REPORT OF THE
JOINT COMMISSION ON HEALTH CARE

# Virginia's Brain Injury Registry

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

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# Preface

House Joint Resolution 219 and Senate Joint Resolution 190 of the 2000 General Assembly Session, as introduced, "directed the Disability Commission to evaluate the current system for reporting brain injuries to the central registry, and the dissemination of information to survivors and their families concerning available assistance." These resolutions were not adopted by the General Assembly but were communicated via letter from the Speaker of the House of Delegates to the Joint Commission on Health Care (JCHC). (The Speaker's letter and the two resolutions are attached as Appendix A.) The Speaker's letter indicates:

> "The House Rules Committee believes that the issues addressed by the resolution merit review. Therefore the Commission is directed to undertake the study and to submit a written report of its findings and any recommendations to the Governor and to the 2001 Session of the General Assembly."

An amendment in the nature of a substitute for House Joint Resolution 219 was drafted but never formally adopted. The language contained in the substitute asked that JCHC address the following study questions:

- the procedures for reporting data to the Registry, including who is required to report and when;
- the comprehensiveness and accuracy of Registry data;
- the timeliness and usefulness of information that is disseminated to acquired brain injury survivors and their families;
- other registries maintained by the Department of Health that experience high reporting compliance follow-up services;
- whether revisions are needed to § 51.5-11 of the *Code of Virginia* to promote timely and complete reporting;
- whether existing exceptions to reporting requirements should be continued or revised;
- whether a system of sanctions should be enacted for non-compliance; and
- whether the Department of Rehabilitative Services continues to be the most appropriate agency location for the Virginia Brain Injury Central Registry.

Based on our research and analysis during this review, we concluded the following:

- Virginia was the first state to require reporting of head or brain injuries to a central registry.

- The *Code of Virginia* § 51.5-11 requires the Department of Rehabilitative Services (DRS) to maintain a brain injury registry. Hospitals and attending physicians are statutorily required to report within 30 days of identification of the injury those persons sustaining brain injury in which "permanent disability is likely to result."

- Reporting brain injuries to DRS is accomplished either by downloading patient information onto diskettes (the procedure used by five of the largest hospitals) or by completing and submitting one-page forms to DRS. The information DRS receives is entered into the brain injury registry and mailing labels are sent to the Brain Injury Association of Virginia (BIAV).

- DRS contracts with BIAV to provide outreach services to brain injury survivors and their families. Virginia's registry is a service-oriented rather than surveillance-oriented registry. The primary reason for the registry is to provide information to survivors and their families about brain injury symptoms and services. BIAV reported that from 1/1/99 through 2/29/00, 114 of the 4,310 (or 2.6 percent) of their outreach cards resulted in a request for information.

- BIAV also has a contract with DRS to provide technical assistance to hospitals to improve compliance with reporting requirements and to assist DRS with its Open Registry Program. The Open Registry Program allows individuals to be added to the brain injury registry either through self-reporting or by being reported by a health care professional. Very few persons are reported to the Open Registry Program.

- Hospitals that provide emergency medical services are required to report to three trauma-related registries – the brain injury and spinal cord injury registries maintained by DRS and the trauma registry maintained by the Virginia Department of Health (VDH). For the last three years, DRS and VDH have worked to develop integrated reporting to one combined trauma registry. VDH indicates that there continue to be implementation issues that need to be addressed including funding and staffing to allow for project completion and to provide for ongoing registry support. The original estimated cost to implement the integrated system was $110,000. VDH has received appropriations of $470,000 to complete the system.

- In terms of the current operation of the brain injury registry by DRS, there are areas in which implementation is generally not consistent with statutory requirements. Most significantly, very few physicians report to the registry, hospitals often do not report brain injury patients who are released from their emergency rooms, and the average reporting time for hospitals exceeds 120 days. It should be noted however, Virginia's statutory requirements in these areas far exceed the reporting criteria required of brain injury registries in other states. Another significant operational concern is the low number of brain injuries that are reported as compared with estimates of the number of injuries that occur. Estimates indicate that 50 to 65 percent of the brain injuries that were serious enough to require hospitalization may not have been reported.

- While not a specific focus of the study, the availability of services for brain injury survivors is a critical issue. DRS estimates that about $2 million will be expended for services for brain injury survivors in FY 2001. Although some brain injury survivors will be served through the recently approved Medicaid waiver for the developmentally disabled, Virginia does not have a specific brain injury home/community based Medicaid waiver. Twenty-one states have such a waiver.

A number of policy options were offered for consideration by the Joint Commission on Health Care regarding the issues discussed in this report. These policy options are listed on pages 33-34.

Our review process on this topic included an initial staff briefing, which comprises the body of this report. This was followed by a public comment period during which time interested parties forwarded written comments to us regarding the report. The public comments (attached at Appendix B) provide additional insight into the various issues covered in this report.

On behalf of the Joint Commission on Health Care and its staff, I would like to thank the Virginia Department of Rehabilitative Services, the Virginia Department of Health, the Brain Injury Association of Virginia, the Jason Foundation, the Virginia Brain Injury Council, Brain Injury Services Inc., Virginia Health Information, the Medical Society of Virginia, the Virginia Hospital and Healthcare Association, and the many associations and health care providers who provided input and information during this study.

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Executive Director

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# I.
# Authority for the Study

House Joint Resolution 219 and Senate Joint Resolution 190 of the 2000 General Assembly Session, as introduced, "directed the Disability Commission to evaluate the current system for reporting brain injuries to the central registry, and the dissemination of information to survivors and their families concerning available assistance." These resolutions were not adopted by the General Assembly but were communicated via letter from the Speaker of the House of Delegates to the Joint Commission on Health Care (JCHC). (The Speaker's letter and the two resolutions are attached as Appendix A.) The Speaker's letter indicates:

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- whether revisions are needed to § 51.5-11 of the *Code of Virginia* to promote timely and complete reporting;
- whether existing exceptions to reporting requirements should be continued or revised;
- whether a system of sanctions should be enacted for non-compliance; and

- whether the Department of Rehabilitative Services continues to be the most appropriate agency location for the Virginia Brain Injury Central Registry.

## Organization of Report

This report is presented in five major sections. This section discusses the authority for the study. Section II provides background information concerning brain injuries. Section III discusses the operation of brain injury registries in Virginia and in other states. Section IV identifies a number of operational issues regarding Virginia's brain injury registry. Section V provides a series of policy options the Joint Commission on Health Care may wish to consider in addressing the issues raised in this study.

# II.
# Background

## Accepted Definitions for Different Types of Brain Injuries

The Brain Injury Association, the national association concerned with brain injury prevention, research, education and advocacy, has adopted a standard definition for both <u>acquired</u> brain injury and <u>traumatic</u> brain injury. Acquired brain injury is defined as "injury to the brain which is not hereditary, congenital or degenerative." The Association further describes acquired brain injury as follows:

> an injury to the brain that has occurred after birth. The injury commonly results in a change in neuronal activity, which affects the physical integrity, metabolic activity or functional ability of the cell. Causes of acquired brain injury include external forces applied to the head and/or neck (e.g., traumatic brain injury with or without skull fracture), anoxic/hypoxic injury (e.g., cardiopulmonary arrest, carbon monoxide poisoning, airway obstruction, hemorrhage), intracranial surgery, vascular disruption (e.g., arteriovenus malformation (AVM), thromboembolic events, fat emboli), glycemia, hepatic encephalopathy, uremic encephalopathy, seizure disorders, and toxic exposures (e.g., substance abuse, ingestion of lead and inhalation of volatile agents). The term does not refer to brain injuries that are congenital or induced by birth trauma.

Traumatic brain injury (TBI) is defined by the Brain Injury Association as "an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It also can result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment."

Preliminary findings of a Colorado study which examined the disability suffered by individuals who were 16 or older when they received a traumatic brain injury revealed; (1) of those who were admitted to a hospital, approximately 30 percent reported some residual disability;

(2) of those who were employed, about 50 percent were still employed; and
(3) of those who were in school, about 12 percent remained in school.

## Traumatic Brain Injuries Are Sustained by Individuals of All Ages; Approximately 1.5 to 2.0 Million Americans Sustain A Brain Injury Each Year

Traumatic brain injuries are suffered by individuals of all ages. For individuals younger than 45, brain injuries are the leading cause of death and disability. A recently released report by the Centers for Disease Control (CDC) stated that current estimates of traumatic brain injury indicate that of the approximately 1.5 to 2.0 million Americans who sustain a brain injury during a one-year period:

- almost 1 million will receive emergency care,
- 230,000 will be admitted to a hospital and survive their injuries,
- 70,000 to 90,000 will sustain a permanent disability, and
- 50,000 will die from their injuries.

Moreover, the CDC estimates that 5.3 million Americans currently have a disability that resulted from a traumatic brain injury.

Brain injuries can be difficult to identify resulting in many injuries remaining undiagnosed or being misdiagnosed. The Brain Injury Association noted the following concerning traumatic brain injuries:

> Recovery is often slow and changes in personality, learning capacity and human potential are often profound. Cognitive and behavioral effects may appear years after the initial injury and persist for a lifetime. This can be particularly problematic for children who are learning basic educational and social skills. Costs in dollars are estimated in the tens of billions, but cannot begin to address the cost to families who are deprived of a loved one who often seems to be replaced with a stranger.

The Centers for Disease Control reported the leading causes of traumatic brain injuries in the United States are motor vehicle accidents, violent acts, falls, and sports injuries. Ninety-one percent of brain injuries resulting from firearms were fatal (and almost two-thirds were considered to be suicides) while only 11 percent of brain injuries resulting from falls were fatal. The risk of sustaining a brain injury is highest for teenagers, young adults, and people over the age of 75. Regardless of age, males are at twice the risk of sustaining a traumatic brain injury.

