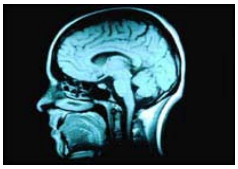

Interim Report: Progress in Expanding Access to Brain Injury Services SJR 80 – Senator Ruff

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Study Mandate

- SJR 80, introduced by Senator Frank M. Ruff, Jr. in 2014, asked that the Joint Legislative Audit and Review Commission (JLARC) review progress in implementing recommendations from the 2007 staff review as well as make additional "recommendations for increasing access to brain injury services" in the Commonwealth
- Senate Rules Committee members requested that the Joint Commission on Health Care (JCHC) complete the review

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Presentation Outline

- Background
- Progress on Recommendations of the 2007 JLARC Study
- Current Concerns that Resulted in the Introduction of SJR 80
- Study Issues for Final Report in 2015

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Acquired Brain Injury (ABI)

- **Acquired brain injury (ABI):** Acquired brain injury is an inclusive term that refers to brain trauma that occurs after birth. ABI does not include diseases that are a result of a progressive loss of cells in the nervous system such as Alzheimer's, Parkinson's, and Amyotrophic lateral sclerosis (ALS), often referred to as "Lou Gehrig's Disease", a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord.
- Two of the leading causes of **acquired brain injury** are stroke and **traumatic brain injury (TBI)**. However, acquired brain injury can also be caused by oxygen deficiency, infectious diseases (e.g., meningitis), toxic chemical exposure, electrical shock, and brain tumors (Virginia Brain Injury Council, 2010, p. 8).

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What is Traumatic Brain Injury (TBI)?

- "A TBI is caused by a bump, blow, or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. Not all blows or jolts to the head result in a TBI. The severity of a TBI may range from 'mild' (i.e., a brief change in mental status or consciousness) to 'severe' (i.e., an extended period of unconsciousness or memory loss after the injury). Most TBIs that occur each year are mild, commonly called concussions and also referred to as mTBI."

Source: Centers for Disease Control and Prevention (CDC), National Center for Injury Prevention and Control. Report to Congress on mild traumatic brain injury in the United States: steps to prevent a serious public health problem. Atlanta (GA): Centers for Disease Control and Prevention; 2003.

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Traumatic Brain Injury Severity Criteria

Severity	Glasgow Coma Scale Score	Posttraumatic Amnesia	Loss of Consciousness
Mild	13–15	<1 day	0–30 minutes
Moderate	9–12	>1 to <7 days	>30 min to <24 hours
Severe	3–8	>7 days	>24 hours

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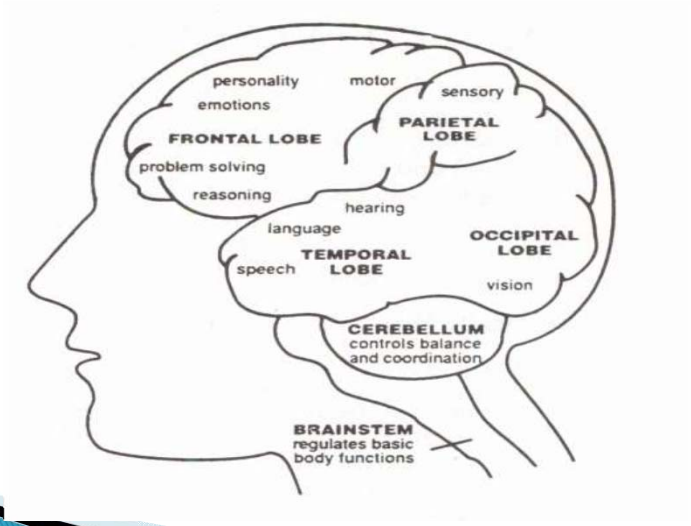
Functions of the Brain



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Neurobehavioral Needs

- **Neurobehavioral:** Neurobehavioral refers to the way the brain affects emotion, behavior, or learning (United States Centers for Disease Control and Prevention, 2014).
- **Neurobehavioral needs:** Neurobehavioral needs refer to the compromising cognitive, behavioral, and/or social changes that result from an acquired brain injury (ABI). Although these needs and their duration vary depending on the severity of the injury, individuals with both mild and severe brain trauma may experience changes in their personalities, find problem solving difficult, experience a lack of motivation, or act impulsively (Wood, 2001; Zasler, Martelli, & Jacobs, 2013; Baddley, 1986; Evans, 2001).

