

Wounded Warrior Project

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Director, Office of Regulation Policy and Management
Department of Veterans Affairs
810 Vermont Avenue, NW
Room 1064
Washington, DC 20420

**RE: RIN 2900–AR96 — Amendments to the Program of Comprehensive Assistance for Family Caregivers
Vol. 89, No. 235 / Friday, December 6, 2024 / 97404–56**

Dear Office of Regulation Policy and Management Director,

The comment that follows provides perspectives from the community of veterans who sustained catastrophic injuries during military service on or after September 11, 2001. For many in this community, the Department of Veterans Affairs’ (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC) has provided critical support that has been necessary to sustain meaningful lives at home and in the care of loved ones serving as caregivers. As VA considers new rules to govern PCAFC, the historical observations and forward-looking perspectives from those currently enrolled can and should provide meaningful guidance.

INTRODUCTION

Wounded Warrior Project (WWP) was founded in 2003 with a mission to honor and empower wounded warriors, and a vision to foster the most successful, well-adjusted generation of wounded Service members in our nation’s history. WWP is committed to serving the post-9/11 generation and all future generations of injured Service members by ensuring they get the care, attention, and support they deserve upon their return home. We also serve the family members and caregivers who are an integral part of the warrior’s recovery and transition back into civilian life.

Historically, WWP advocacy on behalf of severely injured warriors and their caregivers helped secure passage of the *Caregivers and Veterans Omnibus Health Services Act of 2010* (P.L. 111-163) that launched PCAFC. More recently, we lobbied extensively for passage of the *Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* (P.L. 118-210), which will help better align PCAFC with other long-term care programs at VA. As an early and enduring champion for caregivers and the warriors they care for, WWP is uniquely positioned to amplify the concerns of this community through data, experiences, and longstanding relationships that have evolved through our programming footprint.

DUTY ★ HONOR ★ COURAGE ★ COMMITMENT ★ INTEGRITY ★ COUNTRY ★ SERVICE



Today, WWP's advocacy on behalf of severely wounded warriors and their caregivers is largely informed by our community support and care coordination programming. Our Independence Program is a long-term, community-based support program available to warriors living with a moderate to severe traumatic brain injury, spinal cord injury, or other neurological condition that impacts independence. Currently serving over 900 warriors, this program has been designed to help injured Service members and veterans design their own paths from surviving to thriving.

The Independence Program is a partnership between WWP, the warrior, and his or her family or caregiver, and is uniquely structured to adapt to their ever-changing needs. This program pairs warriors who rely on their families and/or caregivers with a specialized case management team to develop a personalized plan to restore meaningful levels of activity, purpose, and independence into their daily lives. These teams focus on increasing access to community services, empowering warriors to achieve goals of living a more independent life, and continuing rehabilitation through alternative therapies.

Services are highly individualized and supplement VA care, including: case management, in-home care, transportation, life skills coaching, traditional therapies (physical, occupational, speech, etc.), alternative therapies (art, music, equine, etc.), and community volunteer opportunities. These services are provided for free and augment or complement what our warriors receive from VA. For many, this is an opportunity to participate in the types of daily tasks, traditional therapies, and meaningful activities critical to long-term rehabilitation and life enrichment that others take for granted.

In this context, WWP has reviewed the proposed rule and offers several recommendations listed below and described in more detail in the analysis section. In order to enhance the importance of these recommendations, we have limited our observations to those sections where we believe the proposed rule lacks clarity or foreshadows adverse results and unintended consequences in the community. We hope that the recommendations that follow provide VA the opportunity to provide sufficient clarity or details that will guide WWP as a liaison and support structure for many of the post-9/11 era veterans and caregivers who rely on a combination of PCAFC and community resources to meet their needs.

PROPOSED RULE ANALYSIS

Wounded Warrior Project is grateful for VA's effort to revisit the regulations governing PCAFC and has appreciated the agency's outreach and collaboration over the past five years to help identify and solve issues related to this critical program. We believe that this proposed rule would improve current PCAFC administration in several ways, but can still be improved to better assist veterans and caregivers – particularly those with the greatest need for support. Our most notable calls for VA action that do not fall neatly within the proposed rule are outlined below. Other comments related to specific proposals presented in the Federal Register are provided in the sections that follow.

