

**STATEMENT OF STEVE SCHWAB,
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BEFORE THE HOUSE COMMITTEE ON VETERANS' AFFAIRS,
UNITED STATES HOUSE OF REPRESENTATIVES ON
"VA CAREGIVER SUPPORT PROGRAM: CORRECTING COURSE FOR VETERAN
CAREGIVERS"**

February 6, 2018

Chairman Roe, Ranking Member Walz, and Members of the Committee, the Elizabeth Dole Foundation is pleased to present its views on the Department of Veterans Affairs' (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC, "the Program").

The Elizabeth Dole Foundation was founded in 2012, just two years after the VA established the Program, and we have followed its trajectory ever since. As the only national organization exclusively focused on the military and veteran caregiver population - the 5.5 million spouses, family members, and other loved ones caring for wounded, ill, or injured veterans at home - the Foundation is uniquely positioned to speak to their point of view. We thank you for the opportunity to provide this testimony.

Our understanding of the military caregiver population is data-driven; in 2012, we commissioned the RAND Corporation to conduct the first-ever needs assessment of military caregivers to better understand this hidden population and the challenges they face caring for our nation's wounded warriors. The findings of this comprehensive two-year study still drive the work of the Foundation today and the work of many of our partners. But while the 2014 landscape survey gave us critical insights into the military and veteran caregiver population, there is still so much that we do not know about supporting these hidden heroes in the long-term.

For the last six years, the Foundation and our Dole Caregiver Fellows, a remarkable group of military caregivers from diverse backgrounds and representing all 50 states, Puerto Rico, and Washington, D.C., have been on the forefront of communicating the caregiver population's experiences and concerns with the Program directly to the VA Central Office. We have worked with both the VA and military caregivers to understand the current systemic challenges, address them, and facilitate an open dialogue between the caregiver population and the VA. We also continually take the pulse on the ever-changing questions and concerns through our Fellows Program and online networks like the Hidden Heroes Caregiver Community; a safe, secure social network where caregivers can find peer support, seek advice, and share stories.

With the passage of the Caregivers and Veterans Omnibus Health Services Act of 2010 and the establishment of the PCAFC, veteran caregivers were finally recognized on a systemic level for the invaluable work they do to assist in the care, rehabilitation, and recovery of our nation's veterans. The 2014 RAND study, commissioned by the Foundation, found that military and

veteran caregivers provide an annual \$14 billion in voluntary, uncompensated care for our nation's veterans and service members, and often shoulder physical, emotional, and financial strain to care for their loved one. Through the Program, qualifying veteran caregivers receive the support they need to take on the economic and personal costs that are intrinsic to caregiving, and in turn, veterans can receive the care they need at home from a loved one, rather than be institutionalized.

The implementation of the program has not been without its challenges. Congress initially intended the PCAFC to serve a small number of caregivers caring for only the most catastrophically wounded veterans. Upon executing the program, the VA realized that many more caregivers needed this program than initially anticipated, and the program expanded to serve the more than 26,000 caregivers that it does today - nearly three times the number of caregivers for which the VA initially planned. The VA uncovered a previously unaddressed need and soon found themselves deluged with veteran caregivers who had, until this point, been caring for their veterans without much support. Because of this, the implementation and administration of the PCAFC have suffered from growing pains as it attempts to accommodate the growing number of veteran caregivers that qualify for the stipend program.

Today, the Foundation has been asked to provide its insight into the challenges that have prevented the Program from giving the maximum level of support that these hidden heroes need. And while we are pleased to have the opportunity to provide our recommendations to help correct these deficiencies, the most significant deficit is that only a limited number of veterans are eligible under the current law. It is unfair that pre-9/11 caregivers, who make up 80 percent of our nation's 5.5 million veteran and military caregivers, are barred from accessing the PCAFC because of their veterans' era of service or diagnosis with a service-connected illness.

We acknowledge that the Program is experiencing significant demand, and the Foundation remains committed to being a part of the solution. But we urge Congress not to overlook the millions of veteran caregivers barred from access to the program merely due to their era of service. Congress should act simultaneously to pass an expansion of the Program to include service-connected illnesses and all periods of service, while also addressing the issues of standardization and clarity. These efforts should not be a zero-sum game.

On November 29, 2017, the Senate Committee on Veterans' Affairs overwhelmingly passed the Caring for Our Veterans Act of 2017, which notably expands the Program to pre-9/11 caregivers. This change could - quite literally - improve the quality of life of millions of Americans. This legislation addresses the need to bolster the program and expands it in a phased, thoughtful manner - while the VA simultaneously implements an improved information technology system. We encourage the House Veterans' Affairs Committee to take up and pass this legislation.

