

February 4, 2025

Submitted via [regulations.gov](https://www.regulations.gov)

Colleen Richardson, PsyD
Executive Director, Caregiver Support Program, Patient Care Services,
Veterans Health Administration
Department of Veterans Affairs,
810 Vermont Ave. NW,
Washington, DC 20420

Re: RIN 2900-AR96 Amendments to the Program of Comprehensive Assistance for Family Caregivers

Dear Ms. Richardson,

We, the undersigned veteran and caregiver organizations, write to submit our feedback on the Department of Veterans Affairs' Notice of Proposed Rulemaking (NPRM) issued on December 6, 2024, proposing changes to 38 C.F.R. §71.20-60. We would first like to thank VA for working with us over the past five years to improve the Program of Comprehensive Assistance for Family Caregivers (PCAFC) and for soliciting our feedback. We believe that this NPRM marks an improvement over the 2020 PCAFC regulations in several key ways. At the same time, we believe there is still considerable room for improvement.

Among the positive changes proposed in this NPRM, our coalition particularly appreciates the following:

- Removal of the phrase "each and every time" from 38 C.F.R. §71.20(a)(3)(i);
- Reduction in the frequency of reassessments; and
- Creation of a path to eligibility for veterans with individual unemployability (IU).

However, more must be done to meet the needs of the veteran and caregiving communities. VA has acknowledged that its administration of PCAFC has been plagued by problems in the past, and members of this coalition have previously expressed concerns about unintuitive and subjective regulatory standards; inconsistent application of eligibility criteria; and overly restrictive interpretations of both the statute and regulations governing the program.

After years of conversations with VA, this NPRM does not fully align with our expectations. We would like to see clear, concise definitions and standards throughout these regulations. We also seek the elimination of overly strict eligibility criteria that do not reflect either the language of the statute or the day-to-day realities of caregiving. The changes that VA has proposed to PCAFC's governing regulations do not fully achieve these goals, and in some instances run contrary to them. A number of coalition members have even suggested that the

2015 regulations laid out PCAFC procedures and eligibility criteria much more clearly, and that we are moving in the wrong direction.

We therefore ask VA to make significant changes to the language in this NPRM before moving forward. The remainder of this comment lays out specific concerns that we believe VA should address. We share VA's ultimate goal of making PCAFC as successful as possible, and we believe that changes in these areas will serve that purpose.

I. We Are Concerned About the Removal of Definitions and Clarifying Language from 38 C.F.R. §71.15.

In the process of streamlining these regulations, VA removed definitions and clarifying language from 38 C.F.R. §71.15. For example, the proposed rule no longer defines "supervision," "protection," "instruction," or closely related terms like "need for supervision." It also omits language on activities of daily living. The current regulation lists the Activities of Daily Living (ADL) of mobility as "mobility (walking, going up stairs, transferring from bed to chair, etc.); VA's proposed rule would cut this down to the single word "mobility."

We believe that these changes run counter to our shared goal of promoting clarity and consistent implementation across VISNs. To create transparency and ensure that veterans across the country are held to the same standards, these regulations must define key terms. While we do not offer a list of all key terms in this comment, we view the terms "supervision," "protection," and "instruction" as in need of definition. Alternatively, we believe definitions of closely related terms such as "in need of supervision" could achieve the same goal. We feel strongly that such definitions should be incorporated into the text of the regulation and not merely laid out in responses to comments, agency directives, or other guidance documents. These definitions are not a mere technicality; they determine whether thousands of veterans and caregivers will receive benefits, or be denied.

The removal of clarifying language is also a step in the wrong direction. In an ideal world, all stakeholders across the country would understand that the ADL of mobility includes transferring from bed to chair and going up stairs. However, VA has not presented evidence to support its claim that this is "commonly understood," and in practice we have found that the definitions of each ADL are common points of confusion and misunderstanding. Further, we believe that VA overstates the extent to which a common understanding of each ADL exists. ADL definitions used by different agencies have specific, individual quirks, which prevent universal consistency and may not be intuitive to all stakeholders. For example, administrators of PCAFC evaluations typically use the Functional Assessment Standardized Items (FASI) instrument, which states that transferring in and out of the bathtub is not part of the ADL of bathing. Line-drawing in these areas is difficult, but essential for the program to succeed.