## Prevention Efforts Have Reduced the Number of Brain Injury Deaths

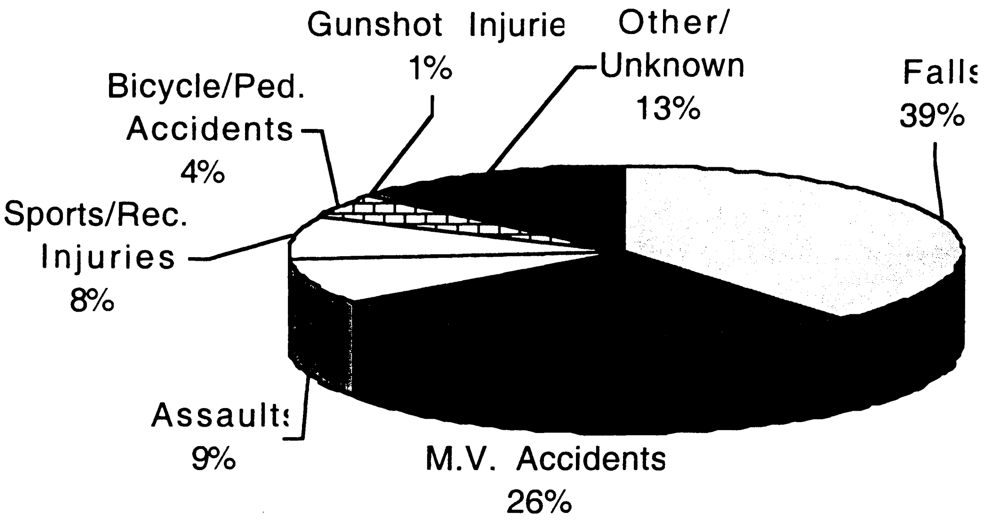
The National Center for Injury Prevention and Control has cited evidence that prevention efforts can have a significant effect on reducing accidental deaths. The Center credits public safety efforts including improvements in the design of motor vehicles and highways, in enforcement of highway safety laws (particularly related to driving while intoxicated, speeding, and seat belt use and motorcycle helmet use) with saving the lives of 240,000 Americans between 1966 and 1990.

## "Falls" Were The Leading Cause of Brain Injury for Persons Reported to the Virginia Brain Injury Registry in 1999

Figure 1 graphically shows the percentage breakdown for reported cause for brain injury in Virginia (regardless of whether the injury resulted in hospital admission or transfer, release from the emergency room, or death). As shown, falls and motor vehicle accidents were the reported cause for nearly two-thirds of the brain injury patients. "Falls" were the leading cause for brain injury for persons reported to the registry (39% of total). Motor vehicle accidents were the second leading cause of brain injury for individuals reported to the registry, but were the leading cause of brain injury for persons admitted to a hospital or transferred to another hospital in Virginia. The practice of reporting to the brain injury registry those patients (elderly patients in particular) who fall and sustain a broken bone and a minor head injury may help to explain the large number of brain injuries reported in Virginia as being caused by falls. In 13 percent of the total number of individuals reported, the cause of the injury was listed as "other" or "unknown."

## Figure 1

## Reported Causes of Brain Injury In Virginia (1999)



**Source:** Department of Rehabilitative Services Brain Injury Registry data for persons injured during calendar year 1999.

# III.
# The Operation of Brain Injury Registries in Virginia and in Other States

## Virginia Has Statutorily Required the Reporting of Brain Injuries Since 1984

Virginia was the first state to require reporting of head or brain injuries to a central registry. Section 2.1-583 of the *Code of Virginia*, which had established a central registry for spinal cord injuries in 1982, was amended in 1984 to require the Commissioner of the Department of Rehabilitative Services (DRS) to "establish and maintain a central registry of persons who sustain head injuries, if permanent disability is likely to result." The reporting requirements for head injuries were the same that had been established for spinal cord injuries: hospitals and attending physicians were required to report within seven days the identity of any person diagnosed as sustaining a spinal cord or head injury.

During the next five years, additional statutory changes were enacted (Figure 2). In 1985, the information contained in both the spinal cord and <u>brain</u> injury registries were explicitly required to remain confidential and were exempted from the provisions of the Virginia Freedom of Information Act. The authorizing statute for the brain injury registry changed from § 2.1-538 to § 51.01-11 due to recodification of the *Code* sections addressing DRS responsibilities. In 1986, the timeframe for reporting both spinal cord and brain injuries was changed from seven to 30 days. In 1987, the timeframe for reporting spinal cord injuries reverted back to seven days (while the timeframe for reporting brain injuries remained 30 days). In 1989, the *Code of Virginia* was amended and § 51.5-11 became the operative section. In addition, the following language was added:

> The Department [of Rehabilitative Services] in cooperation with organizations representing persons with disabilities maintained by the central registry, shall establish and pilot a mechanism which utilizes the data maintained by the central registry pursuant to this section to provide client identification, follow-up and outreach; maintain accurate and up-to-date records concerning the client's functional level and need for services; and facilitate better analysis and utilization of such data for effective program, policy, and fiscal planning purposes.

## Figure 2

## Changes to the *Code of Virginia* Involving the Brain Injury Registry

| Amended *Code* Section | Year *Code* Amended | Summary of Changes Made to the *Code of Virginia* |
|---|---|---|
| § 2.1-583 | 1984 | Language was added to require the Department of Rehabilitative Services to maintain a brain injury registry. |
| §51.01-11 | 1985 | Information contained within the brain injury and spinal cord injury registries was exempted from Freedom of Information Act provisions. The *Code* section was also changed. |
|  | 1986 | The timeframe for reporting both brain injuries and spinal cord injuries was changed from seven to 30 days. |
|  | 1987 | The timeframe for reporting spinal cord injuries was changed to seven days. |
| §51.5-11 | 1989 | Language was added to require the Department of Rehabilitative Services to establish a mechanism for updating registry information which was to be developed on a "pilot" basis. The *Code* section was also changed. |

**Source:** JCHC staff analysis of various *Acts of Assembly*.

There have been no additional statutory changes since 1989. Thus, the current statutory requirements for the brain injury central registry, which are shown in Appendix B, include:

- DRS is the agency required to establish and maintain the brain injury registry,
- hospitals and attending physicians are required to report on any person sustaining a brain injury in which "permanent disability is likely to result" within 30 days of identifying the brain injury,

- DRS is to maintain and pilot a mechanism which allows the registry to be updated to include ongoing functional levels and service needs of individuals included in the registry, and
- Registry information is to be confidential and exempt from the provisions of the Virginia Freedom of Information Act.

### The Brain Injury Central Registry Is Administered by the Department of Rehabilitative Services; The Vast Majority of Brain Injuries Are Reported by Hospitals; While Required To Do So; Physicians Report Almost No Brain Injuries to the Registry

The Department of Rehabilitative Services (DRS) continues to administer the central registry for brain injuries (and the central registry for spinal cord injuries). Although hospitals and attending physicians are statutorily required to submit brain injury reports, DRS staff acknowledge that very few, if any, reports are received from physicians. Considering that attending physicians treat very few patients with brain injuries likely to result in permanent disability outside of the hospital setting, it is understandable that few reports are received from physicians.

Instructions developed for hospitals to use in reporting brain injuries indicate that the "Virginia Brain Injury Central Registry is for <u>people who have sustained an external blow to the head</u> resulting in a brain injury that presents <u>long-term or permanent disability</u>." Rather than define "brain injury," DRS has determined that individuals with injuries meeting the criteria of an external blow to the head and long-term or permanent disability should be reported to the registry. Hospitals currently assign codes to diagnosed diseases or injuries on the basis of *The International Classification of Diseases, Ninth Revision* (ICD-9-CM). Any individual whose injuries have been assigned one of the ICD-9-CM codes shown in Figure 3 should be reported to the registry.

The majority of the 93 Virginia hospitals complete a written form in order to report a brain injury patient to DRS. The one-page form that is used for reporting to the brain injury registry is shown in Appendix C. As noted on the form, DRS asks that hospitals include: (1) patient identifying information; (2) the circumstances resulting in the injury; (3) the patient's initial condition including all applicable ICD-9-CM codes; and (4) the patient's "disposition" in terms of release from the emergency room or admission to the hospital, discharge date, and destination after discharge.

## Figure 3
## Codes To Be Reported to the Brain Injury Registry in Virginia

| ICD-9-CM Code | Description of Injury |
|---|---|
| 348.1 | Anoxic brain damage which results from trauma such as near-drowning, electrocution, asphyxiation but not from heart attack, surgical procedures, stroke, etc. |
| 800.1-800.4, 800.6-800.9 | Fracture of vault of brain |
| 801.1-801.4, 801.6-801.9 | Fracture of base of brain |
| 803.1-803.4, 803.6-803.9 | Other and unqualified skull fractures |
| 804.1-804.4, 804.6-804.9 | Multiple fractures involving skull or face with other bones |
| 850-850.9 | Concussion |
| 851-851.9 | Cerebral laceration and contusion |
| 852-852.5 | Subarachnoid, subdural, and extradural hemorrhage, following injury |
| 853-853.1 | Other and unspecified intracranial hemorrhage following injury |
| 854-854.1 | Intracranial injury of other and unspecified nature |
| 959.01 | Head injury, unspecified |
| 995.55 | Shaken Infant Syndrome |

**Source**: Quick Reference developed by the Brain Injury Association of Virginia.

Although most hospitals send in written forms on patients sustaining brain injury, the majority of patient reports are actually reported on diskettes. This is because four of the five hospitals designated as Level I Trauma Centers submit their reports by diskette. Virginia's Level I Trauma Centers (Medical College of Virginia, University of Virginia, Carilion Roanoke Memorial Hospital, INOVA Fairfax Hospital, and Sentara Norfolk General Hospital) treat the majority of patients sustaining moderate to severe brain injuries.

