injuries at the recommendation of the Disability Commission. The General Assembly approved a small amount of funding for the plan, but this did not include funds for a specialized neurobehavioral treatment facility on WWRC's campus. The 1993 plan should be reviewed and updated. A neurobehavioral treatment facility would provide a safe environment in which to provide intensive, specialized behavioral treatment services to people with brain injuries and challenging behaviors. Such a program could be located at WWRC or at some other location. Given appropriate funding, the program could be directly operated by DRS or a contract provider under the administrative supervision of DRS.

Recommendation 5: DRS, in collaboration with DMAS, should conduct a study of nursing facilities in Virginia to explore strategies which would expand the availability of dedicated brain injury units within nursing facilities.

DMAS reimburses skilled nursing facilities at a higher rate per bed for every bed occupied by a person with a brain injury within a dedicated brain injury unit. Guidelines stipulate that there must be a minimum of 20 beds in the separate unit. The criteria for entry into the unit is that an individual must have a medical diagnosis of brain injury, be in need of skilled nursing facility services, and exhibit agitated and aggressive behavior. Staff must be knowledgeable in brain injury rehabilitation and treatment and are dedicated to the unit. While a nursing facility is not an ideal setting for most people, particularly those with acquired brain injury, a dedicated unit within a nursing facility offers the option of a secure environment with trained staff. Ongoing technical assistance and consultation to nursing facilities who choose to establish a brain injury unit would certainly be a critical component of this action step. Consultation and training for nursing home staff could be provided collaboratively by DMAS and DRS.

Recommendation 6: The Commonwealth should develop long-term supported living options for this population.

There is a significant gap in community-based services and options, particularly long- term residential options, for people with brain injuries and challenging behaviors. Many of these individuals now reside at home with aging parents. When the parents become unable to care for their adult child, or die, the individual is at risk for placement in a state psychiatric facility. Long-term supported housing programs would include not only "bricks and mortar," but the critical component of specialized long-term supervision. With appropriate supports, many individuals with brain injuries can live and work in the community successfully.

Recommendation 7: The Commonwealth, through DRS in collaboration with DMHMRSAS, should support the development of community-based models for the provision of services to persons with brain injuries and challenging behaviors.

The underlying philosophy is that people are treated most effectively in their home communities

within the context of a support team. This model looks at options beyond the traditional one-on-one office-based or group facility-based approaches to service provision. The concept of a community-based treatment team successfully addresses duplication of services and compartmentalization of service provision. Support should be available to individuals in their home communities on a 24-hour, as needed basis. This is similar to long-term case management for people with brain injuries, however this model is distinguished in that it offers 24 hour wrap-around services and supports.

Summary

This report provided a brief overview of the problem facing people with brain injuries who reside in state mental health facilities. Unfortunately, it is a bleak picture of misdiagnosis, lack of appropriate, specialized treatment in the state mental health facilities, lack of community-based residential or treatment options, and lack of a secure treatment environment providing neurobehavioral treatment services to people with brain injuries and severely challenging behaviors. These are not new problems in Virginia. If the recommendations contained in this report are carried out, appropriate treatment and rehabilitation services for Virginia's citizens with brain injuries and challenging behaviors could become a reality.

SENATE JOINT RESOLUTION NO. 158

Requesting the Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Rehabilitative Services to develop an action plan for the appropriate treatment of persons with brain injuries in the mental health system.

Agreed to by the Senate, February 13, 1998
Agreed to by the House of Delegates, March 12, 1998

WHEREAS, each year approximately 10,000 Virginians are reported to the Brain Injury Central Registry; and

WHEREAS, of the total number of brain-injured individuals residing in the Commonwealth, there are 163 reported individuals within the mental health hospital system, and, of those, 74 reside at Western State Hospital; and

WHEREAS, individuals with brain injuries often have disrupted cognitive functioning and, as a result, the ability to understand and control behavior is diminished and interventions that attempt to correct behavior fail; and

WHEREAS, medications given for traditional psychiatric diagnoses may not be appropriate for people with brain injury, but alternative neuropharmacology applications may be effective if appropriately prescribed and supported; and

WHEREAS, an array of services, similar to those proposed for other mental health clients, could enable persons with brain injuries complicated by mental illness to return to the community and function independently; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Rehabilitative Services be requested to develop an action plan for the appropriate treatment of persons with brain injuries in the mental health system. The Department of Mental Health, Mental Retardation and Substance Abuse Services shall serve as lead agency and provide staff support for the study.

All agencies of the Commonwealth shall provide assistance to the Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Rehabilitative Services for this study, upon request.

The Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Rehabilitative Services shall complete their work in time to submit their findings and recommendations to the Governor and the 1999 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

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Commissioner, Department of Mental Health,
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