THE INDEPENDENCE FUND

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Dear Chairman Tester, Ranking Senator Moran, and Members of the Committee:

Thank you for your kind invitation of myself and The Independence Fund to testify before today's hearing, on "*Honoring Our Commitment: Improving VA's Program of Comprehensive Assistance for Family Caregivers*." As you will hear in my testimony today, The Independence Fund's been intimately involved in the Caregiver process and issues since my time as the Elizabeth Dole Foundation Caregiver Fellow for North Carolina. And this hearing could not be more timely, Senators. **Because the current Caregiver program regulation does not honor the commitment you set with Caregivers in the MISSION Act of 2018, is a dramatic step back in the support it provides disabled Veterans and Caregivers, and places every Veteran and the Caregiver who supports them in real danger of falling through the cracks of what has turned into a senseless, compassionless, bureaucratic nightmare.**

As many of you know, The Independence Fund (TIF) was founded in the halls of Walter Reed National Military Medical Center to provide greater mobility independence to the wounded and disabled military personnel returning from Iraq and Afghanistan. We started out providing motorized all-terrain wheelchairs fitted with tank treads to allow not only for easier transport across everyday wheelchair barriers, like a playground or the backyard, but to also give disabled Veterans a chance to get back to the outdoors, whether it be the beach, the woods, or the trails. We just ordered our 2,600th chair this month, representing more than $41 million in just track chairs to America's Veterans.

In 2012, we saw how most of these Veterans had families who shared in the Veterans' recovery, and who provided continuous, by-their-side, assistance in completing all the Activities of Daily Living that you and I take for granted. I am one of those Caregivers, supporting my husband Sergeant Michael Verardo, US Army (Retired), wounded on April 24th, 2010 in Afghanistan while serving with Bravo Company, 2nd Battalion, 508th Parachute Infantry Regiment. Many of you have met my husband, visited his bedside at military hospitals, and followed our family's journey for the past twelve years and 120 surgeries. Mike was catastrophically wounded by an IED blast, his left leg and left arm traumatically amputated, thrown 20 feet in the air, suffering burns, complex polytrauma, traumatic brain injuries, and a host of other wounds. If not for the incredible work of the men of his Company and the Army Medical Corps, he would not have survived. But he did, today he is my husband, and we have three wonderful daughters, who are with me here today. But more about my Caregiver journey later.

As I said, TIF's Caregiver program grew out of the recognition as to how time-consuming and all-encompassing caring for a catastrophically disabled Veteran is. Let me tell you, Senators, no one applies for the Program for Comprehensive Assistance for Family Caregivers (PCAFC) for the money. With the stipend maxing out at about $35,000, the 60 to 100 hours per week, caring every single day and every single night, a typical Caregiver can put in caring for their Veteran comes out to about $6.75 to $11.25 per hour. Senators, on the low end of that scale, that isn't even federal minimum wage, and on the high end of that scale, I can make more driving for Uber or flipping burgers at a local fast-food joint. And don't forget, the new regulation for the PCAFC program we are discussing today makes any type of work outside the home nearly impossible for both Veteran and Caregiver. But more on that later.

TIF's Caregiver program brings together small groups of Caregivers on respite retreats to commiserate and gain support and best practices from their fellow Caregivers, learn important self-help and self-care lessons and skills, and have a little downtime from the rigors of an always on-call Caregiver. We've supported more than 1,700 Caregivers with this program to date, and many of those Caregivers have joined us today virtually to watch this hearing in dear anticipation. We've also hosted themed Caregiver retreats, such as Vietnam Veteran Caregivers, Parental Caregivers, Caregivers of the Minimally Conscious, and Male Caregivers. In the future, we hope to work with VA to also provide initial financial and legal service consulting through our Caregiver retreats to best integrate them into these new services. **Regardless, Senators, The Caregivers which TIF supports are scared and they think this new Caregiver regulation stinks. Many of them are on a group text with me today, so if you want to ask any questions of the TIF Caregivers as a group, just ask, and I'll relay their answers**.

