THE INDEPENDENCE FUND

May 5, 2020

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To: Michael Shores, Director, Office of Regulation Policy and Management, Department of Veterans Affairs

Subj: COMMENT ON RIN 2900-AQ48, PROGRAM OF COMPREHENSIVE ASSISTANCE FOR FAMILY CAREGIVERS IMPROVEMENTS AND AMENDMENTS UNDER THE VA MISSION ACT OF 2018

The Independence Fund provides the following comments on the subject proposed rule, organized by key issue area. Regardless, we invite the Department's attention to the requirements of HR 5701, sponsored by Representatives Hudson and Rice, and recommend the Final Rule incorporate its requirements into the final rule without further legislative action required.

**Initial Assessment, Reassessment, and Appeals Processes**

The Caregiver program initial assessment, reassessment, and appeals process have been marked by deep systemic structural defects which can only be resolved by placing these procedures into the regulation itself, and not promulgating them through policy directive or handbook.

In 2017, after an NPR report indicated upwards of 94% of Caregivers were discharged from the program at some VA Medical Centers, then Secretary Shulkin placed a temporary freeze on discharges and Tier rating demotions within the Caregiver program.

In May, 2018, reports started emerging again of unprecedented numbers of Caregivers being dropped from the Caregiver program, again with reports of upwards of 84% of Caregivers being discharged. These issues came to a head with two November 2018 reports of triple amputees being either dropped from or demoted within the Caregiver program by the Nashville VA Medical Center. The Veteran demoted from Tier 3 to Tier 1 was reinstated after intervention with the Caregiver office by The Independence Fund (TIF), and the VA admitted the proper evaluation process was not followed.

On November 29, 2018, The Independence Fund was joined by 14 other veteran organizations demanding these processes be standardized and enforced nationally, a copy of which is attached. Despite years of the VA having very clear policy from the VA Central Office on how the caregiver program is to be administered, and how initial assessment, reeligiblity, and appeals processes should be run, time and time again the execution in the field has shown itself either incapable, or unwilling, to follow that guidance.

Given that, The Independence Fund recommended to the Administration in December 2018 it invoke a "pause" for all caregiver program tier demotions or "graduations", which the Secretary announced at a Congressional hearing on December 19, 2018, and under which we understand the Department still operates.

Since the enactment of the MISSION Act in June 2018, The Independence Fund has consistently and repeatedly called for clear standardization of the caregiver initial assessment, reassessment, and appeals process, preferably in regulation, through responses to at least two VA formal Requests for Information, two Congressional Committee roundtable discussions in which VA caregiver leadership

participated, three listening sessions hosted by the VA Caregiver office, and a Executive Order 12866 meeting with OMB during the NPRM review period.

The reason for this is clear – the program has shown itself of being consistently executed in the field. Examples of these failures have been well documented by the press reports reference above, but include:

- Spouse Caregivers being dropped from the program, despite apparent indications the Veteran is clearly eligible for the program, because that care is their "spousal" or "wifely" duties;
- Appeal denials providing very little, if any, explanation for the rejection of the appelants' arguments, and simply being one-line rejection letters;
- The appeals process being tainted and lacking any level of transparency because the same VA Medical Centers that participated in the original discharge or demotion decisions were also adjudicating the clinical appeals;
- Caregivers being forced to make lengthy requests for medical records that formed the basis for the discharge or tier demotion, limiting the time the Veteran had to draft their appeal;
- Medical determinations by VA primary care physicians and other clinicians treating the patient in support of continuing in the Caregiver program being ignored by "Clinical Evaluation Teams" who never personally see the Veteran themselves;
- In-person eligibility evaluations being conducted by unqualified Social Workers, and then reviewed remotely by the Clinical Evaluation Teams;
- Veterans being deemed eligible for the Caregiver program at one VA Medical Center, the Veteran moves to another location, and that new VA Medical Center quickly discharging or demoting the Veteran in the Caregiver program;
- Large variations in eligibility determinations for substantially similar cases; and
- Criteria being used to discharge or demote a Veteran within the Caregiver program that are not part of the criteria established by law or regulation (inability to perform ADLs, and/or an inability to be safe by themselves), such as the ability to drive or social media posts of Veterans engaging in activities like adaptive sports or family activities.

Despite The Independence Fund's repeated urging to circumvent this history by placing the initial assessment, reassessment, and appeals processes in the regulation – joined in by several other veteran and caregiver organizations – the VA now proposes to keep the eligibility and appeals determination processes outside the regulation through policy directives only. As recently as March 11, 2020, numerous VSOs advised VA we could not provide adequate public comment on the Proposed Rule without having a better understanding of the assessment, reassessment, and appeals processes, and believed at that time we would get full information on those standards and processes by the end of March 2020. At the follow-on VSO meeting on April 27, 2020, nine days before the public comment end date, VA advised us the reassessment and appeals processes are still in development. While the VA assured the participants in those meetings they had a very specific procedure in mind for these processes, the Proposed Rule itself gives the Department and it's field operations even more flexibility, something to which the Proposed Rule continually points as an objective of how this program will be executed.

Given that, we are still without enough information to comment on whether the Proposed Rule can meet the requirements of the authorizing legislation. Further, even if we were to detail how these standards and processes should be incorporated into the Final Rule, we are concerned that might represent such an expansion of scope to the original Proposed Rule as to require a new round of Proposed Rule Making. Such a dilemma leaves us with only the options of accepting a fundamentally flawed regulation or further delaying access to the caregiver program for Vietnam era veterans, neither of which is acceptable, and with which we are forced to choose only because of the inability of VA to meet the legislative deadlines for caregiver expansion.