RECOMMENDATIONS

1. The VA should continue to work to improve consistency and accountability in the administration and execution of the PCAFC.

For several reasons, the implementation of the PCAFC has suffered from inconsistencies since its inception. Individual Veterans Integrated Service Networks (VISN), of which there are 18 across the country, have the autonomy to run their programs as they see fit. The result is that, although the PCAFC is a national program, there are many inconsistencies across VISNs in the implementation and operationalization of the program. The discrepancies have caused confusion and tension between caregivers, who hear from other caregivers in other parts of the country of the irregularities in the way the program is administered. And while the law is explicit about including traumatic brain injuries, psychological trauma, and other mental disorders in considering a veteran's eligibility, the lack of standardization often causes disparities in the assessment of this need. We've heard reports of caregivers removed from the program, despite a lack of change in their veteran's functioning levels. Without a standardized assessment tool or more explicit guidelines on the determination of eligibility, the VA is hard-pressed to explain to veterans and caregivers as to why they do not qualify for this program.

Much of this discrepancy stems from the reality that the caregivers witness firsthand the issues their veterans deal with on a day-to-day basis, such as not following a medication regime, driving erratically, forgetfulness that endangers their safety or the safety of others. But the review process - which can vary from VISN to VISN - does not always take the caregivers' knowledge into account. This kind of assessment is a difficult one. Understanding the full breadth of safety and supervision takes a combination of clinical assessments of the veteran, a records review that incorporates the notes and feedback of the primary care team and any outside providers, and a real conversation with the caregiver.

Last July, the VA took several steps to address the persistent inconsistency issues. We applaud the VA for devoting the time and resources required for such an extensive program review to ensure that the many voices of military caregivers are heard and that we as a nation can better meet the urgent needs of our veterans. We stand ready to work with the VA to provide guidance, direction, and insight into these demands. The steps taken by the VA in this review included; issuing a national policy directive regarding program operations, staff responsibilities, as well as veteran and caregiver eligibility requirements; developing a standardized letter used by all VA medical centers when communicating program discharges; and taking steps to demonstrate to caregivers that they should be collaborative partners with the VHA in ensuring overall care and well-being of veterans. The changes introduced increased standardization, but the Program still lacks centralization.

The lack of accountability has also led to variations in the way that the program is administered. Even with the development of a standard policy, the Caregiver Support Program Office cannot enforce its directive. They may only advise the local centers that they are in violation of the law or not in compliance with the VHA Directive. The new directive even notes that the Program is structured for each medical center to develop processes to carry out the Program. We understand that the ability of each medical center to self-determine its own needs is central to the operation of the VA system. When operational authority supersedes policy implementation, however, it creates an inconsistent - and at times prejudicial - program environment for caregivers.

The Foundation as far back as three years ago began to hear concerning stories of caregivers unexpectedly dropped from the PCAFC. We started to collect these stories, mapped out the scope of the issue and helped to connect caregivers to essential resources to help them appeal these decisions. We referred the most grievous cases to the Department of Veterans' Affairs for further review and reevaluation, and in some instances, the program revocation overturned. We owe our work to the many caregivers who have stepped up, shared their experiences, and provided all of us the necessary insight into the challenges the Program was experiencing. We must continue to support those caregiver voices through the standardization of this critical VA Program.

2. Congress and the VA should work to more clearly define and communicate PCAFC program eligibility requirements.

PCAFC is the stipend program offered through the VA Caregiver Program. This is currently limited to eligible veterans injured in the line of duty on or after September 11, 2001. Eligibility for the program is a clinical determination that the program will significantly enhance the veteran's ability to live safely in a home setting, support the veterans' potential progress in rehabilitation, and create an environment that promotes the health and well-being of the veteran.

Under current law, the clinical determination is based off the veterans' need for personal care services from another individual for at least six continuous months based on A) an inability to perform one or more activities of daily living (ADLs), B) a need for supervision or protection based on a neurological or other impairment/injury, and/or C) is service connected for a severe injury that was incurred or aggravated in the line of duty in the active military, naval, or air service on or after September 11, 2001, has been rated 100 percent disabled for that serious injury, and has been awarded special monthly compensation that includes an aid and attendance allowance.

The current statutory language allows for broad interpretation of the eligibility requirements and subjective assessment - particularly for activities of daily living and the need for supervision or protection. While this provides for accommodation of a wide range of physical and cognitive

issues, it also allows for variability of implementation that is both time-consuming to the care team making the decision, and often inconsistent concerning the veteran and caregiver.