MISSION Act and the July 31, 2020 Caregiver Program Regulation

The MISSION Act was a landmark piece of legislation, shepherding in crucially needed expansion of community care programs, requiring the VA to fundamentally evaluate its facility and infrastructure through the AIR Commission for delivering modern health care in the 21st Century, and to expand the Caregiver program to pre-9/11 Veterans who fought in wars just like post-9/11 Veterans, were catastrophically wounded in battle just like post-9/11 Veterans, but were denied equal treatment to post-9/11 Veterans. But unlike Community Care and the AIR Commission, the Caregiver expansion was not a fundamentally new procedure for the VA, it was just the expansion of an already existing, and popular, program for catastrophically disabled Veterans and their families.

Before we get into the specifics of our concerns, Senators, let me set the record straight on one issue. We are very encouraged by the appointment of Dr. Colleen Richardson as the Director of the Caregiver Support Program. As some of the Veteran members of the staff like to say, it's readily apparent she "gets it", has a broad and deep understanding of many of the concerns we've raised to date, and is uniquely qualified to shepherd through the necessary changes. The unfortunate fact is, most of what is wrong with this program were put in place long before she arrived, and she inherited a train wreck. We deeply appreciate her attitude and campaign to "Get to Yes" and believe she should be given greater authority and support to ensure compliance in-field execution of this program. As we will discuss later, the issue is a very significant one that the new regulation, written and finalized before Dr. Richardson arrived, is deeply flawed. But it's also that many of the VISNs seem to have this attitude that they are their own health care network unto themselves, and guidance from the VA Central Office is merely "advisory." She needs to have the authority and the senior leadership support to set those field teams straight.

And Senators, the fact of the matter is the VA is not putting in the leadership commitment to ensure field compliance with the national standards developed by VA Central Office is not something new.

Last summer, before the House Veterans Affairs Committee, Julie Kroviak, Deputy Assistant Inspector General for Health Care Inspections in the VA's Office of the Inspector General told the Committee that VA's repeated failures to protect patient safety focused too much on wrong actions by individual employees, and not on the systemic failure of leadership and lack of attention on the VHA's health care culture. "OIG oversight work has shown that these missed opportunities were nearly always due in large part to the actions and, even more often, inactions, of leaders…Changes to [Veterans Health Affairs'] patient safety approaches are necessary and overdue, but impossible without the dedication of strong leaders who recognize that a cultural transformation is required to support meaningful and sustainable change."

Sharon Silas, Director of the Health Care Team at the Government Accountability Office also told the Committee that VA health care has been on GAO's "high-risk list" since 2015 and has failed to improve on that. Specifically, she stated that VA has not developed a plan to fix this and that the VA lacks the necessary leadership commitment across the board. "The number and repetition of recommendations we have made to address deficiencies in oversight and accountability are symptomatic of deeper issues underlying these efforts to oversee [VA's] delivery at health care," Silas said.

Senators, the same is applicable to the Caregiver program. The will is there within the Caregiver Support Office to Get to Yes for these disabled Veterans and Caregivers, but for some reason that does not translate to yes when it should in the field. And until the Caregiver Support Office has the authority to compel those Centralized Evaluation and Assessment Teams (CEATs) to follow the guidance given, even under this fundamentally flawed regulation, nothing will change. And VA Central Office leadership must hold the Veterans Integrated Service Networks, to whom, in part the CEATs report, accountable for the compliance of those CEATs. Without the day-to-day oversight of VA leadership while these new procedures are exercised for the first time, and hopefully after they are refined to address the concerns I will discuss today, we will continue to experience the failure we have to date.

Need for a New Regulation?