### DRS Staff Enter the Brain Injury Reports into the Central Registry; The Primary Function of the Central Registry Has Been to Provide Outreach Services to Traumatic Brain Injury (TBI) Survivors

DRS staff indicate that, historically, within one week of receiving registry information from the hospitals, DRS staff at the Woodrow Wilson Rehabilitation Center (WWRC) have been able to enter the information into the central registry. (However, as discussed in Section IV, recently, there have been delays in entering the information into the Central Registry.) WWRC staff print mailing labels for the TBI survivors for whom valid addresses have been reported. These mailing labels are sent to the Brain Injury Association of Virginia (BIAV) which provide outreach services to TBI survivors and their families. (If a valid address cannot be readily identified by WWRC, no further follow-up is conducted.) To date, the mailing labels generated from the central registry data and the subsequent information mailed to the TBI survivors, represent the primary function/purpose of the registry.

### The Brain Injury Association of Virginia Provides Outreach Services to Brain Injury Survivors and their Families

DRS has contracted with BIAV since 1987 to provide outreach services to persons reported to the registry and to increase reporting to the brain injury registry by hospitals. BIAV, which was established in 1983 as the Virginia Head Injury Foundation, was instrumental in advocating for legislation which established the brain injury registry. DRS awarded the early contracts with BIAV on a sole source basis. For the last nine years, however, the contracts have been competitively awarded to BIAV.

BIAV is required, within 30 days of receiving the mailing labels, to send out to TBI survivors general information about brain injuries and the services that are available. To accomplish this requirement, BIAV has developed a pamphlet that is sent out which briefly describes: (1) what a brain injury is, (2) what some of the common problems associated with brain injury are, and (3) what services are offered by BIAV and DRS. The pamphlet also includes an addressed, postage-paid Request Card that can be mailed back to BIAV if the person would like to receive more detailed information. BIAV reported that from January 1, 1999 through February 29, 2000, only 114 of the 4,310 (or 2.6 percent) Request Cards that were mailed were returned to BIAV, indicating a low level of interest in additional information. In response to the limited response from TBI survivors, some brain injury advocates have suggested authorizing BIAV to send out subsequent mailings to ensure that survivors and families have more than one notice of the availability of information and services.

### BIAV Staff Contact Directly Those Persons Returning a Request Card for More Information

When a Request Card is returned, BIAV staff attempt to call the person if a telephone number has been supplied. BIAV has developed an extensive collection of materials about brain injury issues and the association staff prefer to talk directly to survivors or their family members to allow for the most appropriate materials to be gathered and mailed. There is no charge for materials sent to individuals. If an organization requests a large number of copies, BIAV may charge to recover the photocopying expenses. The DRS contract indicates that each year 8,000 to 10,000 pamphlets will need to be sent out by BIAV which will result in 500 to 2,000 requests for additional information from brain injury survivors and families. (However, as previously noted, recent data do not reflect this level of response.)

### DRS Also Maintains an Open Registry Program for Persons Not Reported to the Central Registry by Hospitals

The DRS contract also includes requirements related to the Open Registry Program. The Open Registry Program allows individuals who have not been reported to the central registry by a hospital or attending physician to be added to the registry through self-reporting or reporting by a healthcare professional. BIAV refers individuals to the program and distributes written materials about the program to a variety of providers including medical and rehabilitation centers and support groups. When individuals are reported through the Open Registry Program, the referral is handled the same way that a hospital-reported referral would be handled. Staff at Woodrow Wilson Rehabilitation Center enter the individual's name on the central registry and send a mailing label to BIAV so a pamphlet will be sent out. DRS staff report that a limited number of individuals have been added to the registry through the Open Registry Program.

## The Brain Injury Association of Virginia Provides Assistance and Training to Hospitals Regarding Reporting Procedures

The DRS contract also requires BIAV to provide technical assistance to hospitals to improve compliance with registry reporting requirements. The current provisions require BIAV each year to: (i) train staff from at least 10 hospitals on reporting requirements either through regional workshops or on-site visits; and (ii) provide individual assistance to at least ten hospitals identified by DRS as having problems with reporting compliance.

The early BIAV contracts with DRS included funding of more than $100,000 a year. Contract funding was gradually reduced over time, however, to $60,000 a year for most of the 1990s. The current contract provides a total of $80,000 a year. This total includes the $60,000 in state general funds that has historically been provided, as well as an additional $20,000 in federal funding. The federal dollars provide for vocational rehabilitation and allow BIAV to work with hospitals on the importance of reporting spinal cord injuries to the registry maintained by DRS. Since the same hospital staff who report on brain injuries are often responsible for reporting on spinal cord injuries, it seemed expedient to have BIAV assist with reporting of both types of injuries.

## An Integrated Trauma Registry Is Being Developed by the Virginia Department of Health to Incorporate the Brain Injury Registry Requirements Into Other Required Trauma Reporting

In addition to the brain injury registry, hospitals that provide emergency medical services are required to report to two additional trauma-related registries – the spinal cord injury registry maintained by DRS and a trauma registry maintained by the Virginia Department of Health (VDH). The VDH trauma registry is required by §32.1-116.1 of the *Code of Virginia* as part of the Emergency Medical Services Patient Care Information System. As provided in statute, the purpose of the system is "to collect data on the incidence, severity and cause of trauma, integrate the information available from other state agencies on trauma and improve the delivery of prehospital and hospital emergency medical services...."

One component of the Emergency Medical Services Patient Care Information System is the VDH trauma registry. Hospitals that provide emergency medical services are required to provide information on "all patients admitted to the institutions' trauma and general surgery services with a diagnosis related to trauma" to the VDH trauma registry. The system is being designed to allow only hospitals to enter the case information for trauma patients. A physician would be required to work with a hospital in order to report on a patient who sustained a brain injury to the registry.

For the past three years, VDH and DRS have worked on integrating their three trauma registries to form one registry for hospital reporting. A memorandum of understanding between VDH and DRS was signed in June of 1997 that addressed this goal. While no timeframe for completing the integration was specified in the memorandum, the estimated cost of having the system developed and operating was $110,000. The memorandum noted that future costs related to data storage, technical assistance, and any other related expenses would be negotiated after the first year the system became operational.

### Implementation of VDH's Integrated Trauma Reporting System Has Been Delayed

VDH staff reported that there have been a number of delays and changes in the design of the integrated reporting system. Currently, reporting to the three trauma registries is done by sending in written forms or by submitting data on diskettes. Once fully developed, the new reporting system will allow hospitals to report trauma cases to the registry online through the Internet. The on-line nature of the system has meant that extensive data security measures have had to be built in to ensure the privacy of the data which has contributed to the delay in implementing the system. The integrated trauma reporting system is discussed in more detail in Section IV.

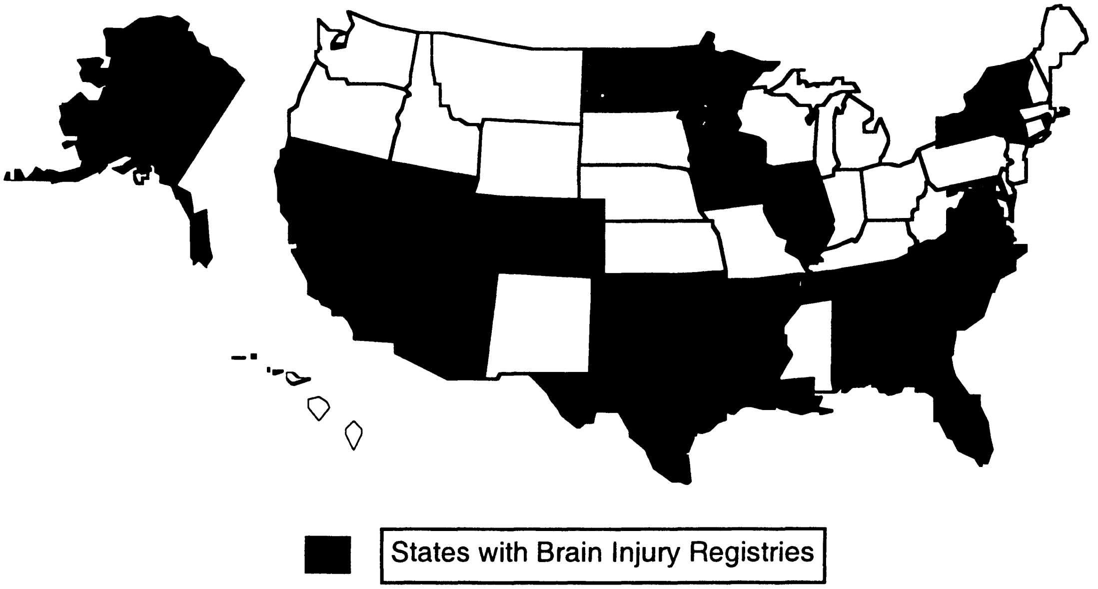
### Twenty-Seven States, Including Virginia, Currently Administer Traumatic Brain Injury Registries

A recent survey by the Centers for Disease Control (CDC) found that as many as 33 states had registry programs at one time, but six states have recently discontinued their programs primarily due to inadequate funding. Figure 4 illustrates the 27 states currently administering a brain injury registry. In nearly all states which administer a brain injury registry, the state agency responsible for health issues (including instances in which the agency was responsible for health and other issues such as the Alaska Department of Health and Social Services) houses the registry. However, Vermont's TBI registry is administered by the Department of Aging and Disability and West Virginia's registry is administered by the

Division of Rehabilitative Services within its Department of Education and the Arts.

