

501(C)(3) Veterans Non-Profit

**STATEMENT FOR THE RECORD
PARALYZED VETERANS OF AMERICA
FOR THE
HOUSE VETERANS' AFFAIRS COMMITTEE
ON
"EVERYDAY HEROES: SUPPORTING THE VETERAN CAREGIVER COMMUNITY"
SEPTEMBER 25, 2024**

Chairman Bost, Ranking Member Takano, and members of the committee, Paralyzed Veterans of America (PVA), would like to thank you for the opportunity to submit our views on the Department of Veterans Affairs' (VA) Caregiver Support Program. PVA members uniquely understand the value of caregiver support. While the VA provides essential health care services to severely disabled veterans, it is their caregivers that provide the day to day services needed to sustain their wellbeing. Caregivers are often the most important component of rehabilitation and maintenance for veterans with catastrophic disabilities because their welfare directly affects the quality of care veterans receive.

Affect of Funding Deficiencies in VA Health Care on Caregivers

In June, PVA warned this committee that VA's Spinal Cord Injury and Disorder (SCI/D) system of care was not sufficiently funded to properly care for all of the SCI/D veterans on the department's registry. Veterans are not the only ones who suffer when health care services are unavailable or even eliminated. Often, their caregivers are forced to fill the gaps that result when critical services such as inpatient respite are eliminated or unavailable.

Staffing levels for the SCI/D system of care are detailed in Veterans Health Administration (VHA) Directive 1176, which was last amended on February 7, 2020. PVA strongly believes in each of the requirements outlined in this directive because they are based on the level of care needed to maintain the health and wellbeing of veterans with SCI/D.

For months, our staff in the field have been telling us critically needed positions at SCI/D centers were going unfilled. Now, essential positions across VHA are being "lost" due to an inability to recruit for them or even "abolished." Specifically, many vacant positions in social work, nursing, and several therapy disciplines have been eliminated. Additionally, when medical staff leave, their vacated

positions are often not being back filled causing strain on the system and ultimately denying veterans access to earned health care services.

Eligible veterans are entitled to up to 30 days of respite care services per calendar year. These hours can be utilized for in-home care, depending on the family's preference and the veteran's needs. Normally, veterans with SCI/D are placed in one of VA's acute or long-term care SCI/D centers to accomplish this. But in many parts of the country, insufficient funding coupled with the elimination of staff positions and unfilled vacancies has severely limited the availability of respite care.

Earlier this year, the husband of PVA's National Senior Vice President needed back surgery. Our Senior Vice President is a quadriplegic and her husband is her primary caregiver. Despite the fact they live close to one of VA's larger SCI/D centers, VA was unable to provide respite prior to his surgery. A friend stepped in to help for a few days, but as soon as he was released from the hospital, her husband had to forego his own recovery and resume caring for her. In this instance, and in many others, VA is failing in one of its very basic obligations to SCI/D veterans. Something is very wrong here and we urge this committee to get to the bottom of it quickly.

Role of the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC)

VA's PCAFC is unique in that it is the only integrated program that provides caregivers with health insurance, a stipend, travel expenses, mental health care, respite care, and injury specific training. Without these support services the quality of care provided by the caregiver is likely to be compromised and the veteran is more likely to experience frequent medical complications and require long-term institutional care. Veterans who access PCAFC are medically stable enough to live outside an institution, but lack the functionality to care for themselves on an ongoing basis.

Despite having been established nearly 15 years ago, executing the program continues to be challenging for the VA. As of August 5, 2024, the VA reported having 13,881 applications in process, but the department is no longer reporting the number of approved applications. Instead, they are reporting the percentage of approvals from the Veterans Integrated Services Network (VISN). Without being able to track the number of applications approved in comparison to the number of pending applications it is difficult to keep track of their progress.

Recently, we learned that other specialty care areas, including VA's PCAFC, are also suffering with staffing shortages. PCAFC vacancies cannot be filled because they were not previously identified as "critical," and we understand that more than 125 of them have been eliminated. Now more than ever, it is important that Congress understand the important correlation between PCAFC, the SCI/D system, and the impact that understaffing due to funding deficiencies has on them.

Reforming VA's PCAFC to Better Serve Veterans and Their Caregivers

VHA is working on a rulemaking to make changes to the current caregiver regulation and an announcement about those proposals was expected months ago. PVA joined 11 other advocacy groups in a letter to the President last month pressing the White House to release proposed changes to the PCAFC. While we wait for the proposed rule, we would like to highlight several concerns that consistently pose challenges for our members in accessing and benefiting from this critical program.

First, we strongly believe that the PCAFC should be reformed to ensure that veterans' efforts to be independent, when possible, do not disqualify them from participating in this program. The current requirement for veterans to need assistance "each time" they perform an activity of daily living (ADL)¹ is overly restrictive and fails to recognize the reality of living with a catastrophic disability. As a result, veterans have been unjustly denied participation in the PCAFC. Instead, VA should adopt a less stringent requirement, such as "regularly requires" assistance.