As was noted in the letter The Independence Fund and 22 other Veteran organizations sent to the Secretary of Veterans Affairs on November 9th, 2021 (a copy of which is attached), and as the Chairman noted in a prior Committee hearing, it appears the VA took the opportunity of the MISSION Act's expansion of the Caregiver program to pre-9/11 Veterans to also make it more difficult to qualify for the program moving forward. No significant reason was ever given for these new eligibility restrictions, it simply looked like the VA thought there were too many Caregivers in the program, and they wanted to get them out.

Nothing in the MISSION Act required the VA to change the eligibility criteria. Yes, the VA had to provide regulatory guidance on the new financial management and legal services to be offered Caregivers, but they did not have to change the eligibility criteria for the program. They could have simply used the regulation in place at that time, certified the Caregiver information technology tracking system as capable of handling the new Caregivers (which also did not require a new IT system – but which delayed the program expansion by two years), and started taking new applications much, much sooner and under the eligibility rules which everyone had used for the prior eight years.

The VA did not need to issue a new regulation, they did not need to change the eligibility requirements, and they didn't even need to waste two years of Veterans being denied the opportunity to apply for these expanded benefits to roll out some new IT system. The VA decided to do all that, and Veterans and Caregivers are the ones who now pay that price, many of whom were denied the opportunity to apply because they died before the new application procedure was in place. But the VA has never been held accountable for this. VA's regulation drastically changed the program's eligibility criteria, the process to determine a Veteran's "need" for assistance, and the entire methodology and basis for the stipend paid to the Caregiver.

Proposed Regulation Comments

It's not like any of this was only discovered after the new regulation started to be implemented. Back in the spring of 2020, during the public comment period on the then-proposed regulation, 273 comments were received, more than 200 of which were made by individuals or organizations directly involved in the policy arena of the Veteran or Caregiver community. Nearly all those 200 comments opposed one aspect or another of the proposed regulation and suggested changes that they felt would better serve our Nation's Veterans. In fact, the Elizabeth Dole Foundation led a group letter effort proposing many changes, none of which I see being addressed in the Final Rule. A copy of The Independence Fund's comment on the proposed regulation is also included for your review.

I suppose I should not have been surprised when the VA published the Final Rule in the summer of 2020 and categorically dismissed almost every one of those recommendations. But I was. I truly hoped the VA would take the public's suggestions into account and publish a regulation that would truly fix the PCAFC. But it didn't.

Eligibility Assessments

One of the biggest problems with the PCAFC is the broad variation in the execution and application of the eligibility initial assessment, reassessment, and appeals processes. This lack of national standardization led the Department to twice pause all program discharges and demotions. We believe this was because standards and processes were only in VA policy directives and handbook and not in regulation, and unfortunately, this exclusion from regulation exists in the new regulation as well.

We strongly advocated for those standards and processes to be in regulation and not simply policy because we all remember how the Department showed itself numerous times incapable of maintaining anything approaching national consistency in the execution of this program and application of these standards. We all remember the 2017 National Public Radio report revealing upwards of 94% of Caregivers were discharged from the PCAFC at some VA Medical Centers. That forced the Secretary to place a temporary freeze on discharges and Tier demotions within the Program. Despite that, NPR again reported in May 2018 that upwards of 84% of Caregivers were yet again discharged from the Caregiver program. And then, in November

2018, two triple amputees were discharged from or demoted within the Program at the Tennessee Valley VA Medical Center, after which VA stated proper evaluation processes were not followed. Again, the Secretary had to impose a national pause on all discharges and demotions that was only lifted with the implementation of the new, expanded program under the new regulation.

But, despite all those well-documented reports as well as innumerable anecdotal instances of problems, the key issue of the initial eligibility assessment, reassessment, and appeals processes was omitted from the Final Rule. As we noted in our comment on the new regulation, we did not have enough information to comment effectively on whether the Proposed Rule could meet the requirements of the authorizing legislation. Further, even if we had detailed how these standards and processes should be incorporated into the Final Rule, we were 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 left 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 was acceptable, and with which we were forced to choose only because of the inability of VA to meet the legislative deadlines for Caregiver expansion.