**Figure 4**

**States With Brain Injury Registries**



**Source:** National Association for State Head Injury Administrators

TBI registries can be differentiated on the basis of whether they are primarily a surveillance tool or whether they are also intended to allow for service outreach. Surveillance-oriented registries typically seek to determine and track the prevalence of TBI for prevention, planning, and research purposes. Service-oriented registries take the additional step of providing information to TBI survivors and their families regarding available services and useful organizations. Of the 27 states that have TBI registries, 15 states have "surveillance-oriented" registries while 12 states, including Virginia, have registries that can be classified as being "service-oriented."

## Virginia's Registry Requires Broader Reporting of Brain Injuries Than Most Other States

The CDC, which determined that few jurisdictions were adequately monitoring the incidence of traumatic brain injuries, began to fund some state registries in 1995. Fifteen of the 27 brain injury registries currently in operation are funded by the CDC through its National Center for Injury Prevention and Control (NCIPC). The operation of those 15 registries is compared with the operation of Virginia's brain injury registry in Figure 5. This comparison shows that Virginia's registry requirements are more rigorous than the requirements established by NCIPC.

**Figure 5**

**A Comparison of Virginia's Brain Injury Registry with 15 Registries Funded by NCIPC**

| Operational Characteristics | Virginia's TBI Registry | Registries Funded by NCIPC in 15 States |
|---|---|---|
| **Type of Registry** | Service oriented. | Ten are surveillance registries while five are service-oriented registries. |
| **Parameters for Reporting** | Hospitals and attending physicians are required to report within 30 days of identifying a patient brain injury. Reporting is not restricted to patients who are admitted to a hospital. | In most states, TBI patients are identified on the basis of hospital admission reports and filed death certificates. (In one state there is an additional requirement for doctors and psychologists to report on patients diagnosed with TBI within 30 days of diagnosis.) |
| **Basis for Reporting** | Required by state statute. | Required by state statute in ten states, operated on the basis of federal grant funding in five states. |

**Source:** JCHC staff analysis of Virginia brain injury registry requirements and NCIPC data.

Many of the differences in the requirements of Virginia's brain injury registry as compared with the registries funded by NCIPC coincide with the differences in the registries' purpose. The primary purpose of Virginia's registry has been to provide information to brain injury survivors and their families to assist them in making decisions and finding services and resources. Virginia's registry requirements, therefore, include reporting within a short timeframe and reporting on patients who are released from an emergency room or are treated by a physician, rather than only on patients who are admitted to a hospital or die. The primary purpose of the NCIPC reporting program involves gathering valid numbers on the incidence of serious head injuries. Thus, in other states, there is no stringent timeframe established for collecting information, and only patients whose brain injuries result in admission to a hospital or death are included in the registry.

# IV.

# Operational Issues Related to Virginia's Brain Injury Registry

## Some Statutory Requirements for the Reporting of Brain Injuries and for Maintaining the Central Registry Are Not Being Fulfilled

Figure 6 summarizes the provisions of § 51.5-11of the *Code of Virginia* as they relate to reporting to the brain injury registry, and compares those provisions with study findings regarding how the registry is being implemented. As shown, there are four areas in which implementation is generally not consistent with statutory language related to the registry.

**Only Brain Injuries Related to Trauma Are Being Reported:** The first difference between statutory language and implementation relates to the types of brain injuries that are included on the registry. Provisions for the spinal cord injury registry included within § 51.5-11 specifically exclude injuries resulting from disease from being included on the registry. The language related to brain injuries however, simply states that "brain injury, if permanent disability is likely to result" should be included on the registry. In establishing the central registry, DRS staff have restricted registry reporting to those brain injuries that result from trauma and not those resulting from congenital conditions, disease or complications from medical conditions or procedures. Brain injuries involving congenital conditions, resulting from stroke, or resulting from oxygen deprivation related to surgical complications are examples of conditions that are not being reported to the registry.

The DRS interpretation of "reportable brain injuries" is generally consistent with the reporting requirements of TBI registries in other states and with Virginia Department of Health requirements for reporting to the trauma registry. However, the interpretation of reportable brain injury does exclude some individuals who could benefit from brain injury outreach from being contacted through the registry program. Some advocates have recommended including acquired brain injuries (e.g. stroke, heart attack) in particular, as well as considering including brain injuries resulting from congenital conditions and disease.

## Figure 6

## Comparison of Statutory Requirements and Implementation of the Brain Injury Registry

| Statutory Requirements | Actual Implementation |
|---|---|
| Any brain injury in which "permanent disability is likely to result" is required to be reported. | DRS has interpreted the reporting requirement to be restricted to brain injuries that result from trauma. |
| Providers are required to report any person treated for a brain injury that is likely to result in a permanent disability. This requirement is not restricted to persons who are admitted to the hospital but includes those released from emergency rooms, and those treated by physicians. | Few, if any, physicians report to the registry; some hospitals, including several designated Level I trauma centers, only report TBIs for individuals who are admitted for brain injuries. |
| Reports are to be made to the registry within 30 days after identification of a brain injury. | The average reporting time for the state in calendar year 1998 was 128 days. |
| A mechanism that would allow the registry to be up-dated to include ongoing functional levels and service needs was to be developed on a pilot basis (for both spinal cord injuries and brain injuries). | A mechanism was attempted in 1996 for spinal cord injuries, but was discontinued; no mechanism currently exists to update functional level and service needs for persons with reported brain injuries. |

**Source**: JCHC staff analysis.

**In Many Instances, Persons with Brain Injuries Released from Emergency Rooms Are Not Reported; Physicians Report Few, If Any Brain Injuries:** The second difference between statutory requirements and actual practice involves hospital reporting of TBI survivors who are released from an emergency room. As noted previously, TBI registries in most other states and the trauma registry maintained by VDH do not require hospitals to report on trauma injuries unless they result in an admission to the hospital. Virginia's statutory language regarding brain injuries, however, requires reporting when permanent disability is likely to result from the injury . . . reporting is not limited to patients admitted to a hospital. A review of DRS' registry data reveals that some hospitals, including some Level I Trauma Centers, report few if any of the TBI patients released from the emergency room.

Representatives of several hospitals indicated that the larger hospitals are not able to report individuals who are treated and released from the emergency room without being admitted due to the high volume of these types of patients. It could be asserted that these individuals are not being reported because permanent disability from their brain injuries was not expected to occur. While hospitals generally have not made that argument, the statutory language is general enough for such an assertion to be made. The fact that some hospitals report TBI survivors released from an emergency room and others do not results in different levels of reporting among hospitals. Moreover, the extent to which individuals who are released from emergency rooms are not reported to the registry will mean that some individuals who could benefit from brain injury outreach will not be contacted through the registry program.

DRS staff indicate that few, if any, attending physicians report patients sustaining TBIs to the registry. This is due, at least in part, to the fact that only injuries likely to result in permanent disability are required to be reported. These serious injuries are more likely to be treated in a hospital rather than a physician's office. DRS staff have not made working with physicians to encourage reporting a priority, choosing instead to use their limited resources to encourage reporting by hospitals where individuals with more serious injuries are typically treated. As previously noted, requiring physicians to report to the registry is different from reporting guidelines for TBI registries in most other states and for the trauma registry maintained by VDH which restrict reporting to hospitals.

**Many Brain Injuries Are Not Reported Within the Required Timeframe:** The timeframe in which providers are expected to report on TBIs is the third area of inconsistency between statutory requirements and actual practice. Section 51.5-11 states that reports will be made to DRS "by the most expeditious means within thirty days after identification of any person sustaining brain injury." DRS reports that in calendar year 1998, the statewide delay in reporting brain injury cases was 128 days. Although this "delay figure" includes the time that elapsed between DRS receiving the reports and actually entering the reports, it is expected that in 1998, "processing" time added no more than 14 days. Several hospital representatives indicated that, particularly for larger hospitals, reporting within 90 days of discharge would be a more reasonable timeframe. A 90-day timeframe is consistent with the expectations VDH has for hospitals to report to its trauma registry. Hospitals also noted that having to report information to three different registries is inefficient and time-consuming.

**Spinal Cord and Brain Injury Registries Are Not Updated:** The fourth area of difference between *Code of Virginia* provisions and actual practice relates to the requirement for DRS to establish a pilot mechanism to update the spinal cord and brain injury registries. The updating was expected to involve developing, on a pilot basis, a mechanism for including ongoing functional levels and service needs of persons reported to the registries. DRS staff indicate that a pilot project was conducted in 1996 to update the information for individuals who had been reported to the spinal cord registry. No attempt was made to update the brain injury registry. The pilot project for updating the spinal cord injury registry was discontinued by DRS after about 150 individuals had been contacted. The pilot was discontinued due to the time involved in updating the records. Each record-update required a telephone contact which took about an hour to complete for each spinal cord injury survivor.

## Recent Problems with the Reporting of Brain Injuries Has Thwarted Earlier Progress Made in Improving Reporting Compliance

Figure 7 illustrates the number of brain injury reports entered into the registry since 1990. Reports to the registry on residents of other states who sustained a brain injury and were treated in a hospital in Virginia are shown separately from the reports on residents of Virginia. It should also be noted that the number of reports to the registry includes some double-counting of a single TBI occurrence. The data in Figure 7 represent the number of reports of brain injury to the registry rather than the number of distinct individuals reported to the registry. For some of the other reports that seek to describe brain injury patients, DRS staff do try to eliminate the cases in which one individual has been treated and reported by two or more hospitals for the same TBI.

