

Remarks made by Anne McDonnell, Executive Director of the Brain Injury Association of Virginia before the Joint Commission on Health Care, September 19, 2007, in response to the Joint Legislative and Audit Review Commission's report, *Access to State Funded Brain Injury Services in Virginia*.

Good morning Mr. Chairman and members of the commission, thank you for the opportunity to speak before you today. My name is Anne McDonnell; I am a family member of two survivors of brain injury and the Executive Director of the Brain Injury Association of Virginia. I very much appreciate the opportunity to respond to the JLARC report, and commend them for an extensive and thoughtful study that validates everything we in the brain injury community have been saying for years: that survivors and families need help; that our system of care for Virginians affected by brain injury is fragmented and overburdened; that more individuals with brain injury are accessing services in Virginia than in surrounding states; and that more needs to be done.

I will respond to the specific recommendations found in the JLARC report, but let me begin by saying that the perception that a brain injury is the result of reckless behavior is just not accurate. The leading cause of brain injury in Virginia is falls, and it is an injury that happens to a friend or family member who misses a step and takes a tumble; to a wife on her honeymoon, whose car is hit by a boulder thrown from an overpass on I-95; to a child who is hit by a car while riding his bike on a neighborhood street; to a woman who is a victim of intimate partner violence.

The newest numbers from the CDC indicate 1.6 million traumatic brain injuries occur in the United States each year. This figure does not include data on those who receive no care, such as abused children; those who sustain non-traumatic injuries such as encephalitis or stroke; or those who are treated in physician's offices or military facilities. Estimates are that thousands of US troops wounded in action since 2001 may have a brain injury. As is acknowledged in the report, soldiers with brain injury who come home to Virginia will tax an already overburdened state system of care. The first recommendation of the JLARC report is the formation of a commission to study the issue of brain injury among returning troops and veterans. This is a topic of great urgency in the brain injury community as well as within the VA, and I can tell you that to my knowledge, key stakeholders in Virginia have not been in one place at the same

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time to talk about how Virginia will serve those who have served her. We strongly support this recommendation.

Two of the three recommendations made in the JLARC report relating to hospital data collection suggest making significant language changes in the Code of Virginia. The Registry is a complicated and multi-layered process that deserves a more thorough review than I have time for today and that deserved better attention than was given in the JLARC report. I am concerned about any action that weakens hospital data collection requirements, and enacting these recommendations will do just that. DRS has been working on many issues related to the Registry, and the work needs to continue. We support the recommendation that a DRS / VDH workgroup identify the best way to collect appropriate data, and that recommendations be reported in the 2008 General Assembly session. We also agree with JLARC that data on mild injuries must be collected; otherwise data DRS needs to inform their program, policy and fiscal planning will be incomplete and therefore inaccurate. One component of the Registry program is outreach and information and referral; JLARC uses the terms interchangeably and says it should be eliminated. The two programs are different, and while we agree outreach needs to be more effective, neither it nor information and referral should be eliminated. There's been a saying for years in the brain injury community – if you can support the family, you will support the survivor. With 78% of survivors receiving 100% of their care from their family, supporting them is critical; it's what keeps many survivors out of institutional care. Continuing the outreach and information and referral component of the Registry program is the best way to provide that support.

Two other recommendations concern DRS contract management and oversight improvements. We support those recommendations, and feel DRS must have additional resources to meet this directive. The agency may be set up for failure if demands are placed on an already strapped program without an infusion of financial and human resources to respond to the tremendous growth in community based brain injury

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programs that has occurred in 5 years, and to be prepared for the growth that could come with the implementation of any new brain injury programs.

