STATEMENT OF CARL BLAKE EXECUTIVE DIRECTOR PARALYZED VETERANS OF AMERICA FOR THE SENATE COMMITTEE ON VETERANS' AFFAIRS ON "AN ABIDING COMMITMENT TO THOSE WHO SERVED: EXAMINING VETERANS' ACCESS TO LONG TERM CARE." JUNE 7, 2023

Chairman Tester, Ranking Member Moran, and members of the Committee, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to submit our views on the nation's obligation to ensure veterans have access to long-term care. No group of veterans better understands the importance of having access to long-term services and supports than PVA members—veterans who have incurred a spinal cord injury or disorder (SCI/D).

Throughout their lives, many veterans with SCI/D require some level of assistance in taking care of their daily needs. Many disabled veterans with the greatest support needs prefer to live at home with their families and in their communities instead of an institutional setting. For decades, PVA has strongly advocated for veterans to receive care in their homes and for their caregivers to receive supports that allow them to continue supporting their veteran.

Once their physical care needs increase and their caregivers' physical abilities decrease, more of these veterans will seek help from a facility-based long-term care system that currently has zero capacity to meet their needs. Over 50 percent of the veterans on VA's SCI/D registry are over the age of 65 and most of their caregivers are aging as well. Nationwide, there are very few long-term care facilities that are capable of appropriately serving veterans with SCI/D. The Department of Veterans Affairs' (VA) number of long-term care beds for veterans with SCI/D is woefully inadequate for a rapidly aging veteran population whose care needs are not readily met in the community. VA operates just six SCI/D long-term care facilities; only one of which lies west of the Mississippi River.

Increasing Access to VA Facility-Based Long-Term Care

According to the Veterans Health Administration (VHA) directive titled, "Spinal Cord Injuries and Disorders System of Care" (VHA Directive 1176), the VA is required to operate at least 181 of its 198 authorized long-term care beds at SCI/D centers. As of last week, 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.

Many aging veterans with SCI/D need VA long-term care services but because of the Department's extremely limited capacity, they occupy acute care SCI/D center beds; are forced to reside in nursing care facilities outside of VA that are not designed, equipped, or staffed to properly serve veterans with SCI/D; or remain in precarious situations in their homes. Too often, not receiving appropriate long-term care results in veterans developing severe medical issues requiring chronic re-admittance back into an acute VA SCI/D center. Thus, community-based long-term care is often not the best option for these veterans.

VA must adequately assess the number of veterans who need facility-based long-term care and receive funding to provide a safe margin of specialty VA long-term care capacity for veterans with SCI/D. They should also develop and implement a comprehensive plan that addresses future SCI/D veteran needs with particular emphasis on the two biggest barriers to long-term care—insufficient staffing and infrastructure.

Barriers to Accessing VA Facility-Based Long-Term Care

Staffing— Staffing shortfalls have a direct, adverse impact on the SCI/D system. Caring for veterans with SCI/D requires sharp assessment, time- and labor-intensive physical skills, and genuine empathy. Nurses who work in SCI/D centers must possess unique attributes and specialized education. All 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.

Depending on the function level of an acute SCI/D patient, a nurse may spend an hour or more each time they enter a veteran's room doing physical transfers, repositioning, wound care, feeding assistance, bowel and bladder care, and other tasks. Nurses in other areas of work may be in and out of a patient's room in a matter of minutes. Despite the increased level of care that veterans with SCI/D require, not all SCI/D nursing staff (including licensed practical nurses and nursing assistants) receive specialty pay, which often elevates turnover rates.

Currently, VA's six SCI/D long-term care facilities are short 55 nurses. Workforce provisions in the RAISE Act (P.L. 117-103) and PACT Act (P.L. 117-168) gave VA more flexibility to fill critical positions like these, but the impact of these new authorities has yet to be realized. Still, more needs to be done. Passage of S. 10, the VA CAREERS Act, would give VA the additional tools needed to allow the department to better compete for the highly qualified medical personnel it needs to care for disabled veterans with the greatest support needs.

