



February 5, 2018

Margaret Kabat
National Director
Caregiver Support Program (10P4C)
Veterans Health Administration
Department of Veterans Affairs
810 Vermont Ave., NW
Washington, DC 20420

Dear Ms. Kabat:

Thank you for the opportunity to comment on the future of the Program of Comprehensive Assistance for Family Caregivers (PCAFC). The Independence Fund, founded 10 years ago, has provided more than \$40 million in adaptive equipment and support services for catastrophically wounded and seriously disabled veterans, as well as caregiver support services for the caregivers of those wounded and disabled veterans. Our Executive Director and our Director of Programs are both caregivers to catastrophically wounded veterans. As well, most of our employees are either disabled Veterans or Caregivers themselves.

Overall, The Independence Fund's greatest concern with the PCAFC program is the apparent lack of standardization for large segments of the program, from initial eligibility to program execution and classification standards, not only across Veterans Intergrated Service Networks (VISNs), but even across VA facilities within a VISN, and even a single VA facility itself. While we understand the need for a clinical determination to establish individualized eligibility based on the need for assistance with activities of daily living, such clinical determination appears to justify not pursuing any type of national standardization for assessment or continuing eligibility standards for the program, essentially leaving those decisions to be implemented arbitrarily by the personal fiat of individual clinicians and VA medical administrators throughout the country.

Because of that, The Independence Fund regularly sees wide variation in the Caregiver tier classification determined for individually similar cases, for what services and support individual Veterans and Caregivers are eligible, and even whether the Caregiver will be allowed to stay in the program or be "graduated." Given the close similarities we see in these underlying cases with vastly different results, this broad variation across regions and even facilities appears to be an arbitrary execution of the law within the Department.

Further The Independence Fund receives numerous anecdotal complaints of VA officials improperly applying the Caregiver eligibility standards, such as they exist, especially with spouse or other family caregivers. One of the most commonly heard improper “rules” is that Caregiver cannot have outside employment besides serving as a Caregiver. Considering the Caregiver stipend is based upon 40 hours per week of Caregiver assistance (even for the most catastrophically wounded, or the barely conscious Veterans), those Administrators who do try to tell Caregivers that they cannot work outside their Caregiver assistance must believe these Caregivers do not provide any additional Caregiver assistance outside normal working hours. That’s outrageous, as is VA officials wrongly telling Caregivers they cannot work outside the caregiving assistance they provide. The regulations regarding PCAFC should specifically state Caregivers can have outside employment beyond the Caregiver assistance they provide.

Within that framework, below are our answers to the specific Request for Comments.

1. Should VA change how “serious injury” is defined for the purpose of eligibility?

Yes.

Per the authorizing legislation, the Secretary is authorized to expand eligibility for PCAFC to an individual’s need for personal care services of, “...such matters as the Secretary considers appropriate (38 USC 1720G(a)(2)(A)-(B)). While there are obviously 100% disabled veterans who do not need and should not qualify for Caregiver support (which would seem to call into question why such a Veteran would be awarded a 100% disability rating), we do believe certain disability ratings, such as Special Medical Compensation rating R1 or R2, should carry with it a presumption of eligibility for the PCAFC program. We believe the Secretary should use that special authority referenced above to establish such a presumption.

A: Should the severity of injury be considered in determining eligibility to ensure VA is supporting family caregivers of Veterans most in need? If so, how should the level of severity be determined?

This question is confusing in its sentence structure. The program was, in our estimation, established on a clear standard of the Veteran not being able to complete activities of daily living. Congressional intent would appear clear that those Veterans are already considered most in need of Caregiver support?

If the Department is asking whether it should further limit access to the Caregiver program beyond the standard already established by Congress, then the answer is categorically no.No.

The question appears to imply the Department wishes to prioritize eligibility in order to ration access, something which The Independence Fund categorically rejects. The

PCAFC program should be administered in a way that any Veteran qualified for the program gains immediate access to it.

However, establishing national eligibility standards would, in our estimation, reduce much of the variability across Caregiver eligibility described above, and would, in our opinion, reduce the need to even conduct such prioritization by providing bright line standards for clinicians and administrators to follow.

C. Should eligibility be limited to only those Veterans who without a family caregiver providing personal care services would otherwise require institutionalization?

Absolutely not.

The paltry stipend paid to current caregivers, and the presumption apparently applied by many of the VA eligibility gatekeepers that family caregivers should automatically be assisting Veterans with activities of daily living (including eating, mobility, hygiene and toileting) without compensation is insulting and atrocious. Essentially, considering to limit the Caregiver program to only those Veterans without a family caregiver available is to leverage the love families have for their disabled Veterans to provide the care the Department would otherwise provide, but at a far cheaper rate. Essentially, the US Government is leveraging that familial love for the Veteran against the family in order to save the US Government money. Considering to further limit eligibility to only those without a family caregiver available is, in our opinion, unconscionable.

2. To be eligible for the program, participation must be determined to be 'in the best interest' of the Veteran. How should 'best interest' be defined.

