



Elizabeth Dole Foundation

CARING FOR MILITARY FAMILIES

May 5, 2020

U.S. Department of Veterans Affairs
810 Vermont Avenue, NW
Washington, DC 20420

Thank you for the opportunity to comment on the Department of Veterans Affairs' (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC). We thank the Department for its continued leadership to support more than 5.5 million veteran caregivers serving across the nation. The PCAFC is a critical program and one of only three stipend programs that help offset the cost of income lost from caregiving responsibilities.

As the preeminent organization empowering, supporting, and honoring our nation's military caregivers, the Elizabeth Dole Foundation seeks to strengthen and empower American military caregivers and their families by raising public awareness, driving research, championing policy, and leading collaborations that make a significant impact on their lives. In 2012, EDF commissioned the RAND Corporation to develop the first comprehensive, evidence-based national study of military and veteran caregivers. Conducted over two years, *Hidden Heroes: America's Military Caregivers* examined the magnitude of military caregiving in the United States, to better understand the unique needs and challenges of this population and identify gaps in the array of programs, policies, and initiatives designed to support military and veteran caregivers. The study revealed a societal crisis requiring a national response.

In the research, the RAND Corporation found that caregivers make an array of financial and legal decisions throughout the course of being a military caregiver. Almost two-thirds of post-9/11 military caregivers reported financial strain as a result of caregiving responsibilities, with many stating that they have taken unpaid leave or stopped working temporarily (48%); cut back on the number of hours worked (39%); took early retirement (11%); quit work entirely (28%); or cut back on educational activities (26%).

hiddenheroes.org

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Research has also shown that the PCAFC and the level of support it offers for caregivers at the VA is incredibly beneficial for the caregiver's health and well-being. In 2019, AARP reported that family caregivers provide approximately \$470 billion worth of unpaid direct care to individuals living in the United States.

However, the PCAFC has not been implemented without its challenges. The PCAFC was initially created in 2010 for a small number of caregivers caring for only the most catastrophically wounded veterans. The VA MISSION Act of 2018 vastly expanded this program, authorizing VA to now offer the program to caregivers for veterans of all eras. Along with the VA MISSION Act of 2018, the VA has also taken the recommendations of the Secretary's Federal Advisory Committee for Veterans Families, Caregivers, and Survivors that is chaired by Senator Elizabeth Dole. The work of this committee can be seen throughout the proposed regulations and we commend the VA for including the work of the Committee.

We commend the VA for the most recent set of proposed regulations that outlines how this expansion will be phased in for caregivers. Below, we have outlined our concerns and feedback to the proposed rule.

1. Expand PCACFC to eligible veterans of all service eras, as specified.

EDF remains concerned that VA has not committed to a specific date of expansion. Since the passage of the MISSION Act in 2018, VA has missed several deadlines for expansion due to attempts to improve its outdated IT system. While the MISSION Act required the implementation of a new IT system, the current issues with the IT system have persisted for years. Given these delays, we ask that the VA commit to publishing monthly updates on progress towards implementation of the IT system through press releases or another public forum. Furthermore, given that VA will likely receive hundreds (if not thousands) of comments related to this proposed rule, we urge VA to also publish monthly updates on progress towards publishing a Final Rule once the public comment period ends.

Additionally, the proposed regulations maintain the 2-year waiting period between Phase 1 expansion and Phase 2 expansion as established in the MISSION Act. As Phase 1 expansion is launched and applications are received and processed, we hope the VA will work through any issues with applications as they arise, thereby improving the overall system as they go. We ask the VA to clarify why an additional two years is needed for evaluating Phase 2 applicants, given the urgent needs of this population, and already encountered delays. We recommend that the VA commit to a shorter timeline for Phase 2 implementation.

EDF does request clarification on those veterans who will be included during Phase 1 of the expansion. Will any veteran who served prior to May 7th, 1975 be eligible under Phase 1? This clarification is essential to providing clear eligibility. In the example below, does Tom meet the eligibility criteria to be included in Phase 1?

