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PARALYZED VETERANS OF AMERICA
BEFORE THE
HOUSE COMMITTEE ON VETERANS' AFFAIRS
SUBCOMMITTEE ON HEALTH
ON
PENDING LEGISLATION

Chairwoman Brownley, Ranking Member Bergman, and members of the Subcommittee, Paralyzed Veterans of America (PVA) would like to thank you for this opportunity to present our views on pending legislation impacting the Department of Veterans Affairs (VA) that is before the Subcommittee. No group of veterans understand the full scope of benefits and care provided by VA better than PVA members—veterans who have incurred a spinal cord injury or disorder (SCI/D). Several of these bills would help to ensure veterans receive much needed aid and support. PVA provides comment on the following bills included in today's hearing.

H.R. 4993, the "Veterans Emergency Care Reimbursement Act of 2021"
On April 16, 2016, the United States Court of Appeals for Veterans Claims (CAVC) struck down a VA regulation that prevented any reimbursement to veterans for emergency care covered by third-party health insurance. The court declared that the regulation was inconsistent with Congress's unambiguous mandate to reimburse a veteran for the reasonable value of emergency treatment the veteran received in a non-VA facility. It has been almost six years since the CAVC ordered the VA to reimburse veterans for the portion of their emergency medical costs that was not covered by a third-party insurer and for which they are otherwise personally liable. To date, the VA has not fully complied with the court ruling. PVA supports H.R. 4993, which modifies the limitation on reimbursement for emergency treatment for veterans covered by private insurance.

H.R. 5738, the "Lactation Spaces for Veteran Moms Act"
PVA believes passage of this bill would help many veteran mothers feel more welcome at VA facilities. There is abundant scientific evidence showing that breastfeeding benefits both babies and mothers and a recent study found a high percentage of women veterans nurse their infants until at least four weeks postpartum.[1] For their health and the health of their babies, veteran mothers and the VA employees that serve them need a safe, private place other than a lavatory to feed or pump breast milk. A few VA facilities have or are thinking about creating dedicated lactation rooms, but they should be required system wide. We recommend adding language stating that lactation rooms should provide square footage in accordance with national accessibility standards and have a wall mounted sink and fixed bench seating to ensure that maneuvering clearances are met for women veterans who use wheelchairs.

[1] Disparities in Breastfeeding Among Military Veterans - PubMed (nih.gov)

H.R. 5754, the "Patient Advocate Tracker Act"
PVA supports H.R. 5754, the Patient Advocate Tracker Act, which would require VA to establish an information technology system that allows a veteran or their designated representative to electronically file a health care-related complaint and view its status. The system would include interim and final actions that the VA has taken to resolve the issue. This would be a tremendous improvement over the current system which oftentimes leaves veterans feeling like their concerns are being ignored.

H.R. 5819, "the Autonomy for Disabled Veterans Act"
Improvements are long overdue for VA's Home Improvements and Structural Alterations (HISA) grant program. As the name suggests, HISA grants help fund improvements and changes to an eligible veteran's home. Examples of qualifying improvements include improving the entrance or exit from their homes, restoring access to the kitchen or bathroom by lowering counters and sinks, and making necessary repairs or upgrades to plumbing or electrical systems due to installation of home medical equipment. The lifetime HISA benefit is worth up to $6,800 for veterans with service-connected conditions and $2,000 for veterans who have a non-service-connected condition. These rates have not changed since 2009 even though the cost of home modifications and labor has risen at least 40 percent during the same timeframe. As a result, the latter figure has become so insufficient it barely covers the cost of installing safety bars inside a veteran's bathroom.

In the past, our service officers reported having veterans who had used the HISA grant more than once because the remainder of the one-time amount would cover at least part of a second project. Today, they rarely have veterans with remaining balances because veterans' entire allowance coupled with their own money is needed to complete one project. This should not be happening. We urge Congress to pass the Autonomy for Disabled Veterans Act, H.R. 5819, which would raise HISA grant rates to $10,000 for service-connected disabled veterans and $5,000 for non-service-connected disabled veterans, and tie HISA grants to the Consumer Price Index (CPI) to help ensure rates remain current.

H.R. 5941, "the Fairness for Rural Veterans Act of 2021"
This bill would create a new priority group for the VA to consider in its process for ranking state veterans home projects across the country. We appreciate the intent behind this legislation but believe the need for facilities should be the main deciding factor in determining rankings for these nursing homes.

H.R. 6647, "Make certain improvements relating to the eligibility of veterans to receive reimbursement for emergency treatment furnished through the Veterans Community Care program"
Many veterans have been denied reimbursement for emergency treatment furnished through the Veterans Community Care program because they failed to obtain care from the VA prior to receiving emergency care. Specifically, under current law, 38 United States Code (USC) 1725(B)(2)(b), a veteran must have received care from the VA within a 24-month period preceding the emergency treatment in order to receive reimbursement. PVA supports H.R. 6647 which would amend the statute to say that the 24-month requirement does not apply if the treatment is furnished during the 60-day period following the date on which the veteran enrolled in VA's health care system.