Total Caregiving Time (for consideration alongside proposed 38 C.F.R. §§ 71.20 and 71.40): Following passage of the *VA MISSION Act* (P.L. 115-182 § 161) in 2018, VA modified PCAFC eligibility criteria as the program grew to expand to veterans and caregivers of all eras. One of the most significant changes was replacing a system that paid stipends to family caregivers based on total hours spent providing personal care services to veterans with a new and now current system that requires the caregiver to (1) provide personal care services each time a veteran completes one of several activities of daily living (ADLs), or to (2) provide supervision, protection, or instruction (“SPI”) on a loosely defined basis.

We appreciate that the proposed rule removes of the defined term “inability to perform an activity of daily living” from 38 C.F.R. § 71.20(a)(3)(i) and the associated standard of requiring that a caregiver provide personal care services “each time” a veteran completes a specific ADL; however, the recommitment to a stipend system that recognizes assistance provided for ADLs or SPI – but not both – would continue to deny recognition of and support for caregivers who aid veterans along both domains.

The old system of stipend tiers would allow personal care services – ADLs and SPI – to be combined in a measure of hours dedicated to providing personal care services and allowed caregivers compensated for the full breadth of their work and commitment. VA correctly points out that “meeting one proposed basis for the higher stipend level does not preclude a Primary Family Caregiver from meeting one or more additional proposed bases that would also allow them to be eligible for the higher stipend level.” VA would indeed continue to consider all personal care services provided by the caregiver; however, it would continue to follow the practice of looking at segments of those services within a singular basis for higher stipend eligibility. A cumulative accounting of all personal care services that could qualify a caregiver for a higher stipend would remain elusive.

As we have shared with VA in working groups and during an Executive Order 12866 meeting, WWP would support returning to a system that allows for VA to assign caregiver stipends based on total hours committed to providing personal care services that include both ADL and SPI support. An alternative may also exist building upon the proposed rule. For example, if VA determines that a veteran requires personal care services to complete two ADLs (falling short of a Level 2 Stipend under proposed 71.40 C.F.R. § (c)(4)(i)(A)(2)(i)) as well as frequent but not continuous need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury (falling short of a Level 2 Stipend under proposed 71.40 C.F.R. § (c)(4)(i)(A)(2)(ii)), then a new basis for eligibility for a higher stipend level should be satisfied. This scenario would more accurately recognize and compensate a caregiver for the full breadth of support that is provided within the current framework of PCFAC.

Other VA Assistance: A primary driver of concern for many caregivers and veterans participating in PCAFC is how using other VA support programs will affect their eligibility for PCAFC. We believe that this proposed rule could be improved with the addition of clear statements about whether a veteran’s use of VA’s Veteran Directed Care Program, Homemaker & Home Health Aide Program, Home-Based Primary Care Program, and Purchased Skilled Home Care Program would affect his or her ability to have a designated Primary Family

Caregiver under PCAFC. *See* 38 U.S.C. § 1720L (b–e) (*see also*, P.L. 118-210 § 123(a)) (“Home- and community-based services: programs”).

We do not believe that using these critical VA programs should necessarily disqualify a veteran from being able to seek the added benefit of participating in PCAFC with a caregiver. Moreover, we believe that the proposed rule should create room for VA to carefully consider what services are provided through VA extended care programs like these (as well as those provided in the community), and how those services either overlap or maintain distinction from the personal care services provided by the caregiver to the veteran and which serve as the basis for assigning a particular stipend level. For example, a veteran might rely on the Homemaker & Home Health Aide Program for help with ADLs including dressing, bathing, and toileting, while relying on the Primary Family Caregiver for help with ADLs including eating. In this scenario, a veteran may continue to use the Home Health Aide Program without jeopardizing the Primary Family Caregiver’s eligibility for a Level 1 Stipend (as outlined in the proposed rule).

Employment: Similar to the preceding discussion, many caregivers and veterans have shared their concern that their employment status is weighed by VA during PCAFC eligibility assessments. The proposed rule should make clear that neither a veteran’s employment or a caregiver’s employment should be used as a determining factor about the veteran’s need for personal care services or the caregiver’s ability to provide those services. Particularly in today’s working environment where many can work from home, we believe that veterans and caregivers should be free to pursue employment and not burdened by the belief – as many hold – that holding a job will disqualify them from PCAFC.