Mary is an Elizabeth Dole Fellow and the family caregiver of her husband, Tom. Tom served in the US Marine Corps from August 1972 to August 1975. Tom was diagnosed with Amyotrophic Lateral Sclerosis (ALS) in June 2010. Tom meets all additional eligibility criteria for the PCAFC program. Due to his service connection illness and his date of discharge would Tom be eligible for the first phase of the program?

2. Define new terms and revise existing terms, some of the new terms would have a substantial impact on eligibility requirements for PCAFC and the benefits available under PCAFC.

Throughout the proposed rule, VA references its goal to shift PCAFC to those veterans with moderate and severe needs. While this shift may allow for cost savings as well as clearer eligibility requirements, we are concerned that the needs of family caregivers for veterans requiring some assistance, or intermittent assistance will not be met, leading to poorer health outcomes for veterans and those who care for them. In the Regulatory Impact Analysis, VA states that it anticipates those currently at Tier 1 (approximately 7,000 participants) will no longer be eligible for the PCAFC, representing almost a one third reduction of the current program. We request that VA clearly state the rationale for this shift and the impact it will have on current participants.

In addition, we urge VA to identify other services and supports available to these caregivers and to verify that these other programs are available consistently, across the country, and are effective in delivering support. Home and community-based services such as VA's Veteran Directed Care Program, Home Based Primary Care, Respite, and Homemaker and Home Health Aide, are often underfunded and the first to be cut when a medical center faces a budget shortfall. EDF urges VA to evaluate these programs and ensure their success and viability, especially as VA shifts the focus of PCAFC.

Terms Related to Eligibility Requirements

In need of personal care services (§ 71.15): VA has added an additional requirement to this definition, leading to a significant change in eligibility. VA has added the requirement that the personal care services must be provided “in person” and without that person being present, “other arrangements” would need to be made, including a secondary caregiver, or respite services. EDF finds this requirement restrictive and limiting, and we believe this will result in significant reductions of current program participants who will no longer be eligible.

While we understand the requirement for the care to be provided “in person,” EDF requests that VA state clearly that the care does not need to be hands on, physical care. The assistance can be provided through supervision, protection, or instruction while the veteran completes an ADL.

Alicia is an Elizabeth Dole Fellow and the family caregiver for her husband, Angelo. Because of a Traumatic Brain Injury (TBI) Angelo cannot manage his medication on his own. Alicia reminds him of which pills he needs to take and when to take them. Once he is reminded, Angelo can take the pills himself.

In addition, EDF requests that VA clearly state in regulation that working is not an exclusion criterion for either the veteran or the family caregiver. While VA has often publicly stated that working is not an exclusion criterion, EDF is aware of many situations when a family was discharged from PCAFC because either the veteran or caregiver worked.

Inability to perform an activity of daily living (§ 71.15): VA proposes to change this requirement for eligibility for PCAFC so that veterans will require assistance on a “daily basis” or “each time” they complete the ADL. EDF has significant concerns about these changes and how caregivers and veterans will be evaluated to determine if support for ADLs is needed on a “daily basis” and “each time” they perform an ADL. We understand that the level of caregiver support needed can vary over time and we are concerned about how the revised criteria may impact caregivers who are applying for enrollment into PCAFC. Of note, the “invisible wounds of war” such as PTSD and TBI often lead to fluctuations in a veteran’s level of functioning.

EDF requests that VA clearly define what it means to “require assistance.” For example, one day, a caregiver may need to wash a veteran during a shower, however on the next day, that same veteran may only require assistance getting in

and out of the shower to bathe. By day three, the same veteran may only require setting the water to an appropriate temperature. Does this veteran meet the criteria for “requiring assistance each time” the ADL is performed? EDF also seeks clarification on how this eligibility requirement will be assessed consistently across VA. What protocol will be used?

