

STATEMENT FOR THE RECORD
OF
PARALYZED VETERANS OF AMERICA
PROVIDED TO THE
HOUSE COMMITTEE ON VETERANS' AFFAIRS
SUBCOMMITTEE ON HEALTH
CONCERNING THE DEPARTMENT OF VETERANS AFFAIRS'
FAMILY CAREGIVER PROGRAM

DECEMBER 3, 2014

Chairman Miller, Ranking Member Michaud, and members of the Committee, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to submit our views pertaining to the Department of Veterans' Affairs Family Caregiver Program. PVA appreciates the Committee's interest in improving this program so that it can ultimately be viable for all generations of veterans.

The intent of P.L. 111-163, the “Caregivers and Veterans Omnibus Health Services Act of 2010” is to improve caregivers’ skills and well-being while lessening the financial burden of their role. Similarly, the law ensures that veterans with catastrophic injuries receive caregiver support that is so critical to their own independence and health. The law offers services to three groups of family caregivers

- i. **General Caregivers:** includes caregiver education and training, use of telehealth technologies, restricted counseling and mental health services, and respite care.
- ii. **Secondary Family Caregivers:** includes all General Caregiver supports, monitoring veterans quality of life, instruction and training specific to their veteran’s needs, paid travel expenses while accompanying veterans to appointments, information and assistance to address the routine, emergency, and specialized caregiving needs and individual and group therapy, counseling and peer support groups.
- iii. **Primary Family Caregivers:** includes all General Caregivers and Secondary Family Caregivers supports, a monthly caregiver stipend, at least 30 days a year of respite care, and CHAMPVA healthcare coverage, if they have none.

Information from the recent GAO report “VA Health Care: Actions Needed to Address Higher-Than-Expected Demand for the Family Caregiver Program,” (GAO-14-675) highlight many issues that require immediate attention. PVA concurs with the findings of the report and we likewise support the recommendations presented by GAO. Members of PVA, veterans with spinal cord injury or disease, generally have a much higher need for caregiver support than the rest of the veteran population. As such, we would like to share our observations, frustrations,

and suggestions to ensure this program provides the best services possible to those veterans with the greatest demonstrated needs.

No 22 year-old husband or wife prepares to become a caregiver for their spouse. They are often thrust into this responsibility, sometimes over night. As a result, the completion of a college degree or the pursuit of a career is diverted into being the sole provider and caregiver for his or her loved one. Often these partners are already juggling childcare and attending to elderly parents. The well-being of a caregiver is an absolutely critical factor in the well-being of the catastrophically injured veteran and their family.

Unfortunately, not all severely disabled veterans with a service-connected injury or illness have full access to the Family Caregiver Program administered by the Department of Veterans Affairs (VA). The Caregiver Program applies only to veterans with an injury that occurred after September 11, 2001. To amend this inequality, PVA recommends Congress remove the post-9/11 injury requirement for the caregiver program and include “serious illness” as a criterion.

The needs of catastrophically disabled veterans are not different because they became injured or ill prior to September 11, 2001. PVA’s members would benefit from this program more than any other population of veterans. And yet, because of an arbitrary date, most of them are denied a critically needed service. No reasonable justification can be provided for why veterans with a catastrophic service-connected injury or illness incurred prior to September 11, 2001 should be excluded from the caregiver program.

Moreover, the need for a caregiver is not lessened simply because a veteran's service left him or her with a catastrophic illness, rather than an injury. For PVA's members, a spinal cord disease is no less catastrophic than a spinal cord injury. Veterans that have been diagnosed with Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS) will eventually experience unrecognizable changes to their daily activities, and unquestionably become dependent on a caregiver. So why are these families less important than those who currently have access to the Family Caregiver Program?

The cost of the services the VA Caregiver Program currently denies to veterans who became catastrophically injured or severely ill prior to September 11, 2001 will ultimately be paid for by society as a whole. The well-being of a family inevitably declines without essential supports. Ensuring that a veteran is able to reside at their home, in their community, has been shown time and again to reduce medical complications, hospital stays and costs. At the same time, the veteran and their family maintain a psychosocial wellness that is impossible to achieve in an institution.

VHA officials originally estimated that around 4,000 caregivers would be approved for the program by September 30, 2014. By May 2014, about 30,400 caregivers had applied for the program, and 15,600 caregivers had been approved. The GAO report explains, "Caregiver Support Program officials told us that after 3 years of operation, demand for the Family Caregiver Program remains high: system-wide there has been no appreciable decrease in the number of caregivers submitting applications for the program."