We understand the potential concern that specific definitions and clarifying language could serve to narrow PCAFC's eligibility criteria by precluding broader, more inclusive understandings of key terms. However, we believe that it is possible to make these improvements without narrowing eligibility criteria. Achieving this goal simply requires careful drafting. Small fixes can go a long way in this area: even the abbreviation "etc." in the list of mobility-related activities cited above is enough to clarify that the list is not exhaustive. Our coalition has also discussed the potential addition of phrases like "including but not limited to" and "such as."

Definitions and clarifying language are essential for veterans, caregivers, advocates, and VA personnel to connect the abstract language of the regulation to real-life scenarios. It is vital that all of these stakeholders be on the same page about how the regulation will be applied, and including both definitions and clarifications in the text of the regulations is the surest way to guarantee this outcome. Regardless of the specific course VA takes, we urge the agency to consider how it might add back key definitions and clarifying language without limiting eligibility criteria.

II. We Are Concerned that Some Proposed Changes to 38 C.F.R. §71.20 Would Make PCAFC's Eligibility More Subjective and Excessively Strict.

While our coalition welcomes some changes made to the eligibility criteria listed in 38 C.F.R. §71.20(a)(3), we remain concerned that other changes would introduce subjectivity to eligibility determinations and/or lead to excessively strict application of eligibility criteria. We tremendously appreciate VA's removal of the requirement that a veteran need assistance with an ADL "each and every time." This is a vital change that we fully support. However, we are concerned that proposed terms like "frequent" and "typically" will be applied in inconsistent and overly restrictive ways. We are also concerned that some of VA's proposed additions to 38 C.F.R. §71.20(a)(3) do not align with either the text of the statute or the day-to-day realities of caregiving.

A. We Urge VA to Reconsider the Addition of "Typically" and "Hands-On" to 38 C.F.R. §71.20(a)(3)(i).

VA proposes to alter 38 C.F.R. §71.20(a)(3)(i) so that a veteran may meet PCAFC eligibility requirements if "the individual typically requires hands-on assistance to complete one or more ADL." Though this proposed use of the word "typically" marks a clear improvement over the previous standard of "each and every time," our coalition believes that the proposed "typically" standard is simultaneously too vague and too restrictive to be workable. Notably, VA does not propose to tie the word "typically" to a specific percentage or a number of times per day or week. Instead, the agency defines "typically required" as "that which is generally necessary." In the absence of further clarification, this determination seems highly subjective, and it is

unclear to us precisely how the agency will apply this standard to the veterans and caregivers that we assist.

We also find that this language does not correspond to the day-to-day realities of caregiving. For many veterans coping with significant disabilities, there may be no such thing as a “typical” day. Disabled veterans’ symptomology and level of functioning may fluctuate based on countless factors, ranging from the date of their last Botox treatment or cortisone injection to how well they slept the night before. The previous “each and every time” standard punished veterans for good days, in which they experienced a temporary reprieve from their most severe symptoms. While an improvement over “each and every time,” the “typically” standard would still perpetuate this problem. If it is impossible to determine what a typical day looks like for a veteran and caregiver, will they simply be denied?

Additionally, the “typically” standard does not seem to reflect the variability in symptomology that disabled veterans often experience throughout a single day. Symptoms like chronic fatigue may not be fully apparent when a veteran first gets out of bed in the morning, but may leave them moored on the couch by the afternoon. Thus, they may need a caregiver’s assistance for sixteen to twenty hours a day out of twenty-four. It is not clear how the proposed “typically” standard would be applied in such a case. We find it highly troubling that under this standard, a veteran who needs help going to the bathroom three out of five times a day and is too fatigued at night to lift a fork or brush their teeth could conceivably be deemed ineligible for the program due to insufficient caregiving need. While clarification on the proposed standard could be somewhat helpful, we urge VA to do more and eliminate the word “typically” altogether.

Additionally, our coalition finds the addition of the word “hands-on” to be unnecessary and confusing. Veterans who need other kinds of assistance with ADLs have always been eligible for PCAFC, and it does not seem like VA intends to change that. The NPRM even states that veterans who need instruction or supervision assistance to complete an ADL are likely eligible under 38 C.F.R. §71.20(a)(3)(iii).¹ Thus, the addition of the word “hands-on” does not substantively change the program’s eligibility criteria.