This was completely predictable and something TIF made aware to the VA during the proposed regulation comment period. As we noted above, examples of these failures have been well documented by the press reports referenced above, but include:

- Spouse Caregivers being dropped from the program, despite apparent indications the Veteran is clearly eligible for the program because that care was supposedly their “spousal” or “wifely” duties;
- Appeal denials providing very little, if any, explanation for the rejection of the appellants’ 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 the prior 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.

Senators, almost every one of these failures is happening again today. It was a failure of VA leadership in the past, and it's a failure of VA leadership now. It is not something that will be fixed by addressing this or that CEAT team or CEAT assessor. It will not be fixed alone by converting this to a benefit run by Veterans Benefit Administration (although that would certainly help, all other things being equal). It will not be fixed by penalizing some poor CEAT member who is trying to figure this out. The fundamental problem is the regulation we have right now is broken, and unless it is fixed, we will not escape this macabre merry-go-round of fear, uncertainty, and dismissal.

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 current annual interval, is insulting to the Veteran, introduces unneeded stress and disruption for both the Veteran and the Caregiver, and is completely unnecessary.

Further, the lack of specificity in the new regulation 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 periodicity.

An example of a situation that would be resolved both with the permanent Caregiver designation and with nationalized processes put into regulations is my experience with two 120-day check-in phone calls I've had immediately after the new regulation went into effect. My experiences with both calls were unnecessarily invasive, inappropriately detailed, and went on forever. I want to pause and share that I emphatically support and recognize the need for welfare checks AND checks and balances in this program. In our case, which is true for many caregivers providing the level of care that Michael requires, I am in regular communication with his VA care team, and I keep all of his care at VA to provide (what I hope to be) cohesive decision making and care. Despite frequent if not weekly contact with my husband's care team and his well-documented medical condition which includes a severe traumatic brain injury, and neurogenic bowel and bladder which requires toileting and catheterization by another person (usually me), never mind the limb loss, we were subjected to questions to include, "Do you take prescription medication to sleep?" (to me), "What medications do you take at what frequency and for what?" (to the Veteran, who is well documented as not administering his own medication). With one of the calls, I received a call out of the blue and was told I had to dedicate the next 90 minutes to the check in call.

In my case, the VA Medical Center with our case grossly misinterpreted the guidelines for these 120-day visits, resulting in a humiliating and demeaning experience for both my husband and myself. This was not unique to our case, as we heard from others who had the same experience with these well checks. The VAMC's interpretation came from what they believed to be VACO's guidance to ask each question literally, without any interpretation for clinical notes or best judgment. This would not have happened were processes instead clearly defined in the Regulation, and allows for far greater transparency in the most intimate part of the Caregiver evaluation process. I understand and support the need for welfare checks for the Veteran, but the manner in which these two Caregiver calls were performed only reminded my husband of the severity of his condition and caused extreme stress when I was told I had to remove him from his respiratory therapist so that he could complete his part of the call.

Similarly, the reassessment functional test was completed by VA Video Connect, and this was equally invasive, impersonal, and bureaucratic. The complexity of the questions asked challenged even myself, but when asked of my husband, were deeply upsetting, leading him to cry during the evaluation, but with the assessor continuing to ask these questions for which he must have well known he was not going to get substantial answers due to my husband's TBI and cognitive processing difficulties. At one point, despite detailed notes by VA providers that demonstrate loss of ADL and IADL functionality, the examiner questioned why my husband could not clean his own bottom since he was provided a shower chair and there should be an opening at the bottom to make that feasible. In front of my husband, I was forced to explain the recurring diaper rash, skin breakdown, and infections that are all documented as part of his VA medical chart, and treated by his VA care team, that stem from bladder incontinence and spillage overnight.

