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MEMORANDUM

TO: The Honorable Thomas K. Norment, Jr.
Co-Chairman, Senate Finance Committee

The Honorable Emmett W. Hanger, Jr.
Co-Chairman, Senate Finance Committee

The Honorable S. Chris Jones
Chairman, House Appropriations Committee

FROM: Cynthia B. Jones

Subject: Report on the Methods to Improve Data Capture on the Annual Incidence of Brain Injury

The 2016 Appropriation Act, Item 310M requires the Department of Medical Assistance Service to report on the efforts and recommendations of the work group convened to: (i) recommend methods to improve data capture on the annual incidence of brain injury as defined in the Code of Virginia, and (ii) review expenditure data on Virginians with brain injury receiving care outside of the state, and evaluate options for providing for their care in the Commonwealth. The department shall report on the workgroup and any recommendations to the Chairmen of the House Appropriations and Senate Finance Committees by December 1, 2016.

Should you have any questions or need additional information, please feel free to contact me at (804) 786-8099.

Enclosure

pc: The Honorable William A. Hazel, Jr., M.D., Secretary of Health and Human Resources

DEPARTMENT OF MEDICAL ASSISTANCE SERVICES

ADMINISTERING MEDICAID AND THE STATE CHILDREN'S HEALTH INSURANCE PROGRAM IN VIRGINIA

DMAS' mission is to provide a system of high quality and cost effective health care services to qualifying Virginians and their families.

Medicaid is a joint federal and state program authorized under Title XIX of the Social Security Act that provides health and long-term care coverage for specific groups of Virginians with low incomes. In Virginia, Medicaid is administered by the Department of Medical Assistance Services (DMAS) and is jointly funded by Virginia and the federal government. Virginia's federal matching rate, known as the Federal Medical Assistance Percentage (FMAP) is generally 50%, meaning Virginia receives $1 of federal matching funds for every $1 Virginia spends on Medicaid.

Medicaid coverage is primarily available to Virginians who are children in low-income families, pregnant women, elderly, individuals with disabilities and parents meeting specific income thresholds.

All states must follow general federal Medicaid guidelines regarding who is covered, but states set their own income and asset eligibility criteria. Virginia's eligibility criteria are among the strictest in the nation.

VIRGINIA'S MEDICAID PROGRAM
DMAS
INNOVATION • QUALITY • VALUE

Report to the General Assembly on the Methods to Improve Data Capture on the Annual Incidence of Brain Injury

Report Mandate:

HB 30, Item 310. M passed by the 2016 General Assembly, states: *The Department of Medical Assistance Services, in collaboration with the departments of Behavioral Health and Developmental Services and Health, shall convene a work group with community stakeholders to: (i) recommend methods to improve data capture on the annual incidence of brain injury as defined in the Code of Virginia, and (ii) review expenditure data on Virginians with brain injury receiving care outside the state, and evaluate options for providing their care in the Commonwealth. The department shall report on efforts of the work group and any recommendations to the Chairmen of the House Appropriations and Senate Finance Committees by December 1, 2016.*

Work Group Activities:

The Department of Medical Assistance Services (DMAS) convened a technical work group to address the specific study mandates. State agencies represented on the work group included the Department of Behavioral Health and Developmental Services (DBHDS), the Department for Aging and Rehabilitative Services (DARS) and the Virginia Department of Health (VDH). To ensure representation of community stakeholders, a representative from the Brain Injury Association of Virginia (BIAV) attended each meeting. As the Joint Commission on Health Care (JCHC) was conducting a broader study, staff from the JCHC participated in the work group discussions.

To ensure that data as well as programmatic areas were addressed, the above listed state agencies provided subject matter experts for both information technology and service delivery/program data capture and to identify methods for enhancement. The workgroup discussed the challenges regarding identification of available data within the gathered agencies, the required steps before considering potential brain injury (BI) data collection needs, and acknowledged the importance of the Commonwealth to continue developing its analytics capacity among agencies under the leadership of the Office of the Secretary of Health and Human Resources.

As directed by the mandate, the work group used the definition from the *Code of Virginia* § 37.2-403: "Brain injury is any injury to the brain that occurs after birth, but before age 65, that is acquired through traumatic or non-traumatic injuries. Non-traumatic injuries may include, but are not limited to anoxia, hypoxia, aneurysm, toxic exposure, encephalopathy, surgical interventions, tumor and stroke. Brain injury does not include hereditary, congenital or degenerative brain disorders, or injuries induced by birth trauma."