Transportation (for consideration alongside proposed 38 C.F.R. § 71.20): We believe that the current PCAFC regulations as well as this proposed rule fail to recognize and compensate for personal care services that include helping a veteran get to and from medical appointments, among other destinations. Ensuring that veterans are able to engage in their communities and attend to their care needs are both critical to their well-being and ability to lead healthy and fulfilling lives.

§ 71.20: Eligible veterans and servicemembers

In our estimation, the proposed changes to 38 C.F.R. § 71.20 would generally expand eligibility. This would conceivably invite more applications; however, it will not necessarily guarantee that more veterans and caregivers are ultimately approved for participation in the PCAFC. The remainder of our comments on this section of the proposed rule are provided as responses to specific questions posed by VA.

- ***Please identify any similarly situated veterans or servicemembers who may not have an IU rating but nonetheless should be found to have a serious injury under the definition of that term in § 71.15 based on other VA ratings or other criteria.***

We believe that “serious injury,” as contemplated by regulations that govern PCAFC, can additionally be found among veterans who have been awarded Special Monthly Compensation

(SMC) by the Veterans Benefits Administration (VBA). Specifically, veterans who receive SMC under the following sections of law:

- (1) 38 C.F.R. § 3.350 (b–e) (Ratings under 38 U.S.C. §§ 1114(l)–(o))
- (2) 38 C.F.R. § 3.350 (h) (Special aid and attendance benefit under 38 U.S.C. § 1114(r))
- (3) 38 C.F.R. § 3.350 (j) (Special aid and attendance benefit for residuals of traumatic brain injury under 38 U.S.C. § 1114 (t))

These SMC benefits are generally provided to (1) veterans with loss or loss of use of an extremity, blindness, or deafness; (2) veterans who require daily assistance with activities of daily living (ADL) due to service-connected disability; and (3) veterans with severe impairments related to traumatic brain injury (TBI).

Regarding veterans with residual symptoms of TBI, we also believe that veterans who are following a VA-directed comprehensive plan for long-term rehabilitation for TBI should also be considered as having a “serious injury.” *See* 38 U.S.C. § 1710D (“Traumatic brain injury: comprehensive program for long-term rehabilitation”).

- ***VA has proposed a definition for the term typically requires that, in part, refers to that which is generally necessary. What other phrasing should VA consider as an alternative to generally necessary and why? Are there other criteria with regard to frequency that should be considered in defining typically requires?***

We caution that any terms and definitions continued or adopted by VA will be read in concert with this Proposed Rule. The graphic published on page 97412 of the proposed rule, under the “Typically Requires” heading (and published at www.federalregister.gov under RIN 2900–AR96) has potential to guide interpretation and application in the field. The spectrum contemplated by the graphic suggests that “typically requires” is something more frequent than “often” but less frequent than “each time.” We do not believe that the proposed definition’s term “that which is generally necessary” provides an appreciable difference between “often” and “typically requires” that can guide consistent assessment and evaluation in the field.

- ***Is there an alternative term other than typically requires that would be better defined to mean that which is generally necessary? For example, would the phrasing usually, most of the time, routinely, or ordinarily requires be clearer than the phrasing typically requires?***

Phrases like “routinely” or “most of the time” may provide a clearer step up from “often;” however, we do not believe that either would successfully alleviate confusion that may be caused by the graphic at page 97412 and published at www.federalregister.gov under RIN 2900–AR96.

- ***What factors should VA consider when determining what is generally necessary?***

Care environments can be dynamic based on a range of factors that should be considered when evaluating what is generally necessary. Such factors include time of day (the impact of things like stiffness, drowsiness, fatigue, and level of activity), whether a specific medical

condition is subject to flare ups or acute needs that require more assistance (for example, conditions like hypertension, Postural Orthostatic Tachycardia Syndrome, posttraumatic stress disorder, or seizure disorders), and general behavioral issues due to cognitive impairment that require supervision and/or intensive care. In all cases, VA assessments should consider the impact of a given condition on a veteran's ability to care for his or herself.