As shown in Figure 7, the number of TBI reports to the registry increased by 66 percent from 1990 to 1996. DRS staff primarily attribute this increase to improved reporting by hospitals rather than a significant increase in the number of brain injuries that occurred. Enhanced efforts to encourage and assist hospitals in reporting on brain injuries were undertaken by DRS and the Brain Injury Association of Virginia during those years.

## Figure 7
## Virginia Brain Injury Registry: Number of Brain Injury Reports
## (1999)

| | Virginia Residents | | Out of State Residents | |
|---|---|---|---|---|
| Calendar Year* | Survived | Deceased | Survived | Deceased |
| **1990** | 5,645 | 166 | 859 | 44 |
| Totals | 5,811 | | 903 | |
| | **6,714** | | | |
| **1991** | 7,371 | 184 | 1,045 | 61 |
| Totals | 7,555 | | 1,106 | |
| | **8,661** | | | |
| **1992** | 8,419 | 176 | 1,100 | 28 |
| Totals | 8,595 | | 1,128 | |
| | **9,723** | | | |
| **1993** | 8,395 | 191 | 2,076 | 59 |
| Totals | 8,586 | | 2,135 | |
| | **10,721** | | | |
| **1994** | 9,126 | 263 | 2,041 | 47 |
| Totals | 9,389 | | 2,088 | |
| | **11,477** | | | |
| **1995** | 9,095 | 237 | 1,772 | 52 |
| Totals | 9,332 | | 1,824 | |
| | **11,156** | | | |
| **1996** | 9,158 | 214 | 1,740 | 50 |
| Totals | 9,372 | | 1,790 | |
| | **11,162** | | | |
| **1997** | 7,841 | 201 | 1,202 | 44 |
| Totals | 8,042 | | 1,246 | |
| | **9,288** | | | |
| **1998** | 6,085 | 136 | 1,173 | 20 |
| Totals | 6,221 | | 1,193 | |
| | **7,414** | | | |
| **1999** | 5,452 | 94 | 940 | 14 |
| Totals | 5,546 | | 954 | |
| | **6,500** | | | |

*Calendar year in which the injury occurred is indicated.

Source: JCHC staff analysis of Virginia Traumatic Brain Injury Registry data.

The decrease in the number of registry reports particularly for the years 1998 and 1999 primarily resulted from reporting problems rather than a substantial decrease in the number of persons sustaining brain injury. The reporting problems seem to involve primarily the data that is reported by Level I Trauma Centers. All but one of the Level I Trauma Centers have been unable to download trauma files for reporting to VDH or DRS since changing to a software package in mid- to late-1999 to ensure Y2K compliance. This means that the brain injury patients treated in the affected hospitals will not be added to the registry or receive the brain injury information from BIAV until the software problems are resolved. This problem recently was exacerbated by DRS not entering patient information into the registry that was contained in hospital diskettes submitted during the time period of late 1999 through early May 2000. DRS temporarily reassigned a staff member in early May to add this diskette information into the registry. Nonetheless, DRS needs to make certain that adequate staffing is provided to ensure diskette data are entered into the registry in a timely manner.

### Estimates of the Number of Traumatic Brain Injuries that Occur in Virginia Indicate Substantial Under-Reporting of Cases

Analyses were conducted to evaluate how the TBI registry information compares with estimates of the number of persons who experience brain injuries. Two different methods were used to estimate the number of brain injuries in Virginia. While the estimates derived from these two methods are substantially different, particularly the estimate of persons dying from TBI, in both analyses, the number of persons in the registry is significantly less than the estimated incidence of TBI in Virginia.

Studies have suggested various methods for estimating the overall incidence of traumatic brain injury. However, any estimate of the total number of TBIs, which occur that do not result in hospital admission or death, would be larger than the number of injuries that hospitals and attending physicians in Virginia are required to report. This is because of the statutory language restricting reporting to injuries expected to result in permanent disability.

The first method for estimating the incidence of TBI in Virginia assumes that Virginia's incidence rate is the same as the nation's estimated TBI-incidence rate. Figure 8 shows the estimates derived from applying the CDC's most recent estimates of TBI incidence in the United

States to Virginia. According to these estimates, each year approximately 37,500 to 50,000 Virginians would sustain TBIs, 25,000 would receive emergency care, 5,750 would be hospitalized, and 1,250 would die from their injuries. In 1997, central registry figures indicate that 2,521 persons were admitted to a hospital and 201 persons died from their brain injury. (It is recognized that the figure for the number of deaths is somewhat understated as that figure would not include deaths that occurred after the case was reported to the registry.)

**Figure 8**

**Estimate of TBI in Virginia Based on Proportion of U.S. Population**

| Incidence Factor Being Estimated | Estimate for the United States | Estimate for Virginia |
|---|---|---|
| Persons sustaining TBI | 1.5 to 2.0 million | 37,500 to 50,000 |
| Persons receiving emergency care for TBI | 1.0 million | 25,000 |
| Persons hospitalized for TBI | 230,000 | 5,750 |
| Persons dying from TBI | 50,000 | 1,250 |

**Source:** JCHC staff analysis using CDC and Census Bureau data.

The analysis described above for estimating the incidence of TBI does not account for differences in Virginia's population make-up that could influence the TBI-incidence. A recent study by the CDC indicated that the TBI incidence is affected by population characteristics, finding that "children, minorities, and the elderly are especially at risk for injury." In September 1992, an estimate of TBI incidence based on "applying age-adjusted national incidence rates to the 1990 census population" was developed for Virginia by the State University of New York (SUNY). The estimates developed in that study are compared with the reported figures for 1997 in Figure 9. This analysis produced a somewhat larger estimate of the number of persons in Virginia expected to be hospitalized for TBI (7,920) than the first analysis (5,750), and a significantly smaller estimate of the number of persons in Virginia expected to die from brain injuries

(538) than the first analysis (1,250). However, both methods indicate there is under-reporting of TBI to the central registry.

**Figure 9**

**TBI Estimate Using Age-Adjusted Incidence Rates Compared with Virginia's TBI Registry Reports**

| Incidence Factor Being Estimated | Estimate Developed by SUNY | Registry Reports for 1997 |
|---|---|---|
| Persons hospitalized for TBI | 7,920 | 2,521 |
| Persons dying from TBI | 538 | 201 |

**Source:** JCHC staff analysis of SUNY and DRS data.

## Implementation Issues Need to Be Addressed by VDH for the Integrated Trauma Registry to Be Viable

VDH and DRS continue to support the goal of having an integrated trauma registry. Hospital representatives contacted for this study also support having one trauma registry to report to rather than three. VDH staff indicated that the integrated reporting system is almost ready for testing in a limited number of hospitals with statewide dissemination being planned for fall of 2000. However, there are some issues regarding implementation of the system that still need to be addressed. These concerns include funding and staffing for project completion and ongoing support, and ensuring the information needs of DRS will be addressed.

VDH has received $470,000 ($70,000 from a highway safety grant from the Department of Motor Vehicles in 1996 and an appropriation of $400,000 during the current biennium) to complete the integrated trauma registry. Although this funding substantially exceeds the original cost estimate of $110,000, implementation has been delayed due in part to the need to fund equipment (computer servers) to support the registry.

To address the different statutory reporting requirements for the spinal cord and brain injury registries, a number of accommodations needed to be made within the integrated trauma registry. For example, the required timeframes for reporting to the registries are very different: within seven days of identification for spinal cord injuries, within 30 days of identification for brain injuries, and within 90 days of hospital discharge for trauma. Staff of Level I Trauma Centers who were contacted and the Virginia Hospital and Healthcare Association representatives agreed that 90 days after discharge was a more reasonable timeframe for all trauma reports. Brain injury advocates, however, have expressed concern that lengthening the reporting timeframe would delay getting outreach information to TBI survivors. One way of addressing these concerns would be to have DRS provide hospitals with written information to give to TBI patients about brain injury and the organizations to contact for assistance. In this way, patients would receive brain injury information more quickly and hospitals would have a more workable reporting timeframe.

Another issue regarding the integrated registry relates to ensuring that DRS staff will have access to spinal cord and brain injury data. DRS currently maintains its own registries so access is not an issue. The integrated reporting system will be maintained by VDH and only hospitals are expected to be authorized to enter information into the system. DRS will need to access certain information from VDH to continue its outreach programs and to maintain its Open Registry Program for self-reported brain injury survivors.

### One Possible Course of Action to Address Noted Concerns Would Be to Make Reporting Guidelines More Consistent with Registry Operations in Other States, And Take Additional Actions To Ensure Brain Injury Information Is Provided For TBI Survivors

One possible course of action that could be taken to address the concerns related to the current brain injury registry involves making Virginia's reporting system more consistent with the TBI registries in other states and with the requirements of the VDH trauma registry. The statutory requirements for reporting brain injuries could be changed to only require hospitals to report on patients who are admitted to the hospital or who die from their injuries prior to hospital admission. This would be consistent with the current requirements for the VDH trauma registry and of the NCIPC guidelines for TBI registries. These reports could be submitted through the integrated trauma reporting system being developed by VDH.

The reporting changes described above would improve the accuracy and consistency of the information in the brain injury registry and would make the reporting system more workable for providers. However, steps would need to be taken to ensure that all TBI survivors, including those not reported to the registry, would receive outreach information. To address the service outreach function of Virginia's TBI registry, a two-pronged approach could be taken. First, DRS/BIAV materials could be provided for hospitals to give directly to TBI patients both in the emergency room and upon admission to the hospital. A copy of the pamphlet that BIAV mails out and a form to allow individuals to report themselves through the Open Registry Program could be included. DRS could continue to maintain a registry for individuals reported through the Open Registry Program which would be separate from the integrated trauma registry maintained by VDH. This would allow the statistics maintained by VDH to be comparable to other Virginia trauma information and the data maintained in most other states. Second, a public awareness campaign could be undertaken to inform the public and health care providers about brain injury. A campaign could be very useful in explaining the importance of the trauma registry and the Open Registry Program, and in addressing the problems of properly diagnosing brain injuries, and the often unrecognized, long-term effects of brain injuries.