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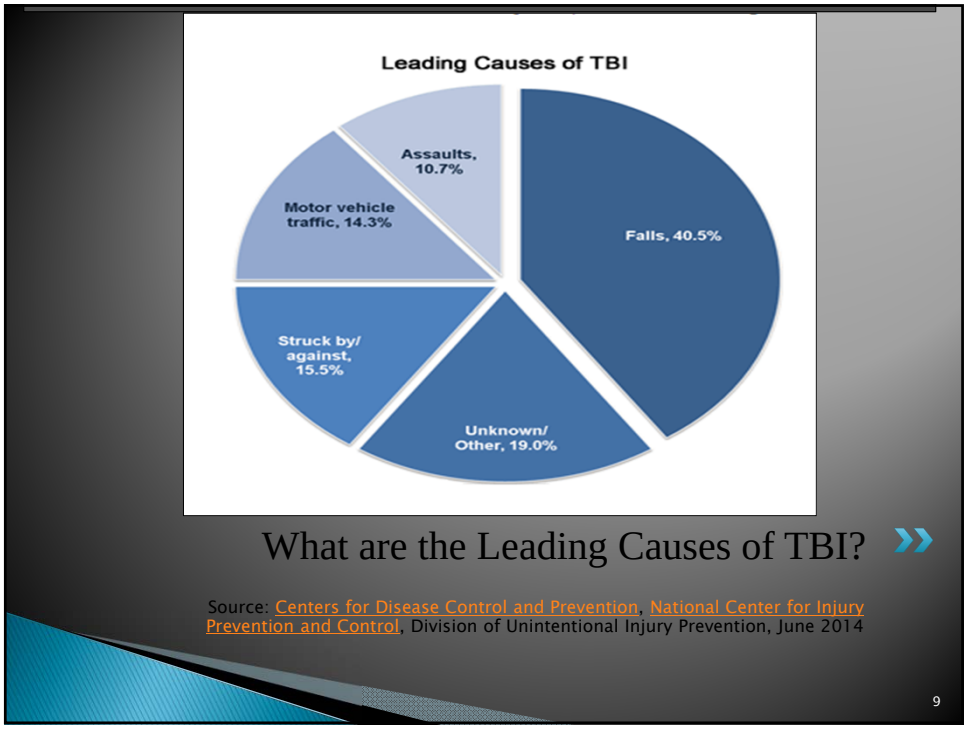

National and State Estimates

- The Centers for Disease Control and Prevention (CDC) estimate that 1.7 million people in the U.S. sustain traumatic brain injuries (TBIs) annually and at least 5.3 million children and adults live with a permanent disability as a result of a TBI
- Every year, an estimated 28,000 Virginians sustain a brain injury; approximately 1,400 die and 5,000 are hospitalized.

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State Services for Individuals with TBI and Their Families

- States began responding to families calling for services and assistance to address the unique cognitive and behavioral needs of individuals with TBI
- Often, these individuals found that their insurance coverage was insufficient to cover the array of short-term and long-term rehabilitation care and supports.
- States began developing infrastructure and capacity for addressing these complex, unique needs associated with TBI-related disabilities

Source: National Association of State Head Injury Administrators (NASHIA)

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State Services for Individuals with TBI and Their Families

- States use a combination of funding streams to support an array of services, including State revenue, dedicated funding (trust fund), usually from traffic fines; Vocational Rehabilitation, federal grants, and Medicaid
- Brain injury services in Virginia are primarily funded through State general funds and non-general funds including funding from the Brain Injury Direct Services Fund and the Commonwealth Neurotrauma Initiative Trust Fund

Source: National Association of State Head Injury Administrators (NASHIA)

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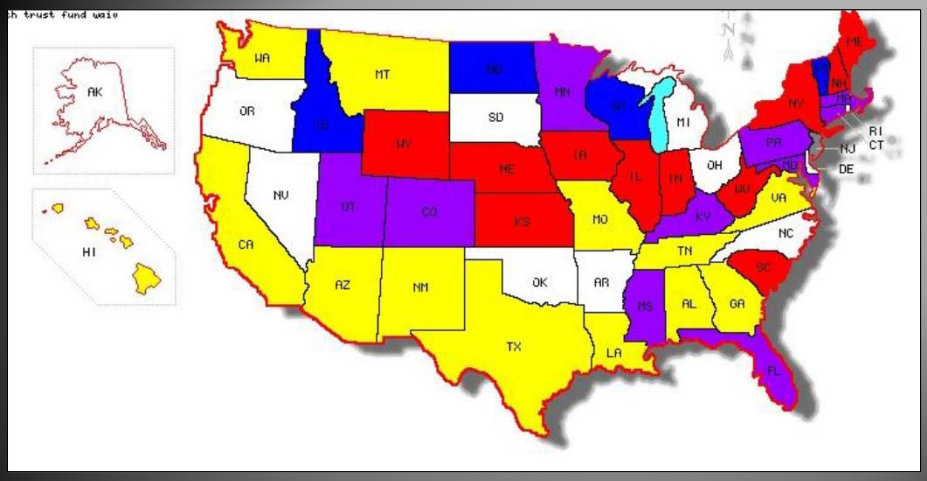