And then, most recently, a psychiatrist who was part of the CEAT, but who never met or evaluated my husband, conducted an internet search to find videos of public speeches he made on Veterans advocacy issues – in 2016 and 2017. Senators, that's five and six years ago. My husband's situation has changed dramatically in those years, with two major surgeries to take his left leg amputation above the knee, and fit him for a new prosthetic. And he didn't make those public speeches alone – I was right there with him every step of the way. But more importantly, when did the internet become part of the clinical evaluation process? That's like a surgeon, looking at a patient with a heart attack, but then Googling the patient's name, finding out they were a high school football player, and declaring, "This can't be a heart attack – here's a video of him playing football!" Senators, this is preposterous, it is insulting, and frankly, I don't know how this is not illegal.

Further, it made me re-live the massive declines, heartache, and loss my daughters and I live with every day as we watch rapid changes to functionality and personality. I WISH my husband was able to do the things that a random VA examiner is accusing him of, but instead I am forced to account in painful detail what is already well documented in his VA medical record: that my daughters are loved by their father, but lack any semblance of traditional activities that they beg me daily for their dad to provide: sports practice, family dinners, school event participation, and even reading and playing are nearly possible on a handful of excellent days each year, but the day to day reality is grim and isolating. And apparently because of that one sentence this psychiatrist dropped in my husband's record, we were just notified that come October 1, 2022, my husband will be reduced to the lowest severity Tier in the Caregiver program. And Senators, I'm the "lucky" one – most Veterans are just being discharged from the program. Thank you for your service, thank you for your sacrifice, now, get out of my VA program! I ask this Committee to ask VA where in any regulation or process does it instruct an examiner to utilize Google to make a clinical determination? And further, what is the cut off for this clear government overreach? For someone with polytrauma and a severe TBI, declines can be rapid.

Roles and Responsibilities of the Caregiver

The new regulation requires 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 always stay awake in order to ensure continuous monitoring.

And the illogic of that physical impossibility strikes at why this is an unnecessary, and likely arbitrary, standard to impose through the new regulation. 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.

To me, this sounds like I'm not allowed to sleep, let alone have any kind of outside-the-home job, which is entirely ridiculous. I run a multimillion-dollar nonprofit organization, am raising three young daughters, AND oversee the provision of excellent care to my husband. Although I perform much of my husband's care personally, I am not a medical professional and thus specialty services that we have at home, including wound care and respiratory care, cannot be performed by me. Further, as my husband requires full-time care, including overnight due to choking and gurgling despite non-invasive ventilation equipment, this requirement would mean that I cannot rest or tend to the needs of the other family members within my home. Even with the Caregiver stipend, and VA home oxygen program and specialized care in the home, we still private pay to ensure my husband has round the clock assistance and supervision. I've been repeatedly warned by well-meaning VA providers that I should only keep doing so quietly to avoid VA determining that Mike needs full time nursing home care.

Nowhere in the Congressional deliberations for The MISSION Act which requires this program expansion 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. I personally believe, therefore, the VA seriously overstepped its bounds by putting such a requirement in the new regulation.

Further, The Independence Fund believes there is insufficient justification for this requirement given in the new regulation's regulatory process explanations, and so there was not sufficient information to comment on this provision. During the Caregiver, Survivor, and Veteran Family Advisory Committee meeting of April 2020, as a member of the Advisory Committee, I 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 TIF for exactly that information were never answered.

"Best Interest" Requirement

The new regulation has a new "best interest" standard, a standard which 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, TIF 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

Many will say that the stipend is not compensation for personal care services rendered by the Caregiver, nor to be considered "pay" for those services, but simply a recognition of the sacrifice they make to care for the Veteran. But then, why does the new regulation calculate the "stipend" rate according to what it would cost to hire a home health care assistant, who absent the Caregiver would be contracted to provide those services? Senators, if it looks like a duck, quacks like a duck, and waddles like a duck, it's probably a duck. Let's be real here – this is compensation for personal care services rendered. And as such, is wholly inadequate.