H.R. 6823, the "Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act of 2022"

PVA gives its strongest support to H.R. 6823, the Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act. This critically important legislation would make urgently needed improvements to VA's Home and Community-Based Services (HCBS), including several that target our concerns about current program shortfalls.

Section two of this bill would raise the cap on how much the VA can pay for the cost of home care from 65 percent of the cost of nursing home care to 100 percent. Recently, a veteran residing in California moved from one part of the state to another. His previous VA medical center authorized 56 hours of expanded care a week, while his new one is authorizing 24 hours per week. The veterans' new VA medical center referenced the 65 percent cost cap as the reason they were unable to approve more coverage. The veteran and his family are currently having to choose between reduced home-nursing support and facility placement, because his family is unable to safely provide the additional care he needs to supplement the newly authorized amount.

The wife of a veteran in North Carolina is currently responsible for providing her husband with 108 hours per week of care due to the 65 percent cap. She has experienced caregiver burnout, and the care of the veteran has noticeably declined. Now, he is at risk for facility placement. Raising the cap would allow veterans whose cost of care exceeds the present cap to continue receiving appropriate HCBS. Most important, it would allow them to maintain their care in their home or other similar location which is the preference of most veterans.

Section three directs the VA to coordinate expanded VA home care programs with other VA programs, like the Program of Comprehensive Assistance for Family Caregivers, and other federal programs, like Medicare's Program of All-Inclusive Care for the Elderly (PACE) program. PACE is a Medicare and Medicaid program that helps people meet their health care needs in the community instead of going to a nursing home or other care facility. Tapping into the programs and resources of other federal, state, and local programs would undoubtably help the VA address veterans' unmet needs.

Section four requires the VA to administer its Veteran Directed Care (VDC) Program, the Homemaker and Home Health Aide Program, the Home-Based Primary Care Program, and the Purchased Skilled Home Care Program at all medical centers within two years of the date of enactment of this legislation. 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. It is also for veterans who are isolated, or whose caregiver is experiencing burden. Veterans are given a budget for services that is managed by the veteran or the veteran's representative.

PVA member Steven McIntosh's current caregiver is his elderly father. As you can imagine, his dad cannot do as much as he used to and his ability to care for his son will diminish as he continues to age. Mr. McIntosh expressed concern about his situation during his annual SCI/D exam and asked about the availability of the VDC program to provide him with additional care services. Regrettably, the program was not available at his VA facility.

Currently, VDC is only available at half of VA's medical centers, with an enrolled population of about 4,900 veterans. Our members and other veterans are consistently asking for help in getting this program implemented at their VA health care facility. PVA member Milton Young has been waiting over two years for the Cleveland VA to implement the program. In January, the VAVA announced plans to add new VDC programs at 70 medical centers over five years. While we support these efforts, many veterans need access to care now. We greatly appreciate the accelerated schedule this legislation provides so every VA medical center can offer a robust VDC program as soon as possible. We also strongly support language that would allow catastrophically disabled veterans to continue to use funds under the VDC program during a period of hospitalization to retain or hire an attendant to assist with their non-medical needs during hospitalization.

The Homemaker and Home Health Aide Program (H/HHA) contracts with community agencies that employ home health aides to care for veterans in their homes, providing skilled services, case management, or help with daily living, or easing caregiver burden. Informal caregivers are more likely to take leave from a job, file fora loan, spend savings, hold multiple jobs, suffer harm to health and intimate relationships or put off life goals. Alleviating some of their burden by expanding access to paid aides will translate into better care and health outcomes for the veteran.

We look forward to expanded availability of this program with some reservation because we know the VA's execution of contracts for H/HHA requires closer examination. Our National President spoke briefly about the difficulties he experienced with this program during the March 8 hearing before the House and Senate Veterans' Affairs Committees on our annual legislative priorities. One Saturday morning late last fall, no nurse arrived to help him get out of bed. The previous day the VA-contracted home health agency informed him that they had not been able to find a nurse to assist him on Saturday morning. He called the scheduler and asked her what he should do. The scheduler informed him that the agency would continue to try to find someone to assist him. When no one showed up the next morning, he called the agency again and was told that nobody would be coming by, even though he had been told they would continue to make calls. He was also told it was his responsibility to find a backup nurse for situations like this.

Trapped in his bed, he realized nobody would be coming for him for many hours which meant he would not be able to eat, drink, care for bodily needs, or take his medications. He was alone and felt abandoned. Luckily, he found someone to come and help him, but this should not have happened. It should not be the responsibility of a catastrophically disabled service-connected veteran to have backup care when the care the VA is ultimately responsible for fails to be provided. Contracts that the VA executes with outside agencies for HCBS programs should specify that the agency must provide the backup caretaker.

VA's Home-Based Primary Care Program (HBPC) provides veterans who are isolated, have difficultly traveling, or whose caregiver is burdened, health care in their home, supervised by a VA physician. Transporting veterans with SCI/D can be a major undertaking so delivering care where they are alleviates a tremendous burden on veterans and their caregivers. Some veterans, particularly those in rural areas, may not even have reliable transportation and without access to HBPC or other HCBS, clinical delays may result. These delays may result in an accumulation of unmeet care needs which can worsen health outcomes.

