



**Paralyzed Veterans  
of America**

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Chartered by the Congress of the United States

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Commission on Care  
ATTN: Nancy M. Schlichting, Chairperson  
1575 I Street, N.W.  
Washington, DC 20005

Dear Ms. Schlichting:

Paralyzed Veterans of America appreciates your invitation to respond to the Commission on Care's Independent Assessment released on September 18, 2015. As you may know, our organization has conducted annual site visits at all 25 Department of Veterans Affairs (VA) Spinal Cord Injury & Disease (SCI/D) Centers around the country and Puerto Rico for over 30 years. This longitudinal perspective of VA's largest in-patient specialized system of acute, rehabilitative, and long term care, as well as the aging paralyzed veteran population it supports, remain our top priority. It is through that lens in which we provide the following evaluation of the findings and recommendations of the Independent Assessment.

### **Finding 1: A disconnect in the alignment of demand, resources, and authorities**

Discussion: The report advances the notion that the veteran population will likely decline by 19 percent and will inversely correlate with a rise in demand for VA healthcare due primarily to aging and improved access. Yet, the report speculates that "VHA may not have a sufficient population of patients to sustain highly specialized service lines with enough volume to achieve and maintain clinical excellence."

Whether those "highly specialized service lines" includes the VA Spinal Cord Injury & Disease system of care in the report is unclear. What is clear, based on VA's own forecasts, is the estimated 14,370 veterans who rely on VA SCI/D care, as well as the additional 14,957 paralyzed veterans who use non-SCI/D VA care, not to mention the 13,173 who do not use VA at all for various reasons, are currently averaging age 66 (up from age 55 ten years ago) and living longer. For that reason, they will need access to the unique, multidisciplinary SCI/D system of care that sustains catastrophically disabled veterans as they confront afflictions such as diabetes, cancer, cardiovascular issues, etc.; conditions that are treated through tertiary services in addition to coping with the effects of spinal cord dysfunction. Improved access to care, which includes outreach, patient education, removing travel barriers, comprehensive annual exams, and adequate staffing will spur demand and more than justify the need to sustain the VA SCI/D system of care that has no private-sector alternative.

### **Recommendation 1: Governance: Align demand, resources, and authorities**

**Supporting recommendation: Require a patient-centered demand model that forecasts resources needed by geographic location to improve access and to make informed resourcing decisions.**

Discussion: Paralyzed Veterans of America wholly embraces the recommendation to explore predictive tools to continually forecast local demand and fine-tune estimates of required resources. VA's current staffing methodologies indicate that every VA SCI/D Center faces understaffing, particularly among bedside nurses, which impacts the number of operating beds thus artificially suppressing demand. If properly staffed based on patient characteristics and actual medical need, versus textbook function, VA SCI/D Centers will gradually right size itself to actual need as opposed to budget.

Paralyzed Veterans of America, in partnership with the Office of Nursing Services and the SCI/D Executive Director's Office, piloted the use of a staffing matrix that customizes the patient and staffing mix around locality-specific differences while providing standardization across the system of care. The integrity of this new staffing methodology will depend on the accuracy of current and projected demand, both met and unmet due to artificial barriers to access. This assertion aligns with finding 3-Non-integrated variations in clinical and business data and tools, and its supporting recommendation calling for standardized clinical and administrative data for accuracy and interoperability.

**Supporting recommendation: Establish a governance board to develop fundamental policy, define the strategic path, insulate VHA leadership from direct political interaction, and ensure accountability for the achievement of established performance measures.**

Discussion: As a veteran service organization, Paralyzed Veterans of America is distinguished by its retention of on-staff clinical and architectural expertise to conduct annual site visits at all 25 SCI/D Centers in VHA. This expertise has made the organization an effective, longtime partner with VA in the development, implementation, and assessment of policies and directives related to spinal cord injury and disease medicine. For this reason, any governance board intending to represent the diverse interests of stakeholders, to include the most catastrophically disabled veterans, should include the direct and substantive participation of Paralyzed Veterans of America.

### **Member Experiences since the implementation of Veterans Choice Care**

We now turn to our assessment of members' experiences as to timeliness and access to VA care since the implementation of the Veterans Access Choice and Accountability Act of 2014. The report devotes much discussion to the gestalt nature of VHA and the importance of integration pursuant to a systems approach to assessing the problems.