Additionally, the report reveals that several thousand post-9/11 veterans and caregivers are not benefiting from the program. They are waiting in the application process or waiting on services for months after they have already been approved. The reasons for these failures are not a mystery. The VA failed to consider that an increase in injured soldiers would be reflected in an increased number of caregiver program applicants. This miscalculation, whether the result of genuine naiveté on the part of the VA or willful disregard for catastrophically disabled veterans and their caregivers, is unacceptable.

Moreover, the GAO report highlights a staggering level of information technology (IT) underperformance. The program is unable to fully realize the comprehensive workload data that would effectively support oversight and management. Lack of an integrated IT system that can offer workload data is a startling admission of incompetence in the 21st century. The report captured stories of manual data entry and ad hoc retrieval of any data not contained within a preprogrammed report.

The Caregiver Application Tracker is a stand-alone system that is not integrated with other VHA systems. This means in order to determine how many veterans in the program are using respite care, staff need to individually “download their data into a spreadsheet and then upload this information to the IT system for respite care use in order to crosswalk the information.” VA medical center requests for additional Caregiver Support Counselor positions are based on informal feedback. The Caregiver Support Program has no means of assessing its own progress or impact without a functioning IT system. It is critical that VA properly address these IT problems as it moves forward with the Family Caregiver Program. This means that VA must

request fully sufficient resources to manage and staff this program and develop the appropriate IT architecture to administer the program, and Congress must ensure that those resource needs are properly met.

With regards to education and training, PVA believes that the law should be amended to meet the caregiver where they are in their skill development (assuming they already have some skills as a caregiver), instead of requiring that they start at the beginning. Many PVA members with spinal cord injury also have a range of co-morbid mental illnesses. We know that family counseling and condition specific education is fundamental to the successful reintegration of the veteran into society.

In an earlier version of the Caregiver Act, Congress would have authorized VA and the Department of Defense to contract for a national survey of family caregivers of seriously disabled veterans and service members, with a report to Congress. Without this information, it is difficult for VA to honestly provide recommendations on funding the caregiver program to Congress. VA estimates the survey would cost approximately \$2 million. PVA strongly recommends that such a national survey be authorized

Caregivers often drop out of school to care for their veteran. Those that manage to work are forced to strategize around the critical and unpredictable needs of their loved ones. Absenteeism, reduced work schedules, and unreliability are inevitable in cases where medical emergencies compete with job demands. The Rand study found civilian caregivers reported missing nine hours of work on average, or 1 day of work per month. By comparison, Post-9/11 caregivers

reported missing 3.5 days of work per month. The lost wages from work in addition to costs associated with providing medical care result in serious financial strain for these veterans and their families.

Intending to alleviate some of the financial burden, the program offers Primary Caregivers a tax-free stipend based on the amount of hourly assistance the veteran requires. The law designates 40 hours a week as the maximum number of hours to receive a stipend. The reality is many caregivers provide services for the veteran more than 40 hours a week and in many cases around the clock. However, there is an unintended negative consequence as a result of the tax-free consideration of the stipend. The tax-free nature of the stipend means caregivers cannot claim stipend payments as income since they are not considered wages. Assuming the caregiver provides a minimum of forty hours a week of service for the next 40 years, that work and its accompanying stipends are not considered earnings for the purposes of Social Security eligibility. The long-term income security of that caregiver after working age could then be put at risk. We believe that Congress should consider the need to change the law in such a way so as to allow these family caregivers who have sacrificed so greatly to support their catastrophically disabled veterans to be eligible for Social Security once they have reached the eligibility age.

As the veteran community is aware, family caregivers offer more than physical assistance. They provide mental health support for veterans dealing with the emotional, psychological, and physical effects of combat. The service of these caregivers and the sacrifices they make in order to care for those who serve cannot be deemed less worthy of support because they wore a uniform prior to September 11, 2001.

Simply put, the Caregiver Program excludes families in need. The current inequities in the law are unfounded and unacceptable. We cannot emphasize enough the need for Congress to reexamine this demarcation in order to better serve all catastrophically disabled veterans and their loved ones.

We would like to thank the Committee for the opportunity to provide a statement for the record, and we look forward to working with you to ensure our catastrophically disabled veterans and their families receive the support they have earned and deserve.

Information Required by Rule XI 2(g)(4) of the House of Representatives

Pursuant to Rule XI 2(g)(4) of the House of Representatives, the following information is provided regarding federal grants and contracts.

Fiscal Year 2014

No federal grants or contracts received.

Fiscal Year 2013

National Council on Disability — Contract for Services — \$35,000.

Fiscal Year 2012

No federal grants or contracts received.