Report Directive 1: Recommend Methods to Improve Data Capture on the Annual Incidence of Brain Injury (BI)

In order to recommend methods to improve data capture, the work group identified all available state sources currently capturing BI data. Using the *Code of Virginia* definition of BI identified above, the work group included traumatic and non-traumatic injuries occurring between the ages of birth and 65 years for the analysis. A table attached to this report titled "Analysis of State Agency Databases Capturing Brain Injury Data" lists each database by agency and program. The following discussion summarizes the information detailed on Attachment 1.

The four state agencies identified 12 programs capturing data on individuals with traumatic and non-traumatic *injuries. The Virginia Statewide Trauma Registry (VSTR) maintained by VDH captures traumatic BI incidences at the time of the occurrence by using standard diagnosis codes (ICD-9 and ICD-10). All licensed hospitals which render emergency medical services in Virginia are required by the Code of Virginia §32.1-116.1 to submit data to the VSTR using the following requirements:*

- Injured/trauma patients admitted to the facility with specific diagnosis codes;
- Includes ALL admissions, including 23 hours admits for observation, as an inpatient (not emergency room (ER) observation unless held in the ER due to no inpatient bed availability);
- Injured/trauma patients transferred from one hospital to another because of acute trauma (patient may be transferred directly from the emergency department or from an inpatient unit); and
- Victims of acute trauma that die within the hospital, including the emergency department and those who die after arrival to the hospital.

The work group also discussed using the All Payer Claims Database (APCD), which is managed by Virginia Health Information under contract to VDH as a resource. The APCD represents health insurance payment information for four million Virginians, including data captured from commercial and Medicaid plans. Other state agencies collect data on individuals with BI when the individual applies for services through these agencies. DARS administers several programs to individuals with BI. DARS manages several BI programs/service contracts in the Commonwealth; data for these programs/contracts is captured using *Brain Injury First* software. Data is captured in "real time" as the software is a case management system used by staff for daily operations. Other DARS databases supporting services for individuals with BI include:

- Vocational Rehabilitative (AWARE Database);
- Wilson Workforce and Rehabilitation Center (AWARE Database);
- Community Rehabilitation Case Management Services (CRCMS);
- Injury Direct Services Fund (manual data collected via spreadsheet);
- Personal Assistance Services for People with Brain Injury (manual data collection); and
- Federal Traumatic Brain Injury Grant (manual data collection).

The Department of Medical Assistance Services reimburses providers for medical and support services rendered to eligible individuals with brain injury as identified in the State Plan for Medical Assistance, and Medicaid home and community-based waivers. DBHDS does not directly or exclusively provide any programs for individuals with a BI. Currently there is no mechanism to uniformly classify or track individuals by their BI diagnosis.

Given the variety of data collected, the types of software used, and existing systems used for multiple purposes, the work group identified methods for improving data capture of annual incidences of BI and the exchange of that data. Recommended methods include:

- Support of a centralized interagency data management system (Center for Data Analytics) currently underway under the leadership of the Office of the Secretary of Health and Human Resources;
- Modifications to each agency's Interagency Agreements (IAGs) to provide for standardized reporting of the annual incidences of BI to DARS, the state agency responsible for the planning and coordination of services to individuals with BI;
- Identify a standard definition for each agency to use to identify and report individuals with BI served by the agency; and
- Enlist both information technology and service delivery/program experts in subsequent efforts to identify and analyze data on the incidence of BI to ensure meaningful outcomes.

Directive 2: Review Expenditures for Virginians with BI Receiving Care Out of State

Currently there is no Medicaid-funded nursing home level neurobehavioral program in the Commonwealth that provides comprehensive services to meet both the medical and behavioral needs of the population with BI. The behaviors exhibited may include aggression to self, peers, and property. There are several other types of behaviors individuals may exhibit, such as, resistance to care, non-compliance with treatment, and disruptive, antagonistic, provocative and explosive behavior, and some may wander and be at risk of elopement. As a result, some

individuals with a BI diagnosis have had difficulty finding a nursing facility placement. Barriers to nursing facility placements also include liability issues and concerns with the ability of the nursing facility to address the range of behavioral issues and associated operational issues related to serving individuals with serious behaviors. On occasion, DMAS is called upon to seek alternative placements for these individuals. In the absence of appropriate placement options within Virginia, DMAS has approved reimbursement, in very select cases, for individual in out-of-state facilities.

DMAS' use of out-of-state placement is a placement of last resort. DMAS staff provides the critical coordination needed to exhaust all possible care alternatives within the Commonwealth prior to relocation of an individual out-of-state. The table below shows the number of individuals with BI placed out-of-state and the cost for the time frame of July 1, 2015 through June 30, 2016.