Need for supervision, protection, or instruction (§ 71.15): VA proposes significant changes to this definition, moving away from specific symptoms such as seizures, to an overall focus on functioning. EDF agrees with this change, as the previous list of deficits was very limiting and often excluded veterans who require significant levels of assistance.

VA proposes to instead focus eligibility on the need for supervision, protection, or instruction “on a daily basis, even if just intermittently each day” and that this assistance increases the veteran’s “ability to maintain his or her personal safety.” EDF urges VA to clearly define these terms to ensure consistency across medical centers.

Serious Injury (§ 71.15): Given the MISSION Act’s expansion to include pre-9/11 veterans and their caregivers in the PCAFC, we understand why VA wanted to establish clearer criteria around eligibility. The VA is proposing to leverage a veteran’s disability rating to establish a “serious injury.” The regulations propose a single or combined rating of 70% or more of service-connected disability; disability ratings are a more common standard used for eligibility across other VA programs. VA has stated that more than 95% of current enrollees should meet the proposed 70% criteria.

We commend the VA for their proposal to revise the “serious injury” definition to include service-connected disease and illness as EDF has expressed concerns over the existing definition for many years. In the past, the lack of clarity around this definition has caused delays for many applicants to the PCAFC, and caregivers or veterans suffering from debilitating service-connected diseases or illnesses have not been eligible to access these services.

Unable to self-sustain in the community (§ 71.15): VA has proposed this definition as its criteria for those veterans with severe needs and establishing the higher tier level for PCAFC. Under this definition, a veteran who requires personal care services each time he or she completes three (3) or more of the seven (7) ADLs and is fully dependent on a caregiver to complete such ADLs or has a need for supervision, protection, or instruction on a continuous basis would be eligible for services at the

higher tier level. While EDF understand the needs to define this higher level of need, we disagree with this definition of “unable to self-sustain in the community,” based on the experience of our Fellows.

Mari is an Elizabeth Dole Fellow and the family caregiver for her husband, Gary. Gary is a paraplegic and suffered significant muscle damage in his lower extremities. While Gary can complete most ADLs independently, he is now facing shoulder damage because of their overuse. Mari provides support and assistance on most days, in order to allow Gary to remain as independent as possible. Without Mari supporting Gary with less than 3 ADLs, Gary would not be able to remain in the community.

We are also concerned about the word “continuous” in this definition. Does continuous mean 24 hours a day, 7 days a week? In our experience, a veteran requiring this level of supervision is in crisis and should be admitted to a higher level of care, or hospitalized. We urge VA to better define this higher tier level for those veterans requiring a severe level of supervision, protection, or instruction.

Lastly, EDF is concerned that without clear protocols and definitions for determining this tier level, inconsistency will continue across medical centers. EDF is not supportive of definitions to ensure that veterans can “self-sustain” in the community. We urge VA to define eligibility to ensure that veterans and family caregivers not only self-sustain but *thrive* in the community.

Requirement that Family Caregiver provide the personal care services (§ 71.25(f)):

EDF has significant concerns about this new requirement. While it makes perfect sense to require that the Primary Caregiver is providing the personal care services to the veteran, EDF is very concerned about the inclusion of the language that the family caregiver only be absent for “brief” periods of time. As VA has demonstrated in multiple published, peer-reviewed articles, caregiving takes a significant toll on family caregivers, impacting their emotional and physical health. Is it VA’s intention that family caregivers always be present? What about caregivers who work? Will they no longer be eligible for PCAFC? EDF urges VA to remove this language in the proposed rule or to clearly define phrases such as “continuous” and “brief absences” to ensure that caregivers aren’t penalized for activities such as seeking employment or respite services.

Liz is an Elizabeth Dole Fellow and the family caregiver for her husband, Chuck. Liz also works full time, sometimes more than 40 hours a week. Because of a Traumatic Brain Injury (TBI), Chuck requires supervision, protection, and instruction to maintain his personal safety. While Liz provides most of this support “in person,” she supports Chuck through reminders on his phone and setting up clear routines with instructions. This level of support would not be sustainable for long periods of time.