Under normal circumstances, where the program to be regulated wasn't already almost two years late in execution, we'd request OMB intervention to help clarify what is and is not possible with regards to a single round of Proposed Rule Making, and to request the comment deadline be extended in order to work this out. But that also is not acceptable as we fear that would simply be used as an excuse to further delay implementation of this regulation.

**Therefore, we recommend this Proposed Rule be moved to Final Rule as soon as possible, and that the review of the Proposed Rule comments be expedited. We realize this will result in the promulgation of a deeply, if not fatally flawed regulation, but at least it will allow Vietnam era veterans to apply for the caregiver benefit as soon as possible. However, we believe the Department should issue a new Notice of Proposed Rulemaking to incorporate whatever initial assessment, reassessment, and appeals processes upon which it may finally decide, into that NPRM so the public can adequately comment on what has been one of the single largest administrative failures of this program to date.**

**Permanent Caregiver Designation**

Many Veterans assisted by caregivers are 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, even at the proposed annual interval, is insulting to the Veteran, introduces uneccessary stress and disruption for both the Veteran and the Caregiver, and completely unnecessary.

Further, the lack of specificity in the Proposed Rule for extending that periodicity is very likely to introduce huge variance into assessment and reeligiblity decisions warned of above. In fact, it could even introduce corruption if caregiver eligibility assessment officials decided they could exact benefits from veterans or caregivers in exchange for longer periods between reassessments.

We do not accept the Department's contention, "that Congress intended for PCAFC participants' eligibility to never be reassessed after the initial assessment determination, particularly as an eligible veteran's and Family Caregiver's continued eligibility for the program can evolve." The Department is making the false comparison to the most severely and catastrophically disabled veterans, to whom we believe this permanent designation should apply, and the entire population of veterans. Further, the Department references 38 USC 1720G as the source of their interpretation of Congressional intent, but does not provide the specific reference in law. The closest the law comes to identifying any such requirement is subsection (a)(9) which only says "The Secretary shall monitor the well-being of each eligible veteran…" and "Visiting an eligible veteran in the eligible veteran's home to review directly the quality of personal care services provided…" Nowhere does it say there has to be any type of reevaluation or review, let alone of any particular periodicity.

**The Independence Fund recommends reassessment be eliminated for the Caregivers of permanently and totally disabled veterans enrolled in the program and that they be given a permanent caregiver eligibility determination. If the VA believes that is not legally permissible, then it should look to the example of the Social Security Disability Income system which will provide up to seven years between eligibity reassessments for the most severely disabled.**

**Roles and Responsibilities of the Caregiver**

The Proposed Rule would change section 71.25(f) to require the caregiver to personally provide all the personal care services required by the veteran. First, we believe this may be a physical impossibility in some cases as the requirement for the "unable to self-sustain in the community" definition is the veteran needs CONTINUOUS supervision, protection, or instruction. That would require the caregiver to stay awake at all times in order to ensure that continuous monitoring.

And the illogic of that physical impossibility strikes at why this is an unnecessary, and likely arbitrary standard to impose through the Proposed Rule. The legislative requirements of the program are for the Department to ensure only the "quality of personal care services provided," and to take "such corrective action with respect to [those] findings of any review of the quality of personal care services…as the Secretary considers appropriate." There are numerous situations, with both veteran and non-veteran caregiving, where excellent care is provided to the veteran where the designated "caregiver" acts, in fact, like a caregiving manager, monitoring his or herself the quality of the care given by third parties with whom the designated caregiver or veteran may contract, and paid for with the stipend provided.

Nowhere in the Congressional deliberations for The MISSION Act which requires this program expansion, and the opportunity for this NPRM, were there discussions of how caregivers who manage and monitor caregiving provided by others provided inadequate quality of care. Nor were there any such discussions in the numerous Congressional roundtables, requests for information, VA hosted listening sessions.

Instead, this appears to be an arbitrary and capricious abuse of regulatory power on the part of the Department to impose a new, unsubstantiated, and legislatively unsupported requirement for participation in the caregiver program to limit participation to the program, and by that, limit potential outlays by the government.

Further, The Independence Fund believes there is insufficient justification given for this new requirement in the NPRM explanations, and so there is not sufficient information to comment on this provision. During the Caregiver, Survivor, and Veteran Family Advisory Committee meeting of April 2020, Sarah Verardo, Chief Executive Officer of The Independence Fund, specifically asked about this provision, and if that meant a Caregiver would not be allowed to work outside the home. The VA officials at that meeting were unable to answer, and preceding and follow up requests by The Independence Fund for exactly that information have not been answered.

**Therefore, The Independence Fund recommends the requirement the caregiver personally deliver all caregiving assistance be striken from the Rule.**

**Abandon the "Best Interest" Requirement**

The way the Proposed Rule would implement a "best interest" standard 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 the Veteran is incapable of making their own health care decisions.

Instead, The Independence Fund believes if a Veteran applies for Caregiver assistance, it should automatically be presumed that it 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.

**Stipend Rate**

The recalculated stipend rate in the Proposed Rule is wholly inadequate. Even with the new algorithm tying this to a GS level commensurate with the pay of a Home Health Aide, 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 by calculated by what institutionalization or inpatient care of that Veteran would cost the US Government, reduce that by 10%-20% to provide the Department some savings, and then provide the remainder of that amount to the Caregiver.