The Purchased Skilled Home Health Care Program is for veterans who have higher levels of need like wound care, speech therapy, or skilled nursing. The VA contracts with a community health agency to provide this care in a veteran's home. Immobility and decreased sensation can cause major problems related to the skin of a veteran with an SCI/D. Having greater access to this program would help keep rural veterans needing wound and other skilled care in their homes. This reduces the strain on the informal caregiver, minimizes transportation issues, and even offers the veteran and their informal care provider an opportunity to have meaningful social contact.

Finally, being a caregiver for a veteran can be incredibly rewarding, but it can also be an all-consuming responsibility. Provisions in this section would enhance support for caregivers by providing them much-needed breaks in order to recharge and restore balance to their lives.

Section five requires the VA to provide a personalized and coordinated handoff of veterans and caregivers denied or discharged from the Program of Comprehensive Assistance for Family Caregivers (PCAFC) into any other home care program for which they may be eligible. We are extremely concerned with the number of PCAFC applications being denied by the VA. Between October 1, 2020, and January 6, 2022, the PCAFC received 127,500 caregiver applications. Of this number, 116,500 applications were processed and 16,600 were approved, while 101,500 were found not eligible and/or denied (87.9 percent).

The VA has reported that the three main reasons veterans were found not eligible or denied are 1) applying during the wrong phase, 2) not having a service-connected condition rated 70 percent or greater, and 3) not meeting the requirement of needing full-time assistance with an activity of daily living (ADL). Two out of the three reasons given for denial are based on VA's stringent regulatory requirements which are inconsistent with Congress's legislative intent. These requirements make it impossible for even many catastrophically disabled veterans to qualify for the PCAFC.

A PVA member with a spinal cord injury at the T-5 level is one of those individuals. He is service connected at 100 percent for loss of use of both feet; 100 percent for loss of anal sphincter control; and 60 percent for neurogenic bladder. His combined service-connected rating of Special Monthly Compensation (SMC), R-1, is the second highest level available. This veteran had been part of the PCAFC for several years but was recently informed that he is being discharged from the program because he no longer meets its requirements. The explanation that was given to the veteran was that it did not appear he needs assistance each time he performs an ADL.

Another member with a spinal cord injury at the T-12 level with identical impacts on health and mobility was removed for the same reason. Like the member above, his combined rating is SMC, R-1. The R-1 rating includes the provision of needing regular aid and attendance, in accordance with 38 USC 1114(r)(1). This veteran has also been part of the PCAFC for several years but is now being unceremoniously discharged from the program.

The removal letter these individuals received mentions the availability of assistance through VA's Program of General Caregiver Support Services which provides peer support mentoring, skills training, coaching, telephone support, online programs, and referrals to available resources to caregivers of veterans. Nothing in the letter cites other programs the *veterans*

may be eligible for. Veterans with catastrophic disabilities have made sacrifices in the service of our nation and giving them anything less than optimal care and support is unconscionable. The provisions in section five would ensure veterans are assessed for participation in other HCBS programs and ensure a smooth transition into any other home-based programs for which they may be eligible, thus, integrating caregiver support across programs.

Veterans and their caregivers often express frustration trying to find information on HCBS. Information about HCBS is available through several websites and other sources which tends to lead to a lack of awareness about all the services that might be available. And when people do not know about services and programs, they do not participate in them. Section six would address this problem by establishing a "one-stop shop" webpage which would centralize information about available programs for families and veterans.

Section seven would make it easier for veterans to find direct care workers or home health aides. Even when veterans have access to HCBS, it can be challenging to find these workers. Throughout the country, acute shortages of home health aides and nursing assistants are threatening care for older veterans and those with serious disabilities. PVA has been a proponent of a vigorous national effort to help curb the effects of these shortages and bolster the direct care workforce.

Higher pay for essential caregivers is a necessary component of attracting and retaining a diverse set of people to provide HCBS. However, 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. We believe the pilot program established in section seven would lessen the difficulty in finding direct care workers at the 10 sites the VA selects and may reveal additional ways the VA could alleviate this problem for veterans nationwide.

Finally, we believe the directed studies in section eight would likely help ensure consistency, eliminate service gaps, and enhance the availability of care for veterans nationally. The requirement to place special emphasis on the availability of specialty care for veterans with spinal cord injuries and dementia is both needed and appreciated. Additionally, there is inconsistency in the VA's ability to meet the inpatient mental health needs of veterans with catastrophic disabilities. The Veterans Health Administration is obligated to provide inpatient mental health care to those in need, which includes veterans with SCI/D. But according to the VA, there is no readily available list of VA facilities that can provide on-site, in-patient mental health care to veterans with SCI/D. Services provided vary based on Veterans Integrated Service Networks (VISNs) and local arrangements to provide care. We hope this lack of care is addressed in this section's request for recommendations for expansion of mental health services and supports for caregivers of veterans.

PVA would once again like to thank the Subcommittee for the opportunity to present our views on the legislation being considered today. We look forward to working with the Subcommittee on this legislation and would be happy to answer any questions.

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 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.

Fiscal Year 2020

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — $253,337.

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.