In summary, we are concerned that with these regulations, the VA has still not addressed one of the biggest concerns we have encountered with eligibility – the actual process for evaluating applicants. To date, there has not been a consistent protocol defined for how the VA evaluates PCAFC applicants. We ask that the VA clarify the applicant evaluation process as well as the role of the centralized eligibility team as part of their work towards the final rule. We also ask that the VA make available for comment the assessment tool that is under development which will eventually be used for evaluating applicants for the program.

Terms Related to PCAFC Benefits

Responsibilities of Family Caregivers (§ 71.25(c)(1)(ii)): VA has included an assessment of the caregiver’s well-being in the initial home visit required prior to admission to PCAFC. We applaud VA for including assessing the caregiver’s well-being. However, we are concerned about how VA will determine the “competence of the caregiver to provide personal care services” during the home visit as described in the proposed rule. The rule states that a caregiver will be assessed on “demonstrating the ability to provide personal care services.” We encourage VA to state how this competence will be determined in order to establish consistency across medical centers. Will the caregiver be required to demonstrate their ability verbally or will they be required to actually demonstrate the required personal care service?

Part of the challenge and burden of the current home visits is that these visits are often accompanied by a change in eligibility status. As part of this shift towards wellness in the proposed rule, we strongly encourage the VA to clearly state in the Final Rule and subsequent policy documents that an outcome of the wellness visit

cannot be a reassessment of the veteran, unless that reassessment would result in the veteran being moved into the higher tier.

3. *Establish an annual reassessment to determine continued eligibility for PCAFC (§ 71.30).*

VA has included an annual reassessment in compliance with the MISSION Act. While we agree that this requirement will increase consistency across medical centers, the proposed regulation continues to leave the frequency of these assessments to local providers. We would encourage VA to limit reassessments to not more than annually. In addition, we would encourage specific guidelines around which veterans would not require an annual reassessment as their status will not change in the future.

4. *Revise the stipend payment calculation for Primary Family Caregivers (§ 71.40(c)(4)).*

VA proposes to change the current payment calculation which uses a Bureau of Labor and Statistics (BLS) rate to the more accurate and standardized GS rate. We support this change, recognizing that some families may see their stipend amount shift as a result of this change and appreciate the one-year waiting period so that families can prepare.

VA also proposes to change PCAFC from a three (3) tier system to a two (2) tier system. We commend the VA for proposing a more streamlined approach to determining the monthly stipend that a caregiver and eligible veteran may receive. We reiterate our concerns above about the process used to identify assessment protocols for determining tier levels. Requirements such as “continuously” and “on a daily basis” must be clearly defined, along with the method used to make such determinations in order to ensure consistency and fairness to veterans and their caregivers.

In some cases, PCAFC participants might see their stipend amount increase or decrease as a result of the proposed new tier system and/or GS-4 stipend calculation. We commend the VA for proposing a one-year transition period before any of these changes become effective, providing participants advance notice and time to make new financial arrangements, if needed.

EDF is aware of several cases in which families are told they are not eligible because they live in two different areas of the country for parts of the year.

Caira is an Elizabeth Dole Fellow and a family caregiver for her husband, Eric. Because of a TBI, Eric is unable to manage his own body temperature and is much more comfortable in a warm climate. For several years, Caira and Eric lived part of the year in Wisconsin and part of the year in Georgia. Caira and Eric are in contact with their case manager and primary care team regardless of their location.

EDF requests VA to clarify that families who live at more than one address during the year are eligible for PCFAC and to state which calculation method would be used to determine their stipend rate.

5. Establish a transition plan for those who may not meet the new eligibility criteria and whose primary Family Caregiver could have their stipend amount impacted by changes to the stipend payment calculation (§ 71.15 and § 71.20(b) and (c)).