Table 1 Number of Out of State Placements and Costs for SFY 2016

Out-of-State Placements	Individuals	Total Cost	Averaged Cost per Individual
Nursing Facility - Neurorehabilitation	10	1,202,935.10	$120,293.51

Although the complexity of care needs for individuals placed out-of-state are enormous, the number of individuals requiring out-of-state placement is quite small making the potential for options for in-state care more feasible. Services provided in these specialized placements are intensive, and designed to reduce and control behaviors in order for the individual to be able to return to Virginia and receive treatment and supports closer to their home and community.

In December 2016, DMAS opened discussions with a Virginia health system to discuss the potential of developing a neurobehavioral/nursing facility program as requested. Discussions to date have included; applicable regulations, policies and procedures germane to the efforts, the desire of this health system to provide services, expertise within the health system available, exploration of other subject matter experts, possible rate elements and applicability of the model in other parts of the state. Current discussions include the acuity needs for individuals who are currently located out of state and program requirements and potential costs in any in-state efforts to replicate programs. DMAS is currently working with the out of state and in state provider on additional data elements to best determine next steps.

Directive 3: Evaluate Options for Provision of Care in the Commonwealth

The work group considered a variety of options to support the care needs of these individuals within the borders of Virginia. The most feasible option is to establish sufficient neurobehavioral resources in the Commonwealth. This option was recommended by the Joint Legislative Audit and Review Commission 2007 report titled "*Access to State-Funded Brain Injury Services in Virginia"*, http://jlarc.virginia.gov/pdfs/reports/Rpt360.pdf the 2010 Virginia Brain Injury Council's report titled "*Neurobehavioral Treatment for Virginians with Brain Injury*" http://services.dlas.virginia.gov/User_db/frmView.aspx?ViewId=1323&s= and the 2016 James Madison University "*Access to Neurobehavioral Services in Virginia."* https://www.vadars.org/cbs/downloads/JMUNeurobehavioralSvcsReport-2016.pdf

One such resource would be an in-patient neurobehavioral rehabilitation program with a bed capacity of 10 to 20 available for individuals with severe behavioral issues. To accomplish this task, the General Assembly would need to provide the mandate, the funding and the authority for regulatory change. An existing Medicaid regulation, 12 VAC 30-90-266, authorizes the Medicaid reimbursement rate for such a program; but current the reimbursement rate, (of $50.00 above the nursing facilities current rate) was established in 1997 is insufficient to meet the operational cost of such a program. The operation of an inpatient neurobehavioral program will require staffing levels and training specific to BI and the associated behavioral issues, which are currently being met out of state.

Summary:

By definition, BI is a serious, multifaceted condition that varies enormously from individual to individual. Because BI can occur suddenly as a result of trauma or through non-traumatic events such as lack of oxygen to the brain, toxic exposure, surgical intervention, stroke and many other occurrences, interventions and supports are provided by many community agencies serving individuals with BI as well as individuals with other medical and behavioral conditions. The challenge continues to be balancing between developing community services to meet the broader needs, such as early intervention, with more targeted services, including specialized neurobehavioral programs for more complex needs. This group focused on the options surrounding a neurobehavioral program. Continuing coordination across the several agencies with ongoing input from individuals with BI and their families will help direct available resources to achieve the highest level of care within the Commonwealth.

