

501(C)(3) Veterans Non-Profit

STATEMENT OF ROSCOE BUTLER

SENIOR HEALTH POLICY ADVISOR

PARALYZED VETERANS OF AMERICA

BEFORE THE

HOUSE COMMITTEE ON VETERANS' AFFAIRS

HEALTH SUBCOMMITTEE

ON

**"CARE COORDINATION: ASSESSING VETERAN NEEDS
AND IMPROVING OUTCOMES"**

JUNE 13, 2023

Chairwoman Miller-Meeks, Ranking Member Brownley, and members of the Subcommittee, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to submit our views on the Department of Veterans Affairs' (VA) efforts to coordinate veterans' care. No group of veterans better understands the importance of having timely access to a full continuum of coordinated health care than PVA members—veterans who have incurred a spinal cord injury or disorder (SCI/D).

Veterans with complex healthcare conditions like SCI/Ds receive care from primary care physicians, a wide range of specialists, visiting nurses, and caregivers—many of whom are family members. Additionally, this care is provided through a number of service points. It may be provided at one of VA's 25 SCI/D centers, through VA's six long-term care centers, or at other VA facilities. It may also be provided through community care providers, in state veterans or community nursing homes, or in the veteran's residence. This often poses a herculean challenge to the many dedicated professionals who are working tirelessly to ensure that the delivery of high-quality acute and long-term care is administered by the right providers in order to achieve optimum care outcomes for veterans.

Veterans with SCI/D who are enrolled in and using VA care generally have an easier time with care coordination than those individuals who are receiving care solely outside the VA system. Appendix D of Veterans Health Administration (VHA) Directive 1176(2) on the SCI/D system of care lists the wide range of doctors, nurses, social workers, psychologists, therapists, and other specialists that serve as part of the interdisciplinary team for each SCI/D center. They include the members of the Patient Aligned Care Team (PACT) who are responsible for care coordination within VA, including at SCI/D spoke sites; in long-term care settings (e.g., VA Community Living Centers and community nursing homes); outreach; and virtual care. Ensuring they have the appropriate staff on their payroll allows VA to more quickly and completely coordinate its care for SCI/D veterans. An example of this coordinated care is a PVA member from Maryland who receives much of his care through his local VA Medical Center, but also utilizes VA's community care network and the Department of Defense's TRICARE program. Since a spinal cord injury in 2006, his VA care team has managed hundreds of dermatology, gastroenterology, hematology, immunology, neurology, occupational and physical therapy, oncology, primary care, pulmonology, rheumatology, and surgical visits both in and out of VA facilities. This veteran and many others like him are thriving because proper coordination of care ensures they are able to receive the right care at the right time and in the right place.

Within the VA's SCI/D system of care, knowing how to care for a veteran with these injuries or illnesses isn't optional, it's a requirement. Unfortunately, a serious knowledge deficit about SCI/D care exists in the private sector. Civilian facilities are simply not equipped or properly staffed to handle SCI/D patients' acute and long-term care needs, so most will not accept them. That number is growing as facilities and agencies decide to drop this capability as staffing shortages persist. Outside of VA, the ability to coordinate care drops dramatically for several reasons.

Caring for veterans with SCI/D requires sharp assessment, time- and labor-intensive physical skills, and genuine empathy. Nurses who work in SCI/D must possess unique attributes and specialized education. All medical providers, Registered Nurses, Licensed Practical Nurses, Certified Nursing Assistants, and Nurse Practitioners working with the SCI/D population are required to have increased education and knowledge focused on health promotion and prevention of complications related to SCI/D. This includes the prevention and treatment of pressure injuries, aspiration pneumonia, urinary tract infections, bowel impactions, sepsis, and limb contractures. Unlike VA, few facilities in the private sector have the highly trained personnel on staff to properly care for SCI/D patients.

Partly due to the lack of proper education and training, many private sector hospitals, agencies, and nursing homes are not able to properly care for veterans with SCI/D. As a result, SCI/D care coordinators must spend a considerable amount of time searching for ones that do. Sometimes SCI/Ds interrupt communication between the brain and the nerves in the spinal cord that control bladder and bowel function. This can cause bladder and bowel dysfunction known as neurogenic

bladder or neurogenic bowel. Other veterans may have tracheotomies that allow air to flow in and out of the windpipe. Some veterans may need a feeding tube due to difficulty swallowing, an eating disorder, or other feeding issues. Each of these conditions require close management and regular physical interventions that private sector facilities often cannot adequately provide. Most private sector facilities cannot provide long-term care for the same reasons. A few private sector health care facilities do a good job of providing acute SCI/D recovery care, but only VA is able to provide the full, lifelong continuum of services for veterans with SCI/D that can increase their lifespan by decades. That is why PVA places tremendous emphasis on preserving and strengthening VA's specialized systems of care.