We've heard cases where a caregiver moved from one part of the country where they had been determined eligible for the program, to another part of the country where they were found ineligible for providing the same support. The eligibility requirements should be clarified and standardized as much as possible, while still allowing clinicians their discretion to make a decision that will lead to the best outcome possible for the veteran. A focused look at how the eligibility requirements are defined and interpreted is required. The directive the VHA released in July provides the definitions for the individual activities of daily living and the need for safety and supervision. However, it does not provide guidance on the assessment and evaluation of those two particular eligibility criteria.

Standardized evaluation metrics and tools should be determined that allow individual medical centers and VISN leadership to establish processes that serve their specific local needs and prevent unfair variance in the national implementation of the program.

3. The VA, along with members of the veterans' community, should more effectively communicate to veterans and their caregivers the programs and services available to them.

It is essential that interested veterans and their caregivers have a good understanding that the Program is one vehicle for intervention and not the only option for support available under the VA's Caregiver Support Program. A confusion of the stipend program as a "benefit" rather than one part of a program meant to help facilitate the clinical need for a caregiver often contributes to frustration on the part of the caregiver. This misunderstanding about the Program results in significant demand and thus an increased strain on the Program.

Miscommunication of the intent of the Program leads to another issue as well. Eligibility for the PCAFC, or the lack thereof, can create resentment among caregivers who feel as though their caregiving role is being "ranked." There is a sense that those who qualify for the program are somehow "better" caregivers than those who are not - when nothing could be further from the truth. The fact is that caregiving occurs on a continuum, and while this program serves a specific portion of that continuum, this does not invalidate the selflessness or dedication of those caregivers who do not participate. This incorrect assessment of the PCAFC is often due in part to a misunderstanding that the Program is a benefit program, rather than a program based on a clinical determination of the needs of the veteran. By emphasizing the true clinical nature of the program, we can help alleviate these misconceptions.

The Caregiver Support Program and the Caregiver Support Coordinators are essential in communicating available support to veterans and their caregivers. However, we must adopt a multi-tiered approach to disseminating information about all programs within the VA's Caregiver Support Program. The communications strategy should also explicitly set expectations and help caregivers understand the growing network of support - of which the PCAFC is just one part.

As a community - the Foundation, the Veteran Service Organizations, the VA, and others - must also provide additional guidance and awareness of other programs available for veteran and caregiver support - which are not eligibility restricted. Within the VA, these programs include in-home care, respite care, services to address mobility, physical rehabilitation, education and training, financial support, referral services, and other caregiver support services. (Table 1) We must also focus our attention on programs and resources outside the VA that can support military and veteran caregivers. Improving communication cannot be a VA problem; we must all work towards a culture of holistic support that meets caregivers where they are and addresses their needs in both the short- and long-term.

The Elizabeth Dole Foundation has taken steps at addressing this communications gap through our Campaign for Inclusive Care, in partnership with the Department of Veterans' Affairs. The campaign focuses on ensuring that veteran and military caregivers fully integrated as part of their veteran or service member's medical team. The Foundation is also working to develop a military caregiver journey map, which maps the key milestones that each caregiver faced along their journey. This map aims to shed light on some of the critical crisis and decision points that the military caregivers go through, and will assist in designing interventions to help caregivers in the future. Additionally, through our Hidden Heroes Cities Program, Dole Caregiver Fellows Program, and partnerships with other organizations, we are bringing awareness and support to caregivers on the community level.

Military and veteran caregivers are essential to the recovery and rehabilitation of our nation's wounded warriors. But they cannot do it alone. It is up to us to ensure that these selfless hidden heroes have the tools they need to facilitate that support. The Elizabeth Dole Foundation is committed to creating and strengthening a holistic system of support that will position these selfless men and women for the best possible outcome for their veteran and their family. We look forward to working with the VA and our partners to make this vision a reality.

TABLE 1

DEPARTMENT OF VETERANS' AFFAIRS CAREGIVER SUPPORT PROGRAM (CSP) LIST OF SERVICES TO SUPPORT VETERANS AND FAMILIES		
In-Home Care Skilled Nursing Home Health Aide Home Based Primary Care Veteran Directed Home & Community Based Care	Education and Training Financial Support Aid and Attendance Family Caregiver Stipend – Post 9/11 Information and Referral Caregiver Website – www.caregiver.va.gov Caregiver Support Line – 855-260-3274	Caregiver Support Caregiver Support Coordinators Peer Support Mentoring Program Building Better Caregivers™ Spouse Telephone Support REACH VA Support Groups
Respite Care Services to Address Mobility Equipment Home Modification Automobile Modification		