State TBI Programs

Yellow – Trust Fund Programs Only; Red – TBI/ABI Medicaid HCBS Waiver Program; Purple – Both Trust Fund and Waiver Programs; Blue – Combined TBI Waiver into other disability HCBS or long-term waiver programs Grey– Transitioning from TBI Waiver to Combined waiver
Source: National Association of State Head Injury Administrators

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JLARC 2007 Report *Access to State-Funded Brain Injury Services in Virginia*

- Item 21F of 2006 Appropriation Act directed JLARC to consider the range of available community-based services, payment options for such services, and the allocation of funding provided through DRS to meet brain injury service needs. The 2007 JLARC study found:
  - Services provided and funded by the State had increased but "some parts of the State have no or very few services…and access to existing services remains limited"; a concern made more pressing by the number of military service members returning with TBIs.
  - Hospital-reporting to the DRS brain injury registry was duplicative of the reporting required to the Health Department's Virginia Statewide Trauma Registry.
  - "The extent to which Virginia provides services for the State's population with brain injury is a policy choice. If additional resources are available, the State may want to address first the needs of those with the most severe functional disabilities."

(At the time of the JLARC report, the Department of Rehabilitative Services had not been combined with the Department for the Aging, which occurred in 2012. Consequently DRS and DARS will be used as appropriate throughout the slides.)

Source: JLARC Report, *Access to State-Funded Brain Injury Services in Virginia*, SD No. 15 (2007) pp. iii-viii.

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Progress on 2007 JLARC Recommendations

Recommendation 1:
Relevant State entities should develop a plan "to address coordination and access to brain injury services by active and retired military"

- The Virginia Wounded Warrior Program was (VWWP) was statutorily established in 2008 to provide a mental health and rehabilitative program for veterans within the Department of Veterans Services in cooperation with DMHMRSAS and DRS.

Implemented

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Progress on 2007 JLARC Recommendations

Recommendation 2:
DRS "should perform or contract with a third party to annually perform program evaluations of at least two State-contracted brain injury providers"

- DARS reported that since FY 2008, the required number of programs evaluated per year has, on average been met or exceeded.
- In FY 2013, DARS staff conducted 8 program evaluations and 2 fiscal audits; in FY 2014, 5 program evaluations and 2 fiscal audits will be conducted.

Implemented

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Progress on 2007 JLARC Recommendations

Recommendation 3:
DRS' "Brain Injury and Spinal Cord Injury Services unit should include language in all State- funded contracts with brain injury service programs requiring each program to submit the annual independent audit that is conducted of each program. DRS should review these documents and share them with the department's Internal Audit Division to ensure appropriate use of State and federal funds."

- DARS includes the requirement for an annual independent financial audit in all State-funded brain injury services program contracts. The audits are shared with the Community Based Services Division fiscal audit specialist who uses the reports when conducting fiscal evaluations of the programs

Implemented

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Progress on 2007 JLARC Recommendations

Recommendation 4:
The General Assembly may wish to consider amending § 32.1-116.1 of the *Code of Virginia* to require (1) all licensed hospitals rendering emergency medical services to report to the Virginia Statewide Trauma Registry (VSTR) patient-level information on all persons diagnosed with a brain and/or spinal cord injury, sustained other than through disease, using the VSTR's reporting requirements, and (2) the Virginia Department of Health (VDH) to transmit such information" to DRS

- SB 197, enacted in 2008, required VDH to make available and share all information contained in the Virginia Statewide Trauma Registry with DRS to allow for the development and implementation of programs and services for persons suffering from brain injuries

Implemented

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Progress on 2007 JLARC Recommendations

Recommendation 5:
"The General Assembly may wish to consider amending …the *Code of Virginia* to eliminate statutory language requiring hospital reporting to the brain injury registry and to direct DRS "to obtain the brain and/or spinal cord injury data collected by the Virginia Statewide Trauma Registry."

- SB197, enacted in 2008, eliminated the statutory language requiring hospital reporting to the brain injury registry by repealing § 51.5-11.
  - However, the unintended consequence is that information is no longer reported to DARS on patients sustaining mild brain injury/concussions who are not hospitalized although mild brain injuries account for 80% of acquired TBIs

Implemented

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Progress on 2007 JLARC Recommendations

Recommendation 6:
DRS should convene a work group including VDH, "brain and spinal cord injury stakeholders, and others as needed to identify the appropriate data elements needed from the VSTR and the most appropriate electronic format for transmitting that information."