Offering competitive pay isn't the only problem. If VA is not able to quickly hire high quality employees, it will lack the staff needed to accomplish its mission. Right now, VA's hiring process often moves too slowly prompting many qualified individuals to accept employment in the private sector. The lengthy time needed for credential checks, introductory paperwork, and other pre-work requirements needs to be scrutinized and streamlined where possible.

Infrastructure—VA's SCI/D system of care is currently comprised of 25 acute care centers and six long-term care centers ranging in age from three to 70 years with an average age of 38. Many of the older centers have only had cosmetic or basic renovations. Thirteen of the 25 acute care and one of the six long-term care SCI/D centers continue to use four-bed patient rooms, accounting for 61 percent of the available in-patient beds. These four-bed patient rooms do not meet VA requirements and are no longer safe due to infection control issues, which often limits available bed capacity whenever patients need to be isolated. Because of the glaring absence of SCI/D long-term care beds throughout the VA system, it is not uncommon for SCI/D veterans who are eligible for long-term care benefits to receive their care while occupying an acute care bed.

As previously stated, only one of VA's six specialized long-term care facilities lies west of the Mississippi River. The facility is located in Long Beach, California, and has just 12 long-term care beds for the thousands of SCI/D veterans that reside in this area of the country. A project for a replacement acute and long-term care center was priority #2 on the Strategic Capital Investment Planning (SCIP) list in fiscal year (FY) 2023. In the Department's FY 2023 budget request, VA provided Congress with notice of its intent to obligate over \$500,000 in Advance Planning and Design Funds to verify the business case (project book) for the project. Solicitation for the project book is slated for the fall, but this is the first phase of a long design process and once the design is completed the project will then need to request funding for construction. Meanwhile, construction of a new SCI/D acute and long-term center at San Diego, California, is currently underway and scheduled to be completed in June 2024. If all goes well, it would add another 20 long-term care beds to VA's inventory, increasing the number of beds west of the Mississippi River to 32.

Another new 30-bed long-term care center at VA North Texas Health Care System in Dallas, Texas, is currently in the bid solicitation phase with construction scheduled to start later this fall. Construction was originally projected to begin this April, but these projects are not immune to the design and construction delays inherent in the VA project funding and delivery system. If everything stays on track, the project could be completed sometime in 2026. However, the North Texas project also includes shell space for an additional 30 long-term care beds (60 total) and would provide all private resident bedroom/ bathrooms, shared resident dining, kitchen, and living areas to support them, as well as common resident gathering areas and space to support staff on that level. The \$45 million necessary to support building out the shell space has not been allocated, as it was viewed on the FY 2023 SCIP list as a potential future above-threshold project. The need for long-term care beds is particularly severe in the south-central region as there is not a VA SCI/D long-term care center within 1,000 miles of Dallas despite a significant regional population of veterans with SCI/D. Not fully funding this project postpones the opportunity to further address the shortage of VA long-term care beds for the aging population of veterans with SCI/D.

A project to expand and renovate the existing long-term care center in Hampton, Virginia, to eliminate four-bed resident bedrooms and shared bathrooms has been delayed due to cost increases. Seven additional projects including brand new long-term care facilities in Augusta, Georgia; Milwaukee, Wisconsin; and Minneapolis, Minnesota, and the replacement of existing ones at Bronx, New York; Brockton, Massachusetts; and Hines, Illinois, have languished for some time due to medical center nonconcurrence or other various reasons. Curiously, the replacement SCI/D center projects designed for the Bronx VA and the Brockton VA intended to modernize and expand capacity were shovel-ready but abandoned by the VA in 2014 and 2012 (respectively).

In reviewing VA's infrastructure, decisionmakers must remember that VA's SCI/D system of care is unique and not replicated outside of the VA. The VA SCI/D system of care provides a coordinated, lifelong continuum of services for SCI/D veterans that is often unmatched anywhere in the community. PVA strongly believes that the VA should return to the past practice of placing greater emphasis on funding facilities that support the types of services, like SCI/D care, which the Department uniquely provides. Greater investment in areas like SCI/D care would greatly strengthen VA's specialty care services and ensure their future availability.