Attachment 1

Analysis of State Agency Databases Capturing Brain Injury Data

Agency	Data Source	Strengths and Challenges
DARS	State Funded Brain Injury Services Programs / Contracts - *Brain Injury First (BI First) Software*	Strengths of Data Source • Good check / balance on basic data (e.g., number of people served), as DARS reports to the BIS Programs what it has received from BI First for each program, and the BISC Unit Manager is able to conduct desk audits on each program. • BI First data are captured in "real time" as the software is a case management system used by staff for daily operations.
		Challenges or Improvement Opportunities • Quality of data depends upon data entry across programs, and not all programs enter it consistently. • Data management system is relatively new to the BIS Programs and to DARS, who are learning to use it, are working the bugs out, etc.
	Vocational Rehabilitation (VR) – *AWARE Database*	Strengths of Data Source • Information on every individual (including those with primary or secondary disability due to a brain injury) who applies for Vocational Rehabilitation services through DARS. • AWARE system has been used for many years, is well-tested and can yield multiple layers of information.
		Challenges or Improvement Opportunities • Improved data collection beyond the required data elements by AWARE users. • Quality of data depends upon the user and not all users are consistently entering the same detail level.
	Wilson Workforce and Rehabilitation Center (WWRC) – *AWARE Database*	Strengths of Data Source • Information on every individual (including those with primary or secondary disability due to a brain injury) who applies for services through WWRC. • AWARE system has been used for many years, is well-tested and can yield multiple layers of information.
		Challenges or Improvement Opportunities • Improved data capture when multiple programs/providers are involved. • Continued collaboration between WWRC and the DRS division staff.
	Community Rehabilitation Case Management Services (CRCMS) Program – *PeerPlace Software System*	Strengths of Data Source • Good check / balance on basic data (e.g., number of people served), as CRCMS manager has ability to conduct desk audits on each case manager's case load. • PeerPlace data will be captured in "real time" as the software is a case management system used by staff for daily operations.
		Challenges or Improvement Opportunities • Quality of data depends upon data entry across case managers, and not all staff enter it consistently. • Data management system currently used will be replaced by a new system (PeerPlace). CRCMS program staff are reviewing the system and will begin testing phase in the coming months.
	Brain Injury Direct Services (BIDS) Fund – *manual data collection via spreadsheet*	Strengths of Data Source • Small amount of funding ($175,000) can be tracked efficiently via in-house spreadsheet (number of people served, services provided, service provider(s), cost of services).
		Challenges or Improvement Opportunities • Difficult to monitor the same level of detailed information on BIDS Fund dollars used by state-funded BIS Programs as "case services dollars."
	Personal Assistance Services for People with Brain Injury (PAS/BI) – *manual data collection*	Strengths of Data Source • Small amount of funding ($107,639) can be tracked efficiently via in-house spreadsheet (number of people served, number of hours of service provided per week / month; service provider(s), cost of services).
		Challenges or Improvement Opportunities • Continued collaborative effort between CRCMS and BISC which operate PAS/BI Program collaboratively. •

	Federal Traumatic Brain Injury Grant – *manual data collection*	Strengths of Data Source • Data are discussed / verified during monthly grant management team meetings so that there is consensus among staff.
		Challenges or Improvement Opportunities • Data regarding public awareness / outreach / educational activities are often estimated (e.g., number of people "reached" through Public Service Announcements, or an exhibit table at a health fair or conference).
DMAS	Medicaid payments for services delivered to recipients with brain injuries (e.g. claims)	Strengths of Data Source • As the data collection drives payments to providers and health plans, data tends to be of high quality and well monitored. • Standardization in diagnosis codes (ICD-9, ICD-10) creates foundation for uniform identification of individuals with brain injury
		Challenges or Improvement Opportunities • Relies upon diagnosis codes found on claims, which is not as reliable as a diagnosis found on a medical record • Limited only to Medicaid beneficiaries • Accessing brain injury related costs for individuals in managed care (i.e. those served by health plans)
VDH	All Payer Claims Database (APCD)	Strengths of Data Source • Represents payment information on 4 million Virginians • Standardization in diagnosis codes (ICD-9, ICD-10) creates foundation for uniform identification of individuals with brain injury • Captures information on both commercial and Medicaid beneficiaries
		Challenges or Improvement Opportunities • Participation in the APCD by commercial plans is voluntary resulting in a potentially incomplete picture of cost and prevalence in Virginia • Does not include the prevalence of brain injury among the uninsured
VDH	Virginia Trauma Registry	Strengths of Data Source • Based on standard diagnosis codes (ICD-9, ICD-10), making identification compatible with medical claims • Entering data into the system is a requirement for hospitals
		Challenges or Improvement Opportunities • No known consequences for hospitals failing to report in the registry • No known data quality monitoring strategy for addressing quality issues • Only includes data on individuals admitted to the hospital; does not capture people who are treated and released from the hospital Emergency Departments, which represents approximately 80% of all brain injuries
DBHDS	Service Authorizations for people who qualify for waiver services. Institutional data from Mental Health and Substance Abuse. CSB tracking through clinical records	Challenges of Data Source • Regardless of the data source; the data is not collected to target BI specific data • Any data from waivers would be duplicate data from DMAS source • Data is not diagnosis specific but reflects how the person qualifies for the waiver services and the diagnosis would have to be made before the individuals twenty-second birthday • The CSB's are unable to provide BI specific information because of the overwhelming number of BI diagnoses, the drop off of diagnosis, and the lack of clinical personnel to differentiate diagnoses related to BI. They capture limited data as it relates to their developmental, intellectual, substance abuse and mental health diagnosis