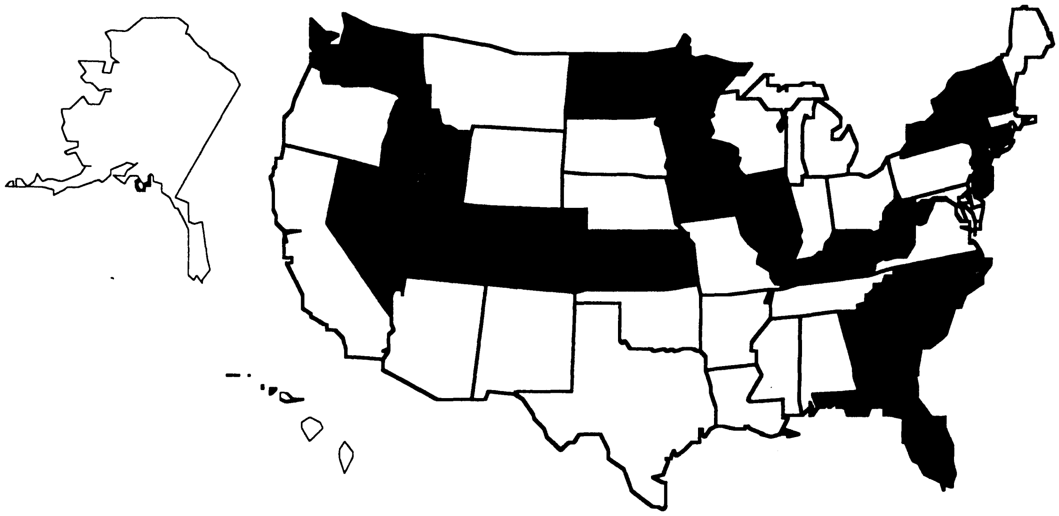
### Advocates and Agency Staff Report That Additional Services For Brain Injury Survivors And Their Families Are A Critical Need that Should Not Be Overlooked

While not a specific focus of the study, the availability of services provided for TBI survivors is a critical issue. A 1997 study by the General Accounting Office (GAO) examined the services provided to individuals with traumatic brain injury. That study reported, "While both the private and public sectors finance acute care services to adults with TBI, federal and state governments pay for a large part of post-acute services received by adults with TBI, primarily because private insurance generally limits post-acute services and does not pay for long-term care, and individuals may quickly exhaust personal resources. In addition, individuals' longevity may be unaffected by the injury, and adults with TBI may require post-acute services for an extended period of time — some for the remainder of their lives." The primary sources of government funding for TBI services discussed in the GAO study included three federal/state programs – Medicaid, Vocational Rehabilitation, and Independent Living Services. These three programs served individuals with wide-ranging disabilities, a relatively small number of whom suffered from traumatic brain injury. Moreover, the study found that relatively few brain injury survivors received the services they needed, even in states which had specifically targeted Medicaid services to address those needs.

According to a 1999 study by the national Brain Injury Association, 21 states have a traumatic brain injury home/community-based Medicaid waiver (Figure 10). Virginia is not among these 21 states. However, in February 2000, Virginia applied to the Health Care Financing Administration (HCFA) for a Medicaid waiver for home and community-based services for persons with developmental disabilities. The waiver was approved by HCFA in early May. The waiver is designed to serve some TBI survivors but will not serve as many survivors as a waiver specifically designed to provide brain injury services. Virginia's Medicaid waiver for developmental disabilities will serve individuals age six and older whose disability became apparent prior to age 22. Children, under the age of six, are already served by Virginia's Medicaid waiver for Mental Retardation. Limiting eligibility to individuals whose disability onset is prior to age 22, is consistent with federal regulations regarding developmental disabilities. The waiver is expected to serve 254 individuals with developmental disabilities in FY 2001 and 323 individuals in FY 2002.

**Figure 10**

**States With TBI Home - Community Based Medicaid Waivers**



■ States with TBI Home-Community Based Medicaid Waivers

**Source:** National Association for State Head Injury Administrators, 1999

## The Commonwealth Spends A Total Of Approximately $10.0 Million Per Year in Support Services That Benefit Persons With Physical Disabilities, About $2 Million Of This Amount Is Specifically Directed To TBI Survivors; Advocates for Brain Injury Survivors Argue the Need Is Much Greater

In FY 2001, the Commonwealth will spend almost $10.0 million on services provided by or contracted through DRS to benefit persons with physical disabilities, including TBI survivors. Figure 11 includes a description of the services, funding, and number of persons that are expected to be included in programs specifically targeted to TBI survivors. As seen in Figure 11, the funding that is specifically directed to serve 800 TBI survivors represents about one-fifth of the $10.0 million total.

Figure 12 provides the same type of description for programs DRS will provide more broadly for physically disabled individuals, some of whom are brain injury survivors. DRS indicated that for all six service categories shown – case management, community living, personal assistance, day programs, supported employment, supported living, and clubhouse programs – there are additional TBI survivors who could be served if resources allowed.

## Figure 11
## Summary of Services Provided Specifically for Brain Injury Survivors
## Fiscal Year 2001

| | | | |
|---|---|---|---|
| **Case management** services including assessment and coordination of services to assist individuals to live in the community and avoid institutionalization. | | | |
| | State Funding | Federal Funding | Persons Served |
| Long-Term Rehabilitation Case Management | $504,000 | $0 | 300 |
| Brain injury Services (nonprofit in Fairfax) | $392,643 | $0 | 250 |
| **Community living** services providing compensatory rather than restorative services including life skills training and treatment for individuals needing at least two medically-related rehabilitation services such as physical, occupational, or speech therapy. | | | |
| | State Funding | Federal Funding | Persons Served |
| DRS Cognitive Rehabilitation Program | $150,000 | $0 | 25 |
| Woodrow Wilson Brain Injury Services Program | $175,000 | $0 | 75 |
| **Personal assistance** involving services such as dressing, bathing, cooking, and housekeeping provided by personal assistants, selected by the consumer. | | | |
| | State Funding | Federal Funding | Persons Served |
| DRS Consumer-Directed Personal Assistance Services Program for People with Brain Injuries | $100,000 | $0 | 13 |
| **Day programs** providing activities designed to help individuals improve their independent living, social, and vocational skills. | | | |
| | State Funding | Federal Funding | Persons Served |
| Brain Injury Services (nonprofit in Fairfax) | $135,000 | $0 | 55 |
| Commonwealth Support Services (nonprofit in Virginia Beach) | $100,000 | $0 | 25 |
| ICON Community Services (nonprofit in Fredericksburg) | $100,000 | $0 | 25 |
| **Supported living** providing services within individual, shared, and group residences. | | | |
| | State Funding | Federal Funding | Persons Served |
| Brain Injury Services (nonprofit in Fairfax) | $203,198 | $0 | 12 |
| **Clubhouse program** involving programming that is primarily supported by the efforts of the Clubhouse members who are also encouraged to be employed outside the clubhouse and to be involved in community activities. | | | |
| | State Funding | Federal Funding | Persons Served |
| Career Support Systems (nonprofit in Richmond) | $25,000 | $75,000 | 20 |
| **TOTAL** | **$1,884,841** | **$75,000** | **800** |

**Source:** JCHC staff summary of DRS data.

## Figure 12
## Summary of Services Provided for Physically Disabled Individuals Including Some Brain Injury Survivors
## (Fiscal Year 2001)

**Employment services** including individualized assistance including job placement and on-site training and follow-up, and sheltered workshops and enclaves.

| | State Funding | Federal Funding | Persons Served |
|---|---|---|---|
| Supported Employment for Persons with Physical Disabilities | $350,000* | $0 | 70 |
| Extended Employment Services | $3,212,458* | $0 | 725** |
| Long-Term Employment Support Services | $4,275,000* | $0 | 1,800** |
| **TOTAL** | **$7,837,458** | **$0** | **2,595** |

* A portion of these amounts is spent on persons with physical disabilities other than brain injuries.
**A number of the persons served will have physical disabilities other than brain injury.
**Source:** JCHC staff summary of DRS data.

In the next few weeks, DRS will report the findings of a needs assessment for brain injury services that was conducted during last year. Assessment findings will be incorporated into a State Plan which will assist DRS in prioritizing and addressing unmet TBI service needs.

# V.
# Policy Options

The following Policy Options are offered for consideration by the Joint Commission on Health Care. They do not represent the entire range of actions that the Joint Commission may wish to pursue with regard to the Brain Injury Registry.