Although VA is able to best provide care for veterans with SCI/D, there are still challenges. These challenges include difficulties in coordinating with other VA services and lack of resources to assist special populations of SCI/D veterans. Also, the lack of facility-based long-term care in VA and in the community causes significant issues in care coordination.

Challenges in Coordinating with Other VA Services

Prosthetics

VA's SCI/D centers and their spoke sites are intentionally designed and staffed so the coordinated, lifelong continuum of services that SCI/D veterans need are readily available. Prosthetics is often cited as one area within VA where coordinating individual veterans' needs can be difficult. Here, timeliness is often an issue as requests for equipment move slowly within the system. Sometimes orders are not placed or they are dropped without any apparent cause. Unfortunately, accountability for these systemic failures is lacking. Supply shortages can aggravate matters further. The inability to receive needed prosthetics in a timely manner frequently prevents veterans from returning home quickly and stimulates preventable increased workloads when VA's care coordination team must do multiple follow-ups just to ensure a veteran receives the devices or other equipment they need.

A wheelchair is an extension of the body of a veteran with an SCI/D. Thus, they can typically tell when a part is wearing out or is broken. Sometimes a part is visibly in need of repair or replacement, but even if veterans report these types of problems, some facilities make them wait until a vendor is dispatched to their residence and confirms its broken before initiating repairs. In these instances, veterans are not being well served by an antiquated process that could hold them hostage for several days or weeks. It also increases the VA care coordination team's workload as they are forced to intervene on behalf of frustrated veterans.

At a small number of VA facilities (2-3), support for prosthetics is essentially “available on demand.” Unfortunately, these locations can be described as “unicorns” because that level of support is rarely available in most other facilities. The VA should study the policies and process at the locations where access to prosthetics is working well, and have them implemented system-wide.

Care for Special Populations

Determining if a veteran can return home is usually the starting point for the care coordination team and accommodating the needs of homeless SCI/D veterans can be particularly challenging. Occasionally, homeless veterans with SCI/D receive treatment at one of VA’s acute SCI/D centers and once they are stabilized there is nowhere to send them because they have no residence. Finding affordable, accessible housing in the veteran’s community often proves to be difficult for VA’s SCI/D care coordinators. Resolving these types of cases are very labor intensive and can take months to resolve. There does not appear to be formal guidance to handle these types of situations and their resolution is often the result of the ingenuity and skill of the SCI/D care coordination team. Congress should examine VA’s existing policies and ability to care and house such veterans.

The population of veterans with SCI/D has undergone substantial changes over the last 50 years. Increasing numbers of women have been serving in the military and they now represent about five percent of the veteran SCI/D population. Additional considerations when coordinating their care usually include the use of a single patient room and the availability of gender-specific care in properly staffed and fully accessible buildings. These qualifications are rarely found in tandem in the private sector. Additionally, in-resident care of SCI/D veterans with substance use disorders (SUD) is virtually nonexistent within VA and the private sector. They may be able to receive counseling but at the end of each day return to home where the potential for a relapse is high. These individuals are not normally housed in acute care centers until the SUD is resolved due to security and safety concerns. Until VA gains the ability to provide this level of care, these veterans will be trapped in a vicious cycle that threatens their health and wellbeing. We hope that this Subcommittee will work with VA to determine how the Department can better serve these cohorts of veterans.

Limited Long-Term Care Services

VA’s lack of long-term care beds is severely impairing its ability to coordinate care for veterans with SCI/Ds. More than half of the veterans on VA’s SCI/D registry are over the age of 65 and most of their caregivers are aging as well. As indicated previously, nationwide, very few long-term care facilities are capable of appropriately serving veterans with SCI/D. VA operates just six SCI/D long-term care facilities; only one of which lies west of the Mississippi River.

According to VHA Directive 1176(2), the VA is required to operate at least 181 of its 198 authorized long-term care beds at SCI/D centers. Recently, only 168 beds were either available for or in use. This number fluctuates depending on several variables like staffing, women residents, isolation precautions, and deaths. When averaged across the country, that equates to about 3.4 beds available per state.

In 2012, VA's own research¹ warned that a wave of elderly veterans with SCI was coming and the Department should prepare for them. At the time, aging veterans, new cases of SCI from recent conflicts, and increasing numbers of women veterans were dramatically changing the profile of VHA's SCI/D population. If the Department heeded its own warning back then and increased its SCI/D long-term care capability, we might not be in the dire situation we are today.