Even with a comprehensive strategy and adequate infrastructure funding, VA's internal capacity to manage a growing portfolio of construction projects is constrained by the number and capability of its construction management staff. To manage a larger, more complex capital asset portfolio, VA must have sufficient personnel with appropriate expertise—both within VA's Central Office and onsite throughout

the VA system, including at the local medical centers. PVA strongly supports S. 42, 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 master plans to improve the planning, management, and budgeting of VA construction and capital asset programs.

Improving the Availability of VA's Home and Community-Based Services

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 communitybased 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.¹ 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.

VA spending for institutional care doubled between 2016 and 2021; however, the number of veterans being cared for in this setting has remained relatively stable—partially attributed to expanding HCBS—indicating the cost of institutional care is rising. Despite doubling HCBS spending between 2016 and 2021, VA currently spends just over 30 percent of its long-term care budget on HCBS, which remains far less than Medicaid's HCBS national spending average for these services among the states. VA must continue its efforts to ensure veterans integrate into and are able to participate in their community, which means having access to needed HCBS.

Caps on HCBS Care

VA is currently prohibited from spending on home care more than 65 percent of what it would cost if the veteran was provided nursing home care. When VA reaches this cap, the Department can either place the veteran into a VA or community care facility or rely on the veteran's caregivers, often family, to bear the extra burden. Depending on the services available in their area, some veterans must turn to their state's Medicaid program to receive the care they need, even for service-connected disabilities.

Amyotrophic lateral sclerosis (ALS) is presumptively related to military service and is rated by VA at the 100 percent level. And yet, we are aware of many ALS veterans who are not receiving proper home care. One veteran with ALS who uses a gastrostomy tube, has a tracheostomy and is ventilator dependent was only able to get a nurse to come to his home for two-hour visits, two times per week to check his vitals. Unfortunately, these hours were not enough to care for his medical complexities and the VA was unable to provide additional services due to cost. Instead, VA told him he could receive 24/7 skilled nursing at a facility. Another ALS veteran needs 120 hours of skilled care per week in order for him to be at home with his wife and family. Medicaid authorized 70 hours per week but the VA was unable to approve the additional coverage due to the cost and instead the veteran is in a much costlier facility. And another ALS veteran lives with his wife in their home but his wife is responsible for around 130 hours of care a week on her own. She can no longer afford to pay out of pocket for additional care. The VA's only option was to place the veteran in a facility due to the cap.

¹ Do noninstitutional long-term care services reduce Medicaid spending?

It isn't just ALS veterans who are impacted by this cap. A 39-year-old SCI veteran who is tracheostomy dependent has been in a facility since 2019 due to the cost of his care. He has a 10-year-old daughter that he has not been able to see since before COVID. Another veteran with a form of multiple sclerosis who has a gastrostomy tube, a tracheostomy, and is ventilator dependent is on the verge of ending up in a facility. His family needs eight hours of care per day on the weekdays but VA is only able to approve 16 hours per week due to the cap.

Congress must eliminate the cap on HCBS and allow the VA to cover the full cost of needed services for these veterans and others like them. It is inexcusable that veterans, particularly those with catastrophic service-connected disabilities, are not able to receive the care they have earned and deserve because of an artificial cap on the care VA can provide to them. Instead, we are exhausting their caregivers and leaving them struggling to cobble together the services and supports they need to stay home with their families.

Veteran Directed Care Program Expansion

PVA strongly supports expanding the Veteran Directed Care (VDC) program to all VA medical centers. The VDC program allows veterans to receive HCBS in a consumer-directed way and is designed for veterans who need personal care services and help with their activities of daily living. Examples of the types of assistance they can receive include help with bathing, dressing, or fixing meals. VDC also offers support for veterans who are isolated, or whose caregiver is overburdened. Veterans are given a budget for services that is managed by the veteran or the veteran's representative.

Unfortunately, the VDC program is not available at many VA medical centers and it currently has an enrollment of only about 6,000 veterans. Our members and other veterans are constantly asking for help in getting this program implemented at their VA health care facility. Milton, a PVA member from Ohio, is one of many veterans waiting more than four years for the Cleveland VA to implement the program. Even if the program is available at a particular facility, veterans may not be aware of it or given the opportunity to enroll. PVA's National President Charles Brown was made aware last year by PVA staff, not VA, that the program was available at his VA medical center. After several attempts to learn about accessing the program, he was told he had not been considered for it. Veterans should be given the choice to access this program where it is available.