At the same time, the addition of the word “hands-on” would cause confusion in a significant subset of cases. For instance, a veteran may primarily need “touch assistance” with an ADL, meaning that the caregiver lightly steadies them as they carry it out. It seems counterintuitive and likely incorrect that this veteran should be denied benefits, given that either a greater or lesser level of assistance with ADLs would render them eligible. But because of the addition of the word “hands-on” to the regulation, they could potentially be denied under both 38 C.F.R. §71.20(a)(3)(i) (requiring “hands-on” assistance) and 38 C.F.R. §71.20(a)(3)(iii) (only covering supervision and instruction). Alternatively, a veteran might need hands-on assistance

¹ 89 F.R. 97420.

with an ADL half the time and supervision assistance the other half. Under VA's current proposal, they would not be squarely eligible under either 38 C.F.R. §71.20(a)(3)(i) or (iii). These problems can be attributed to VA's proposed addition of the word "hands-on," and would be fixed by its removal.

B. We Are Concerned About the Addition of an ADL Restriction to 38 C.F.R. §71.20(a)(3)(iii).

VA proposes to amend 38 C.F.R. §71.20(a)(3)(iii), the portion of the regulations creating a path to eligibility for veterans in need of supervision and/or instruction, so that veterans may only qualify under this provision if they need supervision or instruction "to complete one or more ADL." We have multiple concerns about this change. First and foremost, our coalition believes that VA must align its regulations with the language of the statute and Congress's intent. We are also concerned that adding this restriction would disproportionately impact veterans with cognitive and mental health disabilities.

We respectfully disagree with VA's assertion that the proposed changes to 38 C.F.R. §71.20(a)(3)(iii) align with the text of 38 U.S.C. §1720G. The statute states at 38 U.S.C. §1720G(a)(3)(c)(iii) that a veteran may be eligible if they can establish "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." Functioning in daily life involves far more than ADLs. Additionally, Congress refers to ADLs elsewhere in the statute. If Congress had intended for this provision to only cover supervision and instruction on ADLs, we believe it would have said so.

We are also concerned that this change will disproportionately impact veterans with cognitive and mental health disabilities. Caregivers for these veterans help them initiate tasks when they completely lack executive function; guide them through activities that keep them physically healthy and/or preserve their sense of self; stop them from engaging in dangerous forms of substance use, such as binge drinking and intentional or unintentional overdose; and help them calm down when they have emotional outbursts that could escalate to violence or self-harm if left unaddressed. These forms of instruction and supervision have nothing to do with ADLs, but quite literally save veterans' lives. We urge VA not to limit instruction and supervision to ADLs in 38 C.F.R. §71.20(a)(3)(iii), so that these invaluable forms of caregiving may be recognized.

III. We Have Outstanding Questions and Concerns about the PCAFC Appeals Process That This NPRM Does Not Address.

The promulgation of new regulations creates an opportunity for VA to lay out its vision for the PCAFC appeals process, and we urge VA to take advantage of this opportunity. The current proposal does not include any provisions referencing the appeals process. By contrast, we believe an entire section on PCAFC appeals would be warranted. Over a year after the Federal

Circuit affirmed veterans' and caregivers' right to appeal adverse PCAFC decisions in *Beaudette v. McDonough*, we still have countless unanswered questions. These questions range from the very broad to the very specific, and include the following:

- How does VA understand its obligations in the wake of *Beaudette*?
- What procedures must VHA follow in every PCAFC clinical appeal?
- What safeguards are in place to ensure that the clinical appeals process is fair and equitable?
- How does the clinical appeals process relate to other kinds of appeals? For example, if a veteran receives an adverse decision through a clinical appeal, can they still pursue an appeal to the Board?
- How would a veteran address a stipend miscalculation issue?
- How would a veteran challenge the determination of an effective date?
- What happens if a veteran enters nursing home care or passes away during the pendency of an appeal?

While we would appreciate discrete answers to these questions, we would prefer VA to incorporate a comprehensive guide to the PCAFC appeals process into the text of its regulations. It is vital for members of this coalition, and for the veterans and caregivers we assist, to have clarity on how the appeals process works. An unpredictable process that requires insider knowledge to navigate cannot be considered a well-functioning appeals system. VA has already put a tremendous amount of effort into implementing the Court's decision in *Beaudette*, and we believe this is the right moment to institutionalize and formalize many of the systems it has already developed. This is a key step that VA must take in order to complete the creation of a robust appeals process.

IV. Conclusion

We greatly appreciate VA's commitment to improving the regulations governing PCAFC. Though we have significant concerns about aspects of this proposed regulation, we believe that each of these concerns can be addressed and that none of the challenges we have identified are insurmountable. We look forward to working with VA in the coming weeks and months to ensure that PCAFC lives up to its full potential.

Sincerely,

Elizabeth Dole Foundation
National Veterans Legal Services Program
Quality of Life Foundation
Veteran Warriors
WiseHealth, Inc.
Wounded Warrior Project