- ***What activities or tasks in addition to or other than ADL should VA consider when determining whether a veteran or servicemember has a need for regular or extensive instruction or supervision without which the ability of the veteran to function in daily life would be seriously impaired?***

VA should be considering a veteran's ability to complete instrumental activities of daily living (IADLs), which are tasks that help people live independently in their communities. These tasks are more complex than ADLs and require more planning and thinking. Examples include cooking and preparing meals, cleaning, managing finances and bills, completing paperwork (to include both medical paperwork and financial paperwork) shopping, medication management, and transportation.

Many of the warriors that WWP supports through our Independence Program require 24/7 support or monitoring not due to inability to complete ADLs but instead their inability to *safely* complete IADLs. We believe that factoring a veteran's challenges with completing IADLs would be a significant improvement to measuring a veteran's ability to live independently – and by association, his or her need for a caregiver to assist with personal care services that include both ADLs and IADLs.

- ***VA has explained VA's interpretation of the words "regular" and "extensive" instruction or supervision. How else might "regular" be distinguished from "extensive" instruction or supervision?***

While providing an interpretation of these terms is helpful, we believe that "regular" and "extensive" should be defined. These terms should be defined to leave less room for interpretation and to provide clear eligibility criteria that may be applied consistently by VA staff in the field. The terms "instruction" and "supervision" should be viewed in the context of the veteran and caregiver and that either (or both) are required for the veteran to maintain his or her personal safety on a consistent basis due to cognitive impairment. Without instruction or supervision, the veteran would not be able to maintain his or her personal safety, thus placing his or herself at risk of self-harm or harming others in the community.

Notwithstanding the points above, VA may choose to distinguish "regular" as the type of instruction or supervision that is recurring or generally scheduled and consistent over time. "Extensive" instruction or supervision may lend itself to, for example, specialized training or multiple hours of supervision required each day. In such a case, extensive instruction or supervision would be needed to help manage complex medical or behavioral challenges.

- *VA would not set forth a specific quantitative requirement for the frequency with which a veteran or servicemember may require supervision or protection other than specifying that the individual has a frequent need for supervision or protection. This is because the need for supervision or protection is not limited to a discrete list of activities or circumstances. VA has found that there is no uniform frequency of individuals' need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury. The frequency of need varies based on each individual's unique needs and depends on severity of their symptomology. Is there a different frequency standard VA should consider, and if so, what is that standard?*

We agree that the complexities of injuries, particularly within the context of behavioral health and neurocognitive impairment make it difficult to set a quantitative requirement for the frequency with which a veteran or Service member may require supervision or protection. However, the application to proposed § 71.40 is relevant here. We believe that the proposed regulation fails to create a clear difference between a Level 1 Stipend and Level 2 Stipend as applied to the need for supervision, protection, and/or instruction. Whereas the proposed § 71.20 (a)(1)(3)(ii) speaks to the veteran's "frequent need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury," the proposed Level 2 Stipend at § 71.40 (c)(4)(i)(A)(2) only expands to say that the "frequent need" be "on a continuous basis." Like our interest in seeing the volume and degree of assistance needed for a Level 1 Stipend be stated specifically, we invite VA to specifically state the duration and intensity of supervision needed to qualify for a Level 1 Stipend so that it might be more easily compared to what is required for a Level 2 Stipend.

§ 71.25: Approval and designation of Primary and Secondary Family Caregivers

As the Proposed Rules presents several changes that, among other purposes, seek to provide clarity, we believe that paragraph (b)(2)(i) should be amended to clearly allow for immediate family members – most notably, siblings – to serve as Family Caregivers. RAND's *Supporting Military and Veteran Caregivers* (2024) report observed, "those caring for veterans and service members ages 60 and under are most often spouses, neighbors and friends, or family members, such as siblings or aunts and uncles."

§ 71.30: Reassessment of Eligible Veterans and Caregivers

Wounded Warrior Project generally supports the proposed rule changes to how VA approves and designates Family Caregivers. Striking the requirement for an annual replacement and replacing it with a biannual reassessment would honor the perspectives of many veterans and caregivers who find the annual assessments to be unnecessary, stressful, and burdensome. We believe that less frequent reassessments would also preserve VA resources for other priorities.

