

**STATEMENT OF SARAH S. DEAN
ASSOCIATE LEGISLATIVE DIRECTOR
PARALYZED VETERANS OF AMERICA
FOR THE
HOUSE COMMITTEE ON VETERANS' AFFAIRS
CONCERNING
"VA CAREGIVER SUPPORT PROGRAM:
CORRECTING COURSE FOR VETERAN CAREGIVERS"
FEBRUARY 6, 2018**

Chairman Roe, Ranking Member Walz, and members of the Committee, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to present our views pertaining to the Department of Veterans' Affairs Comprehensive Family Caregiver Program. PVA appreciates the Committee's interest in the improvement and potential expansion of this unique and critical program. No other group better understands the value of caregiver support than PVA members.

While the Department of Veterans Affairs (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 the most important component of rehabilitation and maintenance for veterans with catastrophic injuries. Their welfare directly impacts the quality of care veterans receive. The VA Program of Comprehensive Assistance for Family Caregivers (PCAFC) is one-of-a-kind in the United States. It is the only integrated program that is required to provide health care, 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.

When the program started in 2011 it was estimated 4,000 veterans would apply. Over 45,000 applied, clearly demonstrating the critical need for the program. There are currently 22,000 participants. Given the unique nature of the program and the larger than anticipated demand, VA has encountered several complications including staff shortages, unclear procedures, and an antiquated IT system. Seven years later, after a comprehensive review in 2017 and the issuance of VHA Directive 1152, we believe VA has done a creditable job enacting the intent of Congress. Those PVA members participating in the program have reported positively on their experience. Their caregivers are better equipped to serve the veteran and they experience fewer financial and emotional stresses because of the availability of respite, mental health care and a monthly stipend.

Improvements to the current program

Public conversations around the efficiencies of the program often do not include its function and design. It was clinically modeled for older, catastrophically injured veterans. It is equal parts temporary rehabilitation program and permanent long term care program. The experience of this program is inherently variable. Some post-9/11 veterans are in the beginning of their rehabilitative journey and are establishing a new normal. They may improve to the point of no

longer needing assistance with activities of daily living. However, over time their health may slip, their injuries may exacerbate, and they may return to the program and fluctuate between tiers. Other veterans with more static conditions will remain a steady cohort of program participants. The majority of program discharges are because the veteran is no longer clinically eligible.

PVA notes there has been some inconsistency of admittance and revocation. We believe this is a result of fractured practices at the local level and the use of a sole clinician assessing eligibility. We encourage the use of multidisciplinary teams in eligibility assessments at every facility. Individual providers making the eligibility determination allow for a great deal of subjectivity. The use of multidisciplinary teams in assessments and tier assignments offers more objectivity and stricter adherence to the seven eligibility criteria.

For all the genuine concern regarding wrongful revocation, it is our understanding very few clinical appeals were successful. It appears that the manner in which the local facilities informed the veterans and caregivers of revocation was poorly done, with little warning, if at all. VA must give consistent, and transparent information to veterans regarding eligibility and tier reduction. In the news stories leading up to the suspension of revocations, one theme was explicitly clear; VA must do a better job conveying to the veteran and caregiver that this program is not an earned benefit. It is a medical service based on clinical need. We were pleased to see the updated Roles, Responsibilities, and Requirements form published in July 2017 helps to do just that.

As with any newly established program, it will have flaws. These were exacerbated by the lack of clear policy guidelines until June of 2017 when VHA Directive 1152 was issued, finally providing consistent policy to the field regarding eligibility and discharge requirements. For six years it was unclear who was operationally responsible for what program elements. Now clear lines have been drawn for the VA medical centers, VA primary care services and the Caregiver Support Coordinators.

PVA is pleased with the progress and continual improvement of this program. While there is debate as to how future eligibility and process should look, the program is executing the intent of

the law with the authorities and resources it has. We believe the program has proven its value to the thousands of veterans and caregivers already served. Yet the majority of veterans who rely on caregivers to complete activities of daily living are not eligible.

End the Inequity: Caregiver Expansion

We know the ability of a veteran to remain home, with one's spouse and children, among friends and in a community, is critical to overall wellbeing. At the same time, we know caregivers have sacrificed their own health, their career opportunities, and their financial standing to care for veterans. Because these caregivers have stepped up, some for half a century, they have saved the taxpayer billions of dollars. It is unconscionable that the needs of one group of veterans and the work of their caregivers be recognized and supported, while another group continues to labor in the shadows, unacknowledged with no reprieve, after decades of service.

PVA understands the costs associated with expansion are significant. And in a time of warranted scrutiny of spending by VA, lawmakers are hesitant to support such an expense, no matter how just the cause. But perhaps what should be considered in a challenging budget environment is how much would be saved by delaying a veteran's entry into an institutional setting. If a caregiver can no longer afford it, or becomes ill, their veteran likely has no other option but to be placed in an institution. VA is obligated to pay the full cost of nursing home services for veterans for a service-connected disability. The cruel irony is VA is not allowed to delay such an admission by supporting their caregiver. Consider the long term cost savings for the taxpayer by delaying disabled veterans admittance to the following--

- Average Annual Cost per Veteran for VA Community Living Center: \$379,853.71
- Average Annual Cost per Veteran for Community Nursing Home: \$101,132.20
- Average Annual Cost per Veteran for State Veteran Nursing Home: \$56,042.52
- Average Annual Cost per Veteran for PCAFC: \$19,000

Congress continues to find excuses to deny access. It has never been more urgent for those excuses to stop. As the largest cohort of veterans ages, our Vietnam-era veterans, the demand for long-term care resources will grow significantly. Catastrophically injured veterans will require

the most intensive and expensive institutional care. By providing their caregivers the means to keep them at home with family, they will live healthier lives, and delay higher costs.