VA establishes a transition plan for those who may no longer meet eligibility criteria PCAFC or may have their stipend amount impacted by changes made to the stipend calculation. We appreciate that VA has provided a one-year transition period to complete reassessment, as well as a 60-day advance notice requirement allowing CGs and veterans to contest decisions. This allows for families to receive notice in advance and prepare for any changes.

6. Add financial planning and legal services to benefits available to Primary Family Caregivers (§ 71.40(c)(5) and (6)).

Financial and legal issues are huge areas of concern for caregivers and their families. By extending PCAFC benefits to include these new areas as required under the MISSION Act, VA is recognizing the many issues that caregivers must manage on a day-to-day basis.

In the proposed rule, VA limits both financial planning and legal services to needs of the eligible veteran and Primary Family Caregiver as “the direct result of the personal care services they provide to eligible veterans.” VA only excludes “business or other professional endeavors” from this definition. EDF encourages VA to provide additional clarification on exclusions. For example, if the assistance with legal services is regarding other members of the family such as the children of the family caregiver and veterans, would this be allowed under this rule?

7. *Revise the process for revocation and discharge from PCAFC (§ 71.45).*

VA proposes a 60-day notification period in this proposed rule, prior to discharge from PCAFC, ensuring participants are not immediately dropped from the program without advance notice. This 60-day transition period was championed by the Secretary's Federal Advisory Committee on Families, Caregivers, and Survivors, Chaired by Senator Dole. We are excited to see the Committee's recommendation come to life.

In addition, VA has included a new category of discharge, discharge because of domestic or interpersonal violence in the home. Sadly, we are aware of circumstances in which caregivers have not been able to leave violent situations because they were afraid of losing the stipend and health care benefits provided through the PCAFC. We commend VA for extending services and support to caregivers dealing with domestic violence or intimate partner violence - this is a critical step to help ensure caregivers are safe. We do request that VA add shelter coordinators and safe home coordinators to the list of those designated to provide documentation to VA for the purposes of this new category of discharge to allow for a more inclusive list of those professionals who work with those who have experienced domestic or intimate partner violence.

8. *Reference VA's ability to collect overpayments made under PCAFC (§ 71.47).*

VA references its ability to collect overpayments under PCFAC, something not clearly stated in previous regulations. We agree with VA's ability to collect overpayments to decrease fraud and abuse associated with participation in PCFAC. However, we are aware of circumstances in which an overpayment has occurred because of an error on the part of VA and are very concerned that VA would collect an overpayment when it is their own fault that the overpayment occurred.

In addition, EDF urges VA to provide clarification for legacy participants when it is determined that they do not meet the new eligibility requirements. EDF recommends that VA state clearly that it will not initiate collections on legacy participants, even if it is determined that they were initially approved in error.

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Again, we thank you for the opportunity to provide these comments on this critical VA program. The Elizabeth Dole Foundation is committed to creating and strengthening a holistic system of support that will better serve our nation's military & veteran caregivers for the years to come. We are proud to submit these with comments support of over 76 caregivers and organizations dedicated to supporting caregivers.

We look forward to continued collaboration with the VA and our partners to make this vision a reality. If you have any questions regarding these comments, please email Rashi Romanoff at rashi@elizabethdolefoundation.org.

Thank you,

Steven Schwab
CEO
Elizabeth Dole Foundation

Organizational Sign On:

AARP

Air Force Sergeants Association

Caring Across Generations

National Alliance for Caregiving

National Military Family Association

Paralyzed Veterans of America

Rosalynn Carter Institute for Caregiving

Caregiver Sign On:

Alicia Maddaloni, Alaska

Amanda Flener, Georgia

Angela L. Brooks, Illinois

Anne Adkinson, Oregon

Anne Way, Georgia

Betsy Eves, District of Columbia

Brandy Wrenn, North Carolina

Brian Vines, Alabama

Caira Benson, Florida

Carol Snider, Oregon

Carrie Fisher, Florida

Christina Garcia, Kentucky

Colleen Rose, District of Columbia

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