- DRS worked with VDH to identify data elements needed to conduct outreach. Information Systems staff from both DRS and VDH worked to develop an electronic format for transmitting information from VSTR to DRS which conducts outreach via a contract with the statewide advocacy organization, the Brain Injury Association of Virginia.

Implemented

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Progress on 2007 JLARC Recommendations

Recommendation 7:
DRS "should require all State-funded brain injury service programs to provide the department with [descriptive] information required by §51.5-11(B) of the *Code of Virginia.* The information should be reported each time a provider is contracted or makes contact with a new person with brain injury."

- DARS staff reported that this "recommendation was not implemented primarily because it would be a duplication of effort for the state-funded Brain Injury Services (BIS) Programs to report this information to DARS. The purpose of outreach activities is to inform people about available services and supports…and if an individual is already being served by a BIS Program, there is no need for DARS to receive name / address information so that DARS can mail an outreach and awareness brochure."
- In FY 2014, "DARS contractually required all state-funded BIS Programs to use 'Brain Injury First' software, which would allow DARS to have access for the purpose of collecting a wide variety of information on all individuals receiving services"

Not Implemented

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Progress on 2007 JLARC Recommendations

Recommendation 8:
DRS "should integrate the brain injury information it collects into the department's program, policy, and fiscal planning."

- DARS "reports that the department uses information obtained through its outreach activities in reporting incidence (number of people admitted to the hospital for treatment of a brain injury) and in identifying needs / barriers / gaps in services."

Implemented

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Family Brought Brain Injury Care Concerns to Senator Ruff

- Contacted Senator Ruff about the "lack of suitable placement" for family member who is an adult TBI survivor, due to his erratic behavior
- Visited emergency room on three occasions during the time the family was trying to care for the survivor at home
- Admitted twice to a psychiatric unit of a private hospital in the Richmond area
- Placed at NeuroRestorative in Blacksburg for six months

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Family's Experience

- Family used personal funds ($65,000)
- Family member returned home after personal funds were exhausted
  - In August 2014, family member became combative; wanted to cross 4 lane highway with oncoming traffic
  - Emergency 911 was called; county deputy sheriff took family member to local community services board for evaluation

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Family's Experience

- Temporary detention order (TDO) issued for 30 days
  - Admitted to Central State Hospital
  - Recommitted for 180 days
- Family is looking for placements and was told that a training center or transitional day program would be appropriate and that "bringing him home is not the best option"

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Lack of System of Care to Address Neurobehavioral Needs is a Concern

- The experience of the family who contacted Senator Ruff illustrates the experience of a number of TBI survivors who need specialized residential care due to the lack of funding for appropriate neurobehavioral facility care within Virginia
- Instead individuals are sometimes hospitalized – at times in State psychiatric hospitals
  - In August 2007, 14 persons with TBI were being treated through State hospitals and training centers (JLARC 2007 Report)
  - In September 2014, 18 persons with TBI were being treated through State hospitals and training centers and 9 at the Virginia Center for Behavioral Rehabilitation (data from the Department of Behavioral Health and Developmental Services)

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Lack of System of Care to Address Neurobehavioral Needs is a Concern

- Some individuals receiving Medicaid have been placed in neurobehavioral facility in Massachusetts
  - May be due to a number of factors including lack of Medicaid waiver for brain injury, licensing/reimbursement restrictions and variations of policy within State agencies
- The family who contacted Senator Ruff was told by representatives of several skilled nursing facilities that their family member would not meet admission criteria due to brain injury and neurobehavioral concerns
  - The family had been very pleased with the care provided by the specialized facility in Blacksburg

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Barriers to Accessing Brain Injury Services in the Commonwealth

- The lack of a Medicaid waiver for those who sustained a brain injury after the age of 22; Waiting lists on the developmental disabilities waiver for those who sustained their injury prior to the age of 22
- Absence of publically funded in-state residential neurobehavioral treatment State regulations prohibit the Department of Medical Assistance Services from reimbursing programs that provide services but are not a licensed skilled nursing facility
- Persons with mTBI may not access services due to lack of information about treatment and long term challenges; changes in reporting requirements and elimination of brain injury registry may be contributing factors

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General Issues for 2015 JCHC Study

- How can the unintended consequences of eliminating the brain injury registry be addressed?
- How can the Commonwealth address the general need for additional community-based services?
- How can the unmet need for intensive neurobehavioral treatment and residential services within Virginia be addressed?
- Should the idea of developing a Medicaid waiver for brain injury be reconsidered?

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Visit the Joint Commission on Health Care website
http://jchc.virginia.gov

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