The issue of caregiving will at some point touch all of us. What is unique for service-connected disabled veterans as a group, is that their experience with caregivers will last decades. The Bureau of Labor Statistics projects the home health aide industry to double to meet the need of aging baby boomers. Local agencies will not have sufficient staff to meet the needs of veterans who require a high level of care, but are not yet ready for institutional setting. For veterans like PVA's members, their family caregivers are already there, and they want to continue the job, if we can make it a viable option.

An estimated 40,000 veterans, and their caregivers, are in need of the clinical services of this program. If the cost of expansion is \$3.4 billion over five years (CBO, S. 2921) or \$3.1 billion over five years (CBO, S.2193), then that is what this country owes. Because we are the beneficiaries of their sacrifice. I suspect the majority of Americans would agree. Catastrophically injured, WWII, Korean, and Vietnam veterans, for more than half a century, have been living a life they couldn't possibly have planned for. Their caregivers, most often spouses and now grown children, gave up or never pursued careers and dreams of their own in order to care for their loved ones disabled in support of this nation. They have been made vulnerable, financially and physically, after decades of work. They have saved the taxpayer billions of dollars that otherwise would have been the burden of VA.

Congress will eventually pay for this care one way or another. If it isn't through the caregiver program it will be through overwhelmed home health programs, or high cost VA nursing homes that do not have the necessary capacity. The caregiver program is by far the most just, cost effective, and efficient course of action for the veteran and taxpayer.

Survey data suggests caregivers of pre-9/11 veterans perform more activities of daily living and instrumental daily living skills than post-9/11 caregivers. These caregivers are more likely to endure physical strain; maintaining a veteran with severe physical disabilities means they are bending and lifting for a duration that is likely to jeopardize their own health.

As hard as it has been, and as hard as it will continue to be if Congress does not act, the caregivers of veterans with spinal cord injuries are proud of what they've accomplished. For decades they have maintained the health and wellbeing of a population whose condition once meant a slow death. They have gained skills they never planned to need, they are the reason their children were raised with two parents at home, the reason neighborhoods and churches and family reunions stayed whole. They deserve a break.

Recent years have seen a great deal of discussion about veteran's choice and care in the community; that veterans should have more options for how and where they receive care. This committee has advanced those efforts, many were proposals far more costly than caregiver expansion. What is a more fundamental element of veteran's choice than the choice to receive quality care at home from the people they trust most?

In the seven years since this program began, the barriers to its expansion have always been cost. There will likely never be a projection that isn't significant. But it is what this nation owes and should pay without delay. Admittance to this program is based on clinical need. Denying one group of people a medical service because of era served, and then continuing to deny it because of potential cost is indefensible.

The program is an imperfect solution in place of the perfect solution of healing their wounds. Anecdotal examples of flaws in the program concern us less than the overwhelming degree of satisfaction and gratitude among our members who are currently in the program. As long as human beings are making decisions of eligibility and process there will be flaws. Let us not allow perfection to be the enemy of the good. The majority of PVA members and their caregivers will prefer something over nothing rather than wait for Congress to deem something perfect enough. Let them have better. Their health and the health of their families depends on it. You have a moral obligation to do this. Cost and program imperfections are unacceptable excuses.

PVA would once again like to thank the Committee for the opportunity to submit our views on the programs affecting veterans and their caregivers. We look forward to working with you to ensure our catastrophically disabled veterans and their families receive the medical services and support they need.

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 2018

Department of Veterans Affairs, Office of **National Veterans Sports Programs & Special Events** — Grant to support rehabilitation sports activities — \$181,000.

Fiscal Year 2017

Department of Veterans Affairs, Office of **National Veterans Sports Programs & Special Events** — Grant to support rehabilitation sports activities — \$275,000.

Fiscal Year 2016

Department of Veterans Affairs, Office of **National Veterans Sports Programs & Special Events** — Grant to support rehabilitation sports activities — \$200,000.

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.

Sarah S. Dean
Associate Legislative Director
Government Relations Department
Paralyzed Veterans of America
801 18th Street, N.W.
Washington, D.C. 20006
(202) 416-7712

Sarah S. Dean is an Associate Legislative Director at Paralyzed Veterans of America (PVA). She is responsible for review, analysis and advocacy of veterans health care legislation, particularly women veterans, rural veterans, caregivers, and mental health. She came to PVA in January, 2014, and worked in Veterans Benefits before transitioning to Government Relations in October, 2014. Sarah currently serves on the Department of Veterans Affairs Women's Health CREATE Veterans Council.

Prior to joining PVA, Sarah was an organizer for the North American Indian Center of Boston, where she worked to increase urban Indian access to health care and mental health services. For seven years she was an outdoor educator and expedition guide for Keewaydin Temagami in northern Ontario, Canada. She taught business English for Ford Motor Company in Bogota, Colombia, as well as high school philosophy and social studies. She has organized awareness campaigns around issues of sexual assault and harassment on college campuses.

Sarah was raised in Medina, OH. She attended Northeastern University in Boston, MA, and received a Bachelor of Art degree in American History and Native American Studies. She lives in Washington, D.C.