Paralyzed Veterans of America agrees in principle that patient access cannot be viewed one-dimensionally as measures such as increasing overtime and capping bed censuses without improving scheduling processes and right-sizing staff have proven fruitless. Many have argued that provisions that allow for increased use of healthcare services outside VHA, most recently through the Veterans Choice Act, hold promise, at least in the short term. To the extent that it helps VA ascertain the true scope of demand for general healthcare, we agree.

But so-called "Choice Care" presupposes a number of dangerous assumptions where specialized care services are concerned. Chief among them is the idea that the private sector SCI model systems deliver the same level of comprehensive care as the VA SCI/D system. The fact is while many facilities, such as the Shepherd Center, Craig Hospital, and Kessler, have demonstrated the ability to adequately rehabilitate and treat persons with spinal cord injury, they are not required to maintain CARF accreditation and can therefore vary their discharge, home evaluation, and referral practices.

They also constitute a non-veteran-centric, fragmented system of care that does not offer the coordination of care seen within the network of VA facilities across the country. Lastly, there are no assurances that these facilities are adequately staffed to handle the demand should an increased number of paralyzed veterans be encouraged to seek SCI/D-specific care outside of VHA. Our concern is decision makers will reduce investment in VA specialized care services based on the unempirical derived belief that the private sector can rival the quality of lifelong care provided by VA.

Members of Paralyzed Veterans of America have overwhelmingly enjoyed the benefits of a nationwide system of coordinated, comprehensive VA care from injury to end of life prior to and after the implementation of the Veterans Choice Act. That care, while highly specialized, is inextricably linked to tertiary care services that must be sustained in order to keep SCI/D Centers fully operable. By reducing demand for tertiary services among the non-paralyzed veteran population, the unintended downstream effect is the erosion of those specialized care systems. The growing popularity of alternatives to in-patient care, such as tele-health, medical foster homes, and home-based patient care, suggests a push to steer VHA away from an in-patient care model. This may very well prove beneficial in some ways as geriatric, hospice, and intensive care systems arguably lend themselves well to those lower cost options.

However, tele-health has shown limited value in SCI/D medicine, best functioning as a consultation and education tool as opposed to a treatment protocol for SCI/D-related conditions, such as decubitus ulcers, autonomic dysreflexia, and other life-threatening residuals that must be observed firsthand to be effectively treated. Also, placing veterans with spinal cord dysfunctions into the hands of non-SCI/D providers and caretakers in non-institutional settings increases the probability that those veterans will ultimately end up requiring acute in-patient care for preventable conditions (e.g. skin

breakdown, genitourinary and digestive problems, injuries due to falls) thus contributing to functional regression due to extended periods of inactivity.

The final point in our response addresses an aspect of care in which the Independent Assessment is largely silent: due process rights and protections for veterans seeking care outside of VHA. The Department of VA is in disrepair in many ways, a view shared by many who both support and criticize the agency. However, veterans are assured the best possible protection when compared to non-VA care under Title 38, United States Code, which establishes Congress's oversight of VA health care, a veteran's right to seek redress through clinical appeals, claims under Title 38 USC §1151 and the Federal Tort Claims Act, and the right to free representation by accredited veteran service organizations.

These protections evaporate once a veteran accesses care outside of VHA's reach and control, essentially divorcing the federal government from any responsibility to ensure care is timely, adequate, and monitored against a time-tested standard. Private sector providers are under no obligation to answer to Congress, guarantee adequate staffing levels, or implement pro-veteran, non-adversarial clinical appeal and compensation policies in instances of medical wrongdoing. These entities often mean well, but many are shielded by corporate personhood and answer to shareholders and donors, not the sacred commitment to care for those who protect the country. Paralyzed Veterans of America believes any new framework for delivering healthcare to our Nation's veterans, whether in or outside VA, should at least offer protections equal to that of the status quo, not less than.

Ms. Schlichting, Paralyzed Veterans of America appreciates the hard work of the Commission on Care thus far as we work together to resolve the profound challenge of delivering the best healthcare possible to the 9 million enrolled veterans in the U.S.. As the Commission considers broad solutions that seek to do the greatest good for the greatest number, we ask that you give those smaller segments of the veteran population with the greatest needs and reliance on VA care, our paralyzed veterans, equal deference when considering and recommending policy changes. These men and women choose VA as their provider and hope to see more investment in VHA infrastructure and greater accountability in how it is managed. We are encouraged by your outreach and look forward to the opportunity to further contribute.

Thank you.

Sincerely,



Homer S. Townsend, Jr.  
Executive Director