**Option I** **Take No Action**

**Option II** **Retain current statutory reporting requirements, and provide additional funding (amount to be determined later) to the Department of Rehabilitative Services and the Virginia Department of Health to increase technical assistance and compliance monitoring of hospitals and physicians.**

**Option III** **Introduce legislation transferring responsibility for collecting brain injury and spinal cord reports from the Department of Rehabilitative Services to the Virginia Department of Health (VDH) as part of VDH's new integrated trauma reporting system. The legislation could include some or all of the following provisions:**

- **a. deleting current language in §51.5-11 requiring a pilot mechanism for conducting updates on the functional level and service needs for persons on the registry;**
- **b. requiring that only brain injury patients who are admitted in a hospital would be reported through the integrated reporting system (patients released from emergency rooms and treated in physician offices would not be reported);**
- **c. deleting the requirement that brain injuries are to be reported only "if permanent disability is likely to result;"**
- **d. providing DRS with access to the registry information to continue its outreach services and other agency functions;**
- **e. requiring DRS to provide brochures, pamphlets and other brain injury outreach information to hospitals for distribution to brain injury patients admitted to the hospital and released from emergency rooms;**

f. changing the current timeframe (30 days) for hospitals to report brain injuries to a timeframe that is consistent with the guidelines developed by VDH for the integrated trauma registry; and

g. including a second enactment clause directing the Commissioner of Health to form a task force, with representation from DRS, the Brain Injury Association of Virginia, the Brain Injury Council, and the Virginia Hospital and Healthcare Association to review the status of the new reporting system and identify any further actions needed to improve the completeness and timeliness of the registry information.

Option IV Introduce legislation authorizing the Department of Rehabilitative Services to maintain an Open Registry Program for brain injury survivors who were not reported by a hospital or physician to the central registry. The legislation could include a provision authorizing the Open Registry Program to include survivors of acquired, congenital, or disease-induced brain injuries.

Option V Introduce a budget amendment to provide additional resources (amount to be determined later) to the Department of Rehabilitative Services for a public awareness campaign regarding brain injury including the importance of reporting such injuries to the trauma registry. Funding also would be provided for outreach materials to be provided to hospitals for distribution to brain injury patients.

Option VI Introduce a budget amendment (amount to be determined later) which provides additional resources to the Department of Rehabilitative Services to fund brain injury services as recommended in the revised State Plan.

Option VII Introduce legislation to discontinue the brain injury registry by deleting the current language within §51.5-11 of the *Code of Virginia* that requires the Department of Rehabilitative Services to maintain the central registry.

# APPENDIX A

COMMONWEALTH OF VIRGINIA
HOUSE OF DELEGATES
RICHMOND

S. VANCE WILKINS, JR.
SPEAKER

SPEAKER'S ROOM
STATE CAPITOL
POST OFFICE BOX 406
RICHMOND, VIRGINIA 23218

TWENTY-FOURTH DISTRICT

COMMITTEE ASSIGNMENTS:
RULES (CHAIRMAN)

March 10, 2000

Mr. Patrick W. Finnerty
Executive Director, Joint Commission on Health Care
Old City Hall, Suite 115
1001 East Broad Street
Richmond, Virginia 23219

Dear Mr. Finnerty:

During the 2000 Session of the General Assembly, the House Committee on Rules considered House Joint Resolution 219, patroned by Del. Thomas M. Jackson, Jr. and Senate Joint Resolution 190, patroned by Sen. Linda T. Puller, which directed the Disability Commission to evaluate the current system for reporting brain injuries to the central registry, and the dissemination of information to survivors and their families concerning available assistance. In an effort to reduce the number of study resolutions, House Joint Resolution 219 and Senate Joint Resolution 190 were among those that were not reported. However, the House Rules Committee believes that the issues addressed by the resolution merit review. Therefore, the Commission is directed to undertake the study and to submit a written report of its findings and any recommendations to the Governor and to the 2001 Session of the General Assembly. It is requested that you notify Del. Jackson and Sen. Puller of any meetings that are scheduled by the Commission to consider the study issues, and that you regularly apprise the patrons concerning the Commission's deliberations on such matters. Further, please note that this study request expires at the end of the 2000 legislative year. I am enclosing copies of HJR 219 and SJR 190 for informational purposes so that you may be informed of the objectives of the study.

Your cooperation and assistance in this matter are appreciated.

Sincerely,

S. Vance Wilkins, Jr.
Speaker

/bhe
Enclosure (HJR 219 and SJR 190)
cc: The Honorable Thomas M. Jackson, Jr.
The Honorable Linda T. Puller
The Honorable Bruce F. Jamerson
The Honorable Susan Clarke Schaar

# HOUSE JOINT RESOLUTION NO. 219

Offered January 24, 2000

*Requesting the Disability Commission to evaluate the current system for reporting brain injuries to the central registry and for disseminating information to survivors and their families about available assistance.*

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Patron—Jackson

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Referred to Committee on Rules

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WHEREAS, traumatic brain injury is the leading cause of long-term disability among children and young adults; and

WHEREAS, approximately two million people incur traumatic brain injury each year as a result of vehicle accidents, falls, acts of violence and sports injuries; and

WHEREAS, traumatic brain injury can affect a person cognitively, physically, and emotionally; and

WHEREAS, an unknown number of patients are released from hospital emergency rooms after sustaining a head injury without information on the potential for life-changing disabilities or the proper agencies to contact once symptoms occur; and

WHEREAS, since time without action taken can be destructive to the quality of life for survivors of brain injury and their families, it is crucial that an effective system be in place to provide information to families about the available supports and assistance; and

WHEREAS, § 51.5-11 of the Code of Virginia requires the Department of Rehabilitative Services to "establish and maintain a central registry of persons who sustain spinal cord injury other than through disease, whether or not permanent disability results, and brain injury if permanent disability is likely to result, in order to facilitate the provision of appropriate rehabilitation services by the Department and other state agencies to such persons"; and

WHEREAS, every year, thousands of names are not reported to the registry and those who are reported sometimes do not receive information in a timely manner; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Disability Commission be requested to evaluate the current system for reporting brain injuries to the central registry and for disseminating information to survivors and their families about available assistance. The Disability Commission shall examine: (i) the procedures for reporting data to the registry, including who is required to report and when; (ii) the comprehensiveness and accuracy of registry data; and (iii) the timeliness and usefulness of information that is disseminated to survivors and their families.

All agencies of the Commonwealth shall provide assistance to the Disability Commission, upon request.

The Disability Commission shall complete its work in time to submit its findings and recommendations to the Governor and the 2001 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

007310518

## SENATE JOINT RESOLUTION NO. 190

Offered January 24, 2000

*Requesting the Disability Commission to evaluate the current system for reporting brain injuries to the central registry and for disseminating information to survivors and their families about available assistance.*

---

Patron—Puller

---

Referred to Committee on Rules

---

WHEREAS, traumatic brain injury is the leading cause of long-term disability among children and young adults; and

WHEREAS, approximately two million people incur traumatic brain injury each year as a result of vehicle accidents, falls, acts of violence and sports injuries; and

WHEREAS, traumatic brain injury can affect a person cognitively, physically, and emotionally; and

WHEREAS, an unknown number of patients are released from hospital emergency rooms after sustaining a head injury without information on the potential for life-changing disabilities or the proper agencies to contact once symptoms occur; and

WHEREAS, since time without action taken can be destructive to the quality of life for survivors of brain injury and their families, it is crucial that an effective system be in place to provide information to families about the available supports and assistance; and

WHEREAS, § 51.5-11 of the Code of Virginia requires the Department of Rehabilitative Services to "establish and maintain a central registry of persons who sustain spinal cord injury other than through disease, whether or not permanent disability results, and brain injury if permanent disability is likely to result, in order to facilitate the provision of appropriate rehabilitation services by the Department and other state agencies to such persons"; and

WHEREAS, every year, thousands of names are not reported to the registry and those who are reported sometimes do not receive information in a timely manner; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the Disability Commission be requested to evaluate the current system for reporting brain injuries to the central registry and for disseminating information to survivors and their families about available assistance. The Disability Commission shall examine: (i) the procedures for reporting data to the registry, including who is required to report and when; (ii) the comprehensiveness and accuracy of registry data; and (iii) the timeliness and usefulness of information that is disseminated to survivors and their families.

All agencies of the Commonwealth shall provide assistance to the Disability Commission, upon request.

The Disability Commission shall complete its work in time to submit its findings and recommendations to the Governor and the 2001 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

# APPENDIX B

# JOINT COMMISSION ON HEALTH CARE

## SUMMARY OF PUBLIC COMMENTS: VIRGINIA BRAIN INJURY REGISTRY STUDY

### Individuals/Organizations Submitting Comments

A total of 14 individuals and organizations submitted comments in response to the Virginia Brain Injury Registry Report.

- Brain Injury Association of Virginia, Inc.
- Brain Injury Association of Virginia, Richmond Chapter
- Fran S. Caldwell
- Chippenham and Johnston-Willis Medical Centers
- Hampton Roads Neuropsychology, Inc.
- Barbara Iddings
- The Jason Foundation
- Tom Kehoe
- The Medical Society of Virginia
- Madeline Ray
- Reverend Clyde Shelton
- Southside Virginia Head Injury Support Group
- Virginia Hospital and Healthcare Association
- Virginia Trauma Nurse Coordinator Council

### Policy Options Included in the Virginia Brain Injury Registry Issue Brief

**Option I: Take No Action**

**Option II: Retain current statutory reporting requirements, and provide additional funding (amount to be determined later) to the Department of**

## Overall Summary of Comments

There was a great deal of diversity in the comments that were received. The following table summarizes the comments that were received on each Policy Option. Only responses that indicated positions consistent with the respective options are included in the table. (For example, although an eighth option proposed by one commenter included some of the provisions of the proposed options, this overlap is not shown in the table.) As shown, Options II, IV, V, and VI were supported by the largest number of commenters (seven) while four commenters favored Option III and one favored Option VII. Option VII was specifically opposed by three commenters, Option I was opposed by two commenters, while Options II, III, V, and VI each received one comment in opposition.

| Policy Option | Number of Comments in Support | Number of Comments in Opposition |
|---|---|---|
| I | 0 | 2 |
| II | 7 | 1 |
| III | 4 | 1 |
| IV | 7 | 0 |
| V | 7 | 1 |
| VI | 7 | 1 |
| VII | 1 | 3 |

## Summary of Individual Comments

### Brain Injury Association of Virginia, Inc.

Michael Martelli, Ph.D., President commented on behalf of the Association's Board of Directors "to express our strong support for the continued operation of the Virginia Brain Injury Registry." Dr. Martelli commented in support of Options II, V, and VI. Dr. Martelli stated: "We strongly urge that specific techniques and methods be developed for ensuring timely reporting, up to and including invoking sanctions to emphasize the importance of this information. In addition, any enhancements of the system must include mechanisms for identifying all categories of acquired brain injury, including mild brain injuries, and those treated in emergency rooms, doctors' offices, and trauma centers, but not hospitalized."