Last year, VA announced plans to expand the VDC program to 75 additional sites over a five-year period. We are pleased that VA's Under Secretary for Health recently directed VHA to accelerate the timeline. In April, the President signed the Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers requiring VA to consider not only expanding the program by the end of fiscal year 2024 but also to have an expansion implementation plan ready by this month. We urge Congress to provide the necessary funding so every VA medical center can offer a robust VDC program as quickly as possible. We also call on VA to prioritize medical centers with an SCI/D center as many of these veterans are prime candidates for participating in VDC.

Homemaker and Home Health Aid Care Limitations

Another major concern of our members is VA not authorizing adequate hours to care for their home care needs. As previously noted, the cost of VA purchased home health care services may not exceed 65 percent of the amount it would cost if the veteran was placed in a nursing home. Even if we use costs at

the higher end of the spectrum for nursing homes and home health aides, this formula should result in 50 hours or more of VA home care per month.

A VA physician determines and prescribes the number of home care hours needed by a veteran in accordance with VHA Handbook 1140.6 titled, "Purchased Home Health Care Service Procedures." A physician might put in a consult for 28 hours, but the request may only be authorized for 21 hours or less. Veterans often contact PVA as the hours of care they receive are not adequate, and we must initiate an appeal to secure more assistance.

In April 2018, VHA issued an educational memo entitled, "Home Health Care Changes," describing a new methodology for determining the number of home care hours veterans are to receive. The memo noted that the "changes may dramatically impact the amount of services offered to Veterans enrolled in HHC, specifically engaged with the Home Health Aid and Home Maker Services." PVA has heard concerns from VA SCI/D providers that the current methodology fails to consider the unique home care needs of veterans with SCI/D, including the amount of time and number of providers who might be needed to provide required assistance.

While we recognize VA's challenge with limited resources and that our veterans are not the only ones using VA long-term care, they must receive the hours their doctor believes are needed for their care.

Veterans also have had difficulty receiving authorized care as agencies are having trouble finding sufficient numbers of workers to provide it. People often assume that veterans home care needs are fully cared for because of the care provided through the VA. Unfortunately, that is not always the case. Three months ago, our National President shared his personal story about a day when no nurse arrived to help him get out of bed. The VA-contracted home health agency providing his care was unable to find a nurse to assist him, and after repeated calls, told him that it was his responsibility to find a backup nurse for situations like this. This was extremely disappointing for me to hear. When care providers fail to see the seriousness of our situations, it is dehumanizing, and it cannot be allowed to continue.

Congress must recognize that the veterans population is aging and that veterans like PVA members are catastrophically disabled and at the same time losing regained function due to age. Veterans who must rely on caregivers, including those who have limited or no family support, have earned the right to live in their homes in a dignified and safe manner. VA's community home care providers must be held accountable for providing the care that we have earned with our service.

Direct Care Workforce Shortages

Even when veterans have access to programs like VDC or Homemaker/Home Health, it can be challenging to find home care workers. That is the experience of Ron, a PVA member from Minnesota who sustained a traumatic SCI in a vehicle accident in the spring of 2020. After spending four months in rehabilitation, he was released to an assisted living facility that did not meet his needs; so, he briefly lived with his mother while he and his family built an accessible home. In the fall of 2020, VA authorized 24-hour care for him in his home and Ron was thrilled to have this option. His wife is very supportive but often feels sad and helpless because she is physically unable to care for him. He depends entirely on the home health staff for his daily care, health, and welfare.

Unfortunately, because VA did not have home care staff, he had to go through a community agency. Despite having many hours authorized, he has never found enough qualified people to fill them. He is fortunate when he has someone to get him out of bed and help him through the day. Oftentimes, he goes to bed at 7 p.m. because help isn't available at his usual bedtime of 9 or 10 p.m. He regularly spends weekends in bed because no staff is available to assist him and he is depressed and frustrated because he can't find the direct care workers he needs to assist him with daily activities.