The way "best interest" is currently implemented perpetuates a paternalistic and condescending approach of how the Department should provide care to Veterans, assuming a Veteran is incapable of understanding what health care is and is not in their best interest. Such a "Big Brother" approach to health care decisions implies that the Veteran is incapable of making his or her own health care decisions.

Instead, The Independence Fund believes if a Veteran applies for Caregiver assistance, it should automatically be presumed that such assistance is in the best interest of the Veteran. Given the law requires a "Best Interest" determination by the Secretary, The Independence Fund recommends the "Best Interest" determination be changed to a negative only determination: Unless the Department specifically determines it is not in the best interest of the Veteran to participate in the program, the "Best Interest" test should be presumed to be met by the Veteran's application.

A. How can VA improve consistency in ‘best interest’ determinations for participation in the program?

By changing the “Best Interest” determination into a negative determination: Unless the Department specifically determines it is not in the best interest of the Veteran to participate in the program, the “Best Interest” test should be presumed to be met by the Veteran’s application.

B. Are there any conditions under which participation would not be in a Veterans best interest?

The Independence Fund cannot think of any except where the Caregiver is abusing or taking financial advantage the Veteran, and where ending eligibility is the only way the Department would have to end the abuse.

4. Once approved for the PCAFC should the Veterans eligibility be reassessed at specific time intervals or based on clinical indicators?

Many Veterans assisted by PCAFC are catastrophically, permanently and totally disabled, and as such, their disability ratings are set at that minimum level with no future downgrading allowed. Similarly, The Independence Fund points out the Caregivers for these permanently and totally disabled veterans are, absent a miracle, going to be Caregivers for the rest of that Veteran’s life. Requiring periodic reevaluations, especially at the current 90 day interval, is insulting to the Veteran, introduces unnecessary stress and disruption for both the Veteran and the Caregiver, and completely unnecessary. The Independence Fund recommends reassessment be eliminated for the Caregivers of permanently and totally disabled Veterans enrolled in the program, who are also rated R1 or R2 under the Special Medical Compensation program.

b.1. Should reassessments be standard for every participant?

No.

The Independence Fund recommends reassessment be eliminated for the Caregivers of permanently and totally disabled Veterans enrolled in the program, who are also rated R1 or R2 under the Special Medical Compensation program.

b.2. Are there conditions under which continued eligibility should be presumed and a reassessment not needed?

Yes.

b.3. If so, what would these conditions be?

For the Permanently and Totally Disabled, who are also rated R1 or R2 under the Special Medical Compensation program.

6.b. Under what circumstances should the family caregiver benefits be continued after revocation?...How long should the benefits be continued under such circumstances?

Many caregivers give up careers and all outside employment to care for wounded and disabled veterans. The Caregiver stipend, completely insufficient though it is, is often the only income that Caregiver family has outside the Veteran's VA compensation. When the Veteran dies, that family loses a huge portion of their income, compounded by the fact the Veteran's Caregiver could very well have been out of the workforce for years. Further, the Caregiver loses health insurance coverage they receive under CHAMPVA.

Therefore, The Independence Fund recommends Caregiver stipends and CHAMPVA coverage be continued for at least a year after the death of the enrolled Veteran.

7. ...How should VA calculate stipends?

The Caregiver stipend rate is an embarrassment for our country. With a maximum weekly stipend of 40 times the rate for personal care assistance in that geographical region, for the most catastrophically wounded veteran who nevertheless provide round the clock care, such a paltry sum is an insult to the care Veterans' Caregivers provide. If that family caregiver were not available, the institutionalization of the Veteran would cost the Department far more, likely somewhere in the \$7,500 to \$10,000 per month range, under the best of circumstances. Further, basing the stipend on the presumption the family Caregiver will only provide 40 hours per week for the Veteran is fanciful, and seems to be chosen to save the government money, not properly compensate the Caregiver for his or her services.

Therefore, The Independence Fund recommends the stipend be calculated by what home care licensed vocational nurse care of that Veteran would cost the US Government, times 80 hours per week.

a. Should VA use one BLS rate per state?

No. Costs of living can vary greatly within a State, and varying stipends based on those costs of living is reasonable.

8.b. A Veteran is assigned a stipend tier based on the amount and degree of personal care services provided. How should VA assess and determine the amount and degree of personal care services provided to the Veteran by the family caregiver?

While much of the PCAFC program eligibility is related to needs regarding activities of daily living, given the well established disability rating program the Department already executes, both with the standard disability rating system and the Special Medical Compensation ratings, it should rely upon those standards to the extent that it can, regardless of the underlying activities of daily living standard, as there is likely a strong correlation between the two, and using such ratings would bring much greater transparency and uniformity to the Caregiver tier and compensation systems.

Thank you for the opportunity to submit these comments. If you need further clarification or if you wish to discuss further, I can be reached at B.Carey@IndependenceFund.org or 202-779-1598.

Very Respectfully,

A handwritten signature in black ink, appearing to read 'Bob Carey', is centered on a light gray background.

Bob Carey
Director, Policy & Advocacy