Several topics were discussed in the report, without specific recommendation for action being made. The first was the issue of neurobehavioral and residential services and supports. There are case studies in the report that detail stories of individuals inappropriately placed in facilities and patients who have been sent out of state, on Virginia's dime, to receive the necessary care. A subcommittee of the Virginia Brain Injury Council, which advises the DRS Commissioner on the needs of Virginians with brain injury, is in the final stages of developing a White Paper that provides specific recommendations to address the complete lack of a neurobehavioral treatment options in Virginia. The paper discusses 4 levels of care that encompass short-term, intensive institutional care to community based residential supports and services. It will provide some ideas for pilot programs and funding streams, and will be forwarded it to each of you once it is released. I would also submit that Virginia's system of behavioral health care, which is undergoing some scrutiny right now, impacts our community and the needs of persons with brain injury should be considered as policies are developed and modified.

The treatment needs of persons with brain injury cannot be met in the vacuum of a facility; there must be community based supports available. The JLARC study commends case management as an effective use of resources, and it is. However, its efficacy depends to some extent on the availability of services and funding. State funded programs are serving twice as many people as they were 5 years ago; however, these services are only available in limited areas of the state, and several programs have waiting lists. Increases in state funding, while greatly appreciated, have not kept pace with needs. The erosion of the dollar and impending budget cuts threaten to further undermine service availability. The state of Virginia must make an investment in the expansion and support of critical components within a coordinated state system of care.

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The JLARC report discussed the use of waivers, and we support that strategy as well. A TBI waiver would draw down federal dollars to help fund the program, and create a funding stream for services. DMHMRSAS is using Discharge Assistance Program funding to place 8 persons with brain injury who were in state mental institutions at a community based neurobehavioral program in Southwest VA. Yet, given their current regulations DMAS cannot pay for the exact same care that would enable someone inappropriately placed in a nursing home to live in the community. A waiver would also create a friendlier regulatory environment that would facilitate provider development; Wisconsin saw a 200% increase in the provider pool within ten years after they instituted a waiver.

Most of the heavy lifting relative to the provision of care for persons with brain injury in Virginia is being done by the state and a few private non-profit organizations. Other members of the private sector need to do more. Over the last ten years, we've seen lengths of stays for rehabilitation for brain injury drop a week for acute care and almost 2 weeks for post-acute rehabilitation; people are being discharged sicker and quicker. Private insurance providers refuse to pay for any service they define as cognitive rehabilitation, claiming it isn't medically necessary and citing internal literature reviews that do not support its effectiveness. As an Occupational Therapist who has worked with thousands of survivors to help them increase their independence, I will never be convinced that helping someone develop the skills to manage a very complicated medication regimen is cognitive therapy. In the absence of cognitive skills, health deteriorates. And that makes cognitive rehabilitation medically necessary, if for no other reason than to promote wellness, a customer behavior highly desired by insurance companies. Additionally, the benefits of cognitive rehabilitation have been discussed in more than 700 published research studies and are evident in neuroimaging techniques. Federal and state governments have acknowledged the value of cognitive rehabilitation by allocating taxpayer funds for services. And lawmakers in a few states

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have required private insurance companies to include cognitive rehabilitation and related therapies in their accident and health insurance policies.

The JLARC reports state that the extent to which Virginia provides services for persons with brain injury is a policy choice. Make no mistake about it; you've made policy choices and have been and are still paying for inefficient treatment for survivors—through entitlement programs, in hospitals, nursing homes and state institutions, and in the courts systems and jails; it's time we start paying for effective therapies delivered through a coordinated system of appropriate care. The brain injury community deserves action; we've been talking about these issues for years, and 20 years worth of studies have said the same thing. In the wake of yet another report, let's make these changes happen this time. Let's identify and properly treat these people. Let's pass a seat belt law and stop talking about repealing the helmet law. Let's start getting some federal money to help pay for services and supports. Let's stop tearing families apart and sending patients out of state to receive the treatment they need. Let's get the private sector to bear their share of the responsibility. Let's make the market more accessible.

If you have further questions or need any information to assist the policy process, the Brain Injury Association of Virginia has historical, clinical, policy and personal knowledge that can help and would be very pleased to assist you any way. Thank you for your time.