A pair construction projects will add roughly 50 more SCI/D long term care beds to VA's inventory in the next few years. Other projects have been identified but need funding allocated in order to progress. Until then, a high number of aging veterans with SCI/D who need long-term care services will be occupying acute care SCI/D center beds or be forced to reside in nursing care facilities outside of VA that are not designed, equipped, or staffed to properly serve veterans with SCI/D. Others will remain in precarious situations in their homes and VA care coordinators will continue its struggle to find appropriate agencies or individuals to deliver their care. PVA strongly supports H.R. 3225, the Build, Utilize, Invest, Learn and Deliver (BUILD) for Veterans Act of 2023, which seeks to improve staffing to manage construction of VA assets and ensure that there are concrete plans to improve the planning, management, and budgeting of VA construction and capital asset programs.

The lack of capacity to provide long-term care for SCI/D veterans within VA and the private sector mean VA care coordinators spend a tremendous amount of their time attempting to locate providers, facilities, or agencies in the private sector to meet SCI/D veteran's long-term care needs. Truth be told, access to long-term care was extremely scarce prior to COVID, and VA's SCI/D care coordinators worry that it is getting scarcer. We understand that nursing homes and home health agencies often pursue contracts with VA, but many don't maintain them long. Most lack, and are unwilling to achieve, the necessary training to perform the critical tasks like bowel and bladder care or tracheostomy care that some veterans with SCI/D need. Facilities lacking proper staffing are often unwilling to procure additional personnel for SCI/D veterans whose greater care needs consume a larger than anticipated share of their existing workforce's time. Even if they are willing to hire additional personnel, nationwide provider and nursing shortages will often preclude them from finding the personnel that they need. These "starts and stops" are frustrating to veterans and those who coordinate their care.

¹ "Who are the women and men in Veterans Health Administration's current spinal cord injury population?" <https://www.rehab.research.va.gov/jour/2012/493/pdf/page351.pdf>.

Most veterans with Amyotrophic Lateral Sclerosis (ALS) and some with a spinal cord injury will eventually require ventilator care. VA has an extremely limited number of vent-capable beds for SCI/D veterans and they are often maxed out with patients. In most states, this level of care for SCI/D patients does not exist outside of the VA; thus, it is a daily occurrence that care coordinators are combing the country looking for an available bed. We work regularly with VA to assess its SCI/D system of care and those we speak with during our annual visit to each SCI/D center agree that the Department desperately needs to expand its ventilator capability.

The 65 percent statutory cap on what VA can pay for home care can also impact care coordination because it limits care options which may contribute to unfortunate results. Recently, a PVA member in Texas with ALS whose home care was limited by the VA cap developed a problem with his gallbladder bag. Since he wasn't receiving the much-needed assistance from VA at home, the family sought help from the local private sector medical system because they believed VA had already demonstrated an inability to meet his needs. While there, the veteran developed complications due to an undiagnosed pneumonia which led to him being intubated. Mentally and physically, his condition deteriorated rapidly, and the veteran passed away.

In light of the limited access to VA facility-based long-term care and the desire of many veterans with SCI/D to receive non-institutional long-term care, VA must expand access to home and community-based services (HCBS) to meet the growing demand for long-term services and supports. Facility-based long-term care services are expensive, with institutional care costs exceeding costs for HCBS. Studies have shown that expanding HCBS entails a short-term increase in spending followed by a slower rate of institutional spending and overall long-term care cost containment.² Reductions in cost can be achieved by transitioning and diverting veterans from nursing home care to HCBS, if they prefer it, and the care provided meets their needs.

Passage of H.R. 542, the Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act, would improve care coordination for SCI/D veterans by making critically needed improvements to VA HCBS including raising the cap on non-institutional care, expanding the Veteran Directed Care program, creating a pilot program to address direct care worker shortages, and improving family caregiver supports. We cannot stress enough how important it is for Congress to pass this important legislation sooner rather than later.

PVA appreciates the Subcommittee's interest in this critical area, and I would be happy to answer any questions you may have.

² [Do noninstitutional long-term care services reduce Medicaid spending?](#)

Information Required by Rule XI 2(g) of the House of Representatives

Pursuant to Rule XI 2(g) of the House of Representatives, the following information is provided regarding federal grants and contracts.

Fiscal Year 2023

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — \$479,000.

Fiscal Year 2022

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — \$ 437,745.

Fiscal Year 2021

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — \$455,700.

Disclosure of Foreign Payments

Paralyzed Veterans of America is largely supported by donations from the general public. However, in some very rare cases we receive direct donations from foreign nationals. In addition, we receive funding from corporations and foundations which in some cases are U.S. subsidiaries of non-U.S. companies.