Dr. Martelli expressed opposition to Options I and VII noting that both options "are completely unacceptable. Survivors of brain injury, their loved ones and caregivers, and healthcare professionals throughout the state depend on this vital source of information for a variety of uses, not the least of which is ensuring that information regarding brain injury and available resources reaches people quickly. It is extremely important that this registry be continued and enhanced."

**Brain Injury Association of Virginia, Richmond Chapter**

Richard Spomer, LBSW, President, commented in support of Options II, IV, V, and VI. Mr. Spomer indicated that as a brain injury survivor and professional social worker he hopes that legislative action will be taken to accomplish these four options.

**Fran S. Caldwell**

Fran S. Caldwell commented in support of Options II, V, and VI. Ms. Caldwell stated, "As a caregiver I have found that information dealing with brain injuries and funding for programs have been less than adequate and BIAV has been a valuable asset to me and my family in dealing with the many varied problems that have arisen with my husband."

**Chippenham and Johnston-Willis Medical Centers**

Margaret Lewis, COO, commented in support of Options II, III, and V.

**Hampton Roads Neuropsychology, Inc.**

Scott W. Sautter, Ph.D., on behalf of Hampton Roads Neuropsychology, Inc. expressed support of Options II, IV, and VI. Dr. Sautter indicated his support for allowing the Department of Rehabilitative Services to continue to maintain the Brain Injury Registry (Option II), by establishing "an online reporting system [which] would be the most efficient means of documentation, and in turn would provide a more timely and reliable manner of communicating to the Brain Injury Association of Virginia the individuals in need of services." Dr. Sautter also supports reporting all acquired brain injuries since "separating the definitions of acquired and traumatic brain injury is confusing and does not help to appropriately serve the injured individuals or their families." In commenting in support of Option IV, Dr. Sautter indicated that the Open Registry Program should be continued and that professionals who are most likely to treat individuals with brain injury should be specifically encouraged to report. Dr. Sautter reported support for Option VI stating that once steps are taken to appropriately define brain injury and to better determine the incidence of acquired brain injury, the Legislature [will be provided with] accurate data from which to make informed decisions about allocation of funds. Increased funding can then be made available to the injured persons through a variety of services...."

Dr. Sautter reported opposition to Option VII stating that "doing away with the registry will be more costly in misspent dollars allocated inappropriately by uninformed decision-making, which will increase the burden of care to families ill equipped in knowledge with devastating emotional consequences."

## Barbara Iddings

Barbara Iddings, a survivor of mild traumatic brain injury, commented in support of Options II, IV, V, and VI. In support of these four options, Ms. Iddings indicated: "Too often [support group] members relate stories of not having 'information and education' in the early stages post injury and how that lack caused increased stress, trauma, and a direct effect on the quality of living; and at times, great delays in recovery."

Ms. Iddings commented in opposition to Option III, noting there would be no requirement to report individuals with mild brain injury to the registry. Ms. Iddings stated that "these individuals suffer tremendous alterations in their lives. Without quick recognition, treatment, and education, an individual who might return to an independent, self-supporting life style becomes dependent on society for their basic needs, which includes financial support. Indeed, it would be cost effective to include these individuals in the Registry."

**The Jason Foundation**

Fran Rooker, President, offered an eighth recommendation for the Commission's consideration. This recommendation incorporates some provisions that are similar to the provisions offered in Options III, IV, V, and VI. In general, Option VIII would involve the following:

1.) transfer responsibility for collecting brain injury and spinal cord injury reports to the Virginia Department of Health;
2.) allow the Department of Rehabilitative Services to retain responsibility for maintaining the brain injury and spinal cord injury central registries and for conducting all related outreach services;
3.) require that all survivors of brain injury, regardless of the cause of the injury or whether permanent disability is likely to result, to be reported to the brain injury registry;
4.) establish a task force whose membership would be similar to the task force recommended in Option III but whose purpose would be to "oversee a two-year site-based (Carilion Roanoke Memorial Trauma Center) effort to put into effect a point of entry electronic system of required reporting of patients released from an emergency room with a diagnosis and/or coding of brain injury/head injury;"
5.) authorize the Department of Rehabilitative Services to continue to maintain an Open Registry Program which "could be the method by which physicians are required to report;"
6.) provide funding for the Department of Rehabilitative Services to allow for public awareness campaigns and to provide outreach materials for hospitals to give to brain injury survivors; and
7.) provide funding for additional brain injury services "as recommended in the revised State Plan, and as found

appropriate for the increased number of survivors of brain injury reported to the center registry through the integrated trauma and affiliated reporting systems."

## Tom Kehoe

Tom Kehoe, the parent of a brain injury survivor, indicated that questions regarding the operation of the brain injury registry should be answered in order to determine how to address the registry's current operation. Mr. Kehoe noted, "I would suggest that we revisit the basic requirement for a registry and determine whether we should be reporting TBI or ABI; what is the required reporting timeframe; should we allow (encourage) an Open Registry; do we need a pilot mechanism; are sanctions viable; should we have more than one system (three registries?); do we need Point of entry Reporting System; should we tie this to expanded BI services; etc. These are basic requirements that need to be settled before we decide upon management options. Unfortunately, the study did not address requirements; choosing instead to rush into a number of unfathomable management options." Mr. Kehoe indicated that four options should result from a study of brain injury registry requirements. First, to maintain the status quo. Second, to require the Department of Rehabilitative Services to "develop a (resourced) 'get well' plan." Third to require the Department of Health to "develop (also resourced) a 'transfer of responsibility' plan." Fourth, to delete the requirement in the *Code of Virginia* to have a registry.

Mr. Kehoe did not express support or opposition for any of the seven suggested options.

## The Medical Society of Virginia

Michael Jurgensen, Director of Health Policy, expressed support for Options III and IV. Option III was noted as providing "the most effective means of addressing the current problems as outlined in the brief. In addition, Option IV offers the opportunity for other patients and providers who may not have used the Central Registry to still report."

Mr. Jurgensen commented in opposition to Options I, II, V, or VI as those options do not "adequately address resolution to the current problems of the registry." Option VII was not supported because discontinuing the registry was seen as "depriv[ing] patients, providers, and researchers of a potentially useful resource in the treatment and rehabilitation of patients suffering from serious brain injuries."

### Madeline Ray

Madeline Ray noted that as a survivor of brain injury, she wanted to comment in support of Options II, IV, V, and VI. Ms. Ray stated that "right now we have very limited opportunities and programs for survivors especially in our area [Roanoke]. Brain injury can happen to anyone at anytime and we all need help."

### Reverend Clyde Shelton

Reverend Clyde Shelton expressed support for expanding the brain injury registry to include all brain injured persons and for Option VI, to provide additional resources to fund brain injury services. Reverend Shelton noted, "It is extremely difficult to know who our brain injured people are. The local and regional chapters and support groups have limited means. We can offer encouragement and hope along with some social activities. Without contact with them even these cannot be extended. Please help in order that brain injured can be identified and informed there are some who are interested in them. In regard to additional resources it is our experience...that after the hospital and the therapy the brain injured and their families are left to function alone."

### Southside Virginia Head Injury Support Group

Fifteen members of the Southside Virginia Head Injury Support Group commented in support of the brain injury registry remaining active and being "expanded upon to include Option VIII as recommended by The Jason Foundation."

## Virginia Hospital and Healthcare Association

Katherine M. Webb, Senior Vice President commented in support of Options VII, (part of) III, IV, and V. Ms. Webb indicated, "Virginia's hospitals and health systems are committed to the concept of health care provider accountability. For this reason, we have consistently supported the collection and timely analysis of data on quality of patient care. However, we believe that it is essential to ensure that only those specific data collection efforts that enhance patient care are continued and that they are as efficient as possible." Ms. Webb supported implementing Option VII which would discontinue the brain injury registry in concert with provisions in Option III to require data on brain and spinal cord injury to be reported as part of an integrated trauma registry administered by the Virginia Department of Health. "The DRS and DOH should share information from the trauma registry as needed to allow service outreach and follow-up and the DRS could work to educate the public on brain injury, consistent with Options IV and V."

## Virginia Trauma Nurse Coordinator Council

Lou Ann G. Miller, RN, BSN, Chairman, commented in support of some of the provisions of Option III and in support of Option IV. In addressing Option III, Ms. Miller indicated support for: (1) having a single trauma registry; (2) reporting on only "brain-injured patients who are admitted, transferred, or die as a result of injury;" (3) changing reporting timeframes to be within 90 days of discharge, transfer or death; (4) ensuring that "any registry initiatives through the Department of Health undergo close scrutiny and ongoing review;" and (5) including representatives from the Trauma Nurse Coordinator Council, Trauma Registrars, and the Emergency Nurses Association on any task force that is formed. With regard to Option IV, Ms. Miller stated, "In order to maintain the integrity of Virginia Department of Health's new integrated trauma reporting system all information must come through a validated source, i.e. hospitals. While we encourage the Department of Rehabilitative Services to maintain an open registry program we strongly urge this be maintained as a separate entity."

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