In addition, we continue to be concerned by the requirement for veterans to have a 70 percent disability rating in order to be eligible for the PCAFC. As PVA noted in our May 2020 comments on the proposed rule, the necessary VA rating should be lowered to 50 percent or more; or as combined with any other service-connected disability or disabilities for a combined rating of 50 percent or more." Congress believed that these veterans were of the highest concern, and assigned them to VA health care priority group one, which is the highest priority group a veteran can be assigned."² We firmly believe the current rating requirement is too restrictive as it has prevented many deserving veterans from being eligible for the program and it should be lowered to 50 percent.

VA should also address the onerous criteria for assignment to the highest tier under the PCAFC. Veterans with significantly different levels of disability are assigned to the lowest tier, because of the overly restrictive criteria for the highest tier. Our National President, who is a quadriplegic, is in the PCAFC and was assigned the lowest tier. Out of curiosity, he asked a nurse in the program what it would take for a veteran to be placed in the higher tier. Essentially, she told him the veteran would have to be bedbound and incoherent in order for that to happen.

VA's current requirement fails to recognize that veterans who are able to have a measure of independence still may need significant caregiver assistance in completing their ADLs. PVA raised this concern in our comments to VA's proposed rule in May 2020. We noted that, "Requiring a veteran to be fully dependent on a caregiver each time he or she completes three or more ADLs will result in few veterans being eligible for the higher-level stipend. VA should reconsider this requirement because it

¹ 38 C.F.R. § 71.15.

² Paralyzed Veterans of America, Comment Letter on Proposed Rule about the Program of Comprehensive Assistance for Family Caregivers Improvements and Amendments Under the VA MISSION Act of 2018 (May 5, 2020).

works against the department's efforts to foster veterans' independence wherever and whenever possible and promotes total reliance on a caregiver."³ This concern has now become a reality and VA must remedy this problem when revising the PCAFC rule. In the alternative, VA should provide additional tiers to recognize the diversity of care needs and the burden on family caregivers.

In September 2022, VA announced the extension of legacy veterans and their family caregivers in the program through September 2025. The extension allows the department to continue supporting this cohort of veteran caregivers, while they worked to ensure that PCAFC met the unique needs of veterans of all eras and their caregivers. This cohort of legacy veterans and their caregivers are once again facing an uncertain future. Many of them have been found eligible for the program over the years and endured multiple pauses, regulation and leadership changes, lack of previous program standardization, and questionable assessments. The physical and emotional toll on them is tremendous, and they deserve some degree of certainty that will allow the Caregiver Support Program to focus on its mission of supporting all generations of caregivers.

Additional Supports Needed for Caregivers

A 2023 AARP report titled, "Valuing the Invaluable,"⁴ determined that family caregivers provide an average of 18 hours of unpaid care per week. We have no doubt that commitment is even higher whenever a veteran is involved. Many caregivers of veterans are taking care of other family members and maintaining jobs outside the home. Too many are forced, however, to reduce their hours or leave the workforce entirely. The physical, emotional and financial toll of family caregiving is enormous so it is extremely important that VA and Congress do more for them.

PVA supports the Credit for Caring Act (H.R. 7165) which would provide an annual, nonrefundable federal tax credit of up to \$5,000 to eligible family caregivers to help address the financial challenges of caring for older parents, spouses, and other loved ones, while remaining in the workforce. Another PVA endorsed bill, the Alleviating Barriers for Caregivers (ABC) Act (H.R. 8018) would eliminate red tape for caregivers who interact with Medicare, Medicaid, and Social Security. Also, the PVA-supported Social Security Caregiver Credit Act (H.R. 3729) would provide credits under Social Security to ensure that caregivers are not penalized in retirement for taking time out of the workforce to perform caregiving duties. The changes enacted by these bills alone would go far in supporting those who care for the nation's veterans at home.

³ Id.

⁴ [Valuing the Invaluable](#)

A growing number of veterans with chronic illnesses or other disabling conditions receive care from unpaid family members. Many of these family caregivers are also employed outside the home. While some are able to alter their work schedules or take time off from their jobs to provide hands on care, others are compelled to leave their jobs to assume a fulltime caregiver role. Numerous barriers often impede this important family decision, and the caregiver having access to their own health insurance is likely to be chief among them. The primary caregivers of veterans in PCAFC are fortunate because they receive medical insurance coverage through VA's Civilian Health and Medical Program (CHAMPVA). Granting access to CHAMPVA for other disabled veterans who are not eligible for the PCAFC or who are not 100 percent permanent and total would also benefit their caregivers, and keep many of these veterans out of much more costly, institutional long-term care.

Finally, we cannot overlook the importance of passing the many caregiver-related provisions in the Elizabeth Dole Home Care Act (H.R. 542) which have now been incorporated into the much larger omnibus package entitled, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act (H.R. 8371). This includes a requirement that the VA provide a personalized and coordinated handoff of veterans and caregivers denied or discharged from the PCAFC into any other home care program for which they may be eligible. Passage of this legislation is one of PVA's top legislative priorities in 2024. We urge Congress to complete action on this critically important legislation immediately after it returns in November.

PVA would once again like to thank the committee for the opportunity to submit our views on supporting veterans' caregivers, and would be happy to take any questions for the record.

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.

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.