For many of the same reasons, we encourage VA to add a rule that permits a permanent – or static – designation for certain veterans and caregivers to further ground the agency's operations in the lived experience of many veterans and caregivers. Such a system might

contemplate a single or final assessment for conditions that are unlikely to improve and/or conditions that are likely to progressively worsen. For example, veterans with Parkinson's Disease, amyotrophic lateral sclerosis (ALS), severe neurocognitive impairment from TBI, or a terminal cancer diagnosis should have the opportunity to receive a permanent designation. We believe that for veterans and caregivers in these situations that the continuation of care at VA and participation in PCAFC wellness checks would be sufficient to retain the permanent designation and obviate the need for reassessments for PCAFC eligibility.

§ 71.40: Caregiver benefits

We believe that the proposed changes to paragraphs (c)(4)(i)(A)(1) and (c)(4)(i)(A)(2) could be written in closer alignment with each other. More specifically, the proposed "Level 1 Stipend" should be more clearly drafted to define what is required. For example, although the proposed eligibility rule at § 71.20 (a)(1)(3)(i) contemplates that a veteran typically requires hands-on assistance to complete one or more ADL, only the proposed § 71.40 (c)(4)(i)(A)(2) specifies the volume (three or more) and degree (substantially dependent) of ADL assistance. The proposed § 71.40 (c)(4)(i)(A)(1) could be re-written to state that a veteran needs assistance with one or two ADLs, and for each ADL, the veteran is substantially dependent on the Primary Caregiver for hands-on assistance.

Moreover, the proposed regulation fails to create a clear difference between a Level 1 Stipend and Level 2 Stipend as applied to the need for supervision, protection, and/or instruction. Whereas the proposed § 71.20 (a)(1)(3)(ii) speaks to the veteran's "frequent need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury," the proposed Level 2 Stipend at § 71.40 (c)(4)(i)(A)(2)(ii) only expands to say that the "frequent need" be "on a continuous basis." Like our interest in seeing the volume and degree of assistance needed for a Level 1 Stipend be stated specifically, we invite VA to specifically state the duration and intensity of supervision needed to qualify for a Level 1 Stipend so that it might be more easily compared to what is required for a Level 2 Stipend.

§ 71.45: Revocation and discharge of Family Caregivers

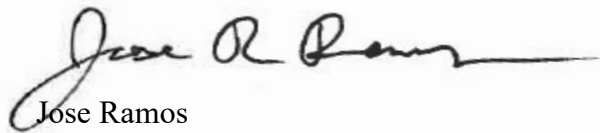
We endorse VA's proposal to create criteria governing discharge from PCFAC when a caregiver has alleged domestic violence (DV) or intimate partner violence (IPV) perpetrated by the eligible veteran. We have encountered scenarios like these in our Independence Program, for example, when a warrior's TBI contributes to behavioral challenges and physical aggression toward the caregiver. In such situations, transitioning the warrior to a long-term care facility may be the safest option; however, when this happens among those participating in PCAFC, this often results in the caregiver losing their stipend. This can lead to sudden financial challenges for the caregiver and their family, many of whom will present with an irregular work history and face hardship finding full time gainful employment after years of acting as Primary Family Caregiver.

In consideration of the comments above, we have observed that some caregivers may remain in DV or IPV situations for various reasons, including a sense of duty or limited financial options. In cases where a caregiver is discharged from PCAFC due to DV or IPV, we encourage VA to supplement timeframes outlined in proposed § 71.45 (b)(2)(iii)(B) with language that would help the agency provide caregivers with resources to shelters, referrals to DV services, financial and mental health counseling referrals, and other supports. Without such measures, caregivers may face increased risks and fewer options for safety and stability.

CLOSING REMARKS

In closing, we thank VA for the opportunity to provide these comments intended for the improvement of the PCAFC and the ultimate benefit of thousands of deserving veterans and caregivers. WWP stands by as your partner in meeting the needs of all who served – and all who support them. We remain committed to assisting VA in implementing an improved and expanded PCAFC and look forward to helping in any way we can.

Sincerely,

A handwritten signature in black ink, appearing to read "Jose R. Ramos", with a long horizontal flourish extending to the right.

Jose Ramos
Vice President
for Government and Community Relations