The shortage of caregivers or home care workers is not unique to the VA. Across the country, there is an increasing shortage of direct care workers, and a national effort is needed to expand and strengthen this workforce. I share these stories to emphasize how precarious the HCBS/long-term care system is and how the lack of home care providers is adversely impacting the care and quality-of-life of veterans with SCI/D. Veterans with disabilities have the right to quality care in their homes. Increasing pay for essential caregivers is a necessary component of attracting and retaining a diverse set of people to provide HCBS but raising pay alone is not sufficient to solve the crisis we face. Utilizing multiple strategies such as raising public awareness about the need and value of caregiving jobs, providing prospective workers quality training, and developing caregiving as a sound career choice are a few of the other changes that could help turn this problem around.

In light of the tremendous need to improve access to HCBS, PVA strongly supports S. 141, the Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act. This critically important legislation would make urgently needed improvements to VA HCBS, including several that target our concerns about current program shortfalls.

We appreciated the Committee's markup of an amended version of this legislation and were disappointed when a recent attempt to advance this bill along with five others in an omnibus package did not succeed. We sincerely hope the differences that led to that failed effort can be resolved, so veterans can receive the long-term care they desperately need. At the same time, I ask you to continue working with your counterparts in the House, with VA, and the Congressional Budget Office to resolve concerns with lifting the cap on the amount VA can pay for home care and pass it into law this year. We greatly appreciate the commitment to resolve this issue, and PVA is ready to assist you any way we can to expedite passage. Lifting the cap on VA-provided HCBS is vital to the health, safety, and independence of veterans who have paid the highest price for their service to our nation. The cost of providing them with needed services and supports cannot be a limitation we place on their care.

Strengthening Assistance for Family Caregivers

Finally, a conversation about long-term care would not be complete without commenting on VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC). Executing this program continues to be challenging for the VA and we were pleased that the Department extended the transition period for legacy applicants and legacy participants until September 30, 2025.

We are disappointed, however, that action has yet to be taken to revise the restrictive rules that are preventing seriously injured disabled veterans who have the greatest support needs from qualifying for the program. To their credit, VA worked closely with caregivers; veterans; and stakeholders, including PVA, to identify changes that could be made under existing authorities and those that would require congressional action. Unfortunately, no changes have been made yet and each day of delay prevents hundreds of veterans and their caregivers from accessing the benefits this important program provides.

We are also concerned with the way VA decides which tier veterans are assigned to in the PCAFC. VA currently has two categories for determining stipend payments, tier one and tier two. Tier one is for veterans whom VA has determined can self-sustain in the community. Tier two is for veterans who cannot do so. The VA defines "unable to self-sustain in the community" to mean an eligible veteran that requires personal care services each time he or she completes three or more of the seven activities of daily living (ADLs), and is fully dependent on a caregiver to complete such ADLs or has a need for supervision, protection, or instruction on a continuous basis. VA defines inability to perform an ADL to mean the veteran or servicemember requires personal care services each time he or she completes one or more of the ADLs.

VA has determined that many PVA members are eligible for Special Monthly Compensation (SMC). SMC is a higher rate of compensation paid due to special circumstances, such as the need for aid and attendance by another person or a specific disability, such as loss of use of one hand or leg. SMC ratings range from K through S, with R-2 being the highest level. We are at a loss to explain how our members with the highest SMC rating receive the lower level of compensation through PCAFC if they can even get in the program at all. PVA National's Senior Vice President Robert Thomas is one of these individuals. Mr. Thomas is a quadriplegic who suffered an injury while serving in the Army back in 1991. He also has an SMC rating of R-2—*the highest level*. However, he applied for VA's PCAFC and was subsequently approved but assigned into tier one—*the lowest PCAFC payment tier*. We are concerned that VA has two separate programs to determine the need for assistance with ADLs that are resulting in different determinations. PCAFC plays an important role in the effective delivery of long-term care and we encourage this Committee to expand its oversight of the program and work with VA to eliminate these types of decisions.

PVA appreciates this opportunity to express our views on veteran's access to long-term care and we look forward to working with the Committee to eliminate some of the identified barriers.