The recalculated stipend rate in the new regulation is simply an insult to the Caregivers involved. 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.

Impact of the New Regulation and Eligibility Criteria

Now, we are seeing the harsh impact of those changes. First, as announced by the VA concurrent with the Interim Final Rule issued September 22, 2021, the VA then believed about 6,700 "Legacy" Veterans will be discharged from the Caregiver program upon the expiration of the Legacy Applicants eligibility extension come October 1, 2022. Representing more than one-third of all the Legacy Caregivers, this wholesale dismissal of disabled Veterans from the Caregiver program is completely unwarranted, especially when one considers it was the VA who determined these Veterans eligible for the program in the first place under the old regulation. The VA wrote that old regulation, they operated under it for by then nine years, and they never raised these concerns about the eligibility criteria being too loose. As if being so disabled in the service of your country that you are no longer being able to do a simple Activity of Daily Living (ADL) like feeding yourself, bathing yourself, going to the bathroom without needing someone to help you, or being able to dress yourself are somehow proof that the VA is giving away the store to malingering Veterans and fraudulent Caregivers. I'm offended, many of the Caregivers and Veterans TIF supports I know are offended, and the Members of this Committee should be offended the VA is treating its Veterans so shabbily.

Assessment Process and Cases

These are not one-off cases. Since the new regulation went in effect, scores of Veterans and Caregivers have asked TIF for assistance, telling us harrowing stories of invasive and accusatory assessments and interviews, and mind-bogging decisions to disenroll or reduce the assessed severity of the Veteran's personal care needs, despite the very VA assessments saying otherwise. These pleas for assistance have dramatically increased since the VA started to reassess the "Legacy" Veterans this last fall. And these issues appear to be systemic and without justification. Here are a few examples of Veterans and Caregivers we are assisting to give you some context to the fear pervasive throughout the Caregiver community:

- One Veteran has been rated 100% Permanent and Totally Disabled since his medical discharge from the service. His rated service-connected disabilities include: depression, osteoarthritis of the spine, thoracic spinal cord injury, traumatic brain injury (TBI), the cognitive deficit as a secondary effect of the TBI, the secondary effect of intracranial injury, hypersomnia, post-concussion syndrome, chronic pain syndrome, post-traumatic stress disorder (PTSD), intractable chronic post-traumatic headache, and impaired mobility. The VA even acknowledged he cannot walk and requires the use of a power wheelchair to replace the ADL of mobility and walking, but the VA also acknowledged he cannot operate his power wheelchair alone and needs constant supervision.

- Another Veteran was rated as having a spinal cord injury, TBI, seizures, autonomic dysreflexia, neurogenic bladder condition, blackouts, memory loss, disorientation, and complex regional pain syndrome due to the IED blast wounds he received in 2007. His autonomic dysreflexia requires his blood pressure to be checked every four hours. His neurogenic bladder condition means he must be catheterized at least 3 times a day to avoid abdominal distension. His complex regional pain puts his pain level at a 7-10 out of 10 every day for the last four years, keeping him bedridden for weeks or even months. He is paralyzed from the waist down. When he gets out of bed, his feet give out, and unaided, he falls. He requires assistance every time he transfers or walks with a cane and brace, and all medications must be managed and delivered by his Caregiver. While he was at the highest tier level, a Tier 3 under the prior regulations, under the new regulations he’s been advised he will be disenrolled from the program.

- One triple amputee The Independence Fund serves who lost both arms and a leg will be disenrolled from the program because the Caregiver evaluation team said he can take care of his 19-month-old daughter, was completely independent, capable of completing all ADLs, and that even had participated in a soccer game! The VA specifically stated there was no indication of moderate to severe functional impairment in completing any ADL all the time continuously for the next six months. As if he is a starfish for whom his amputated limbs will magically grow back.

- Another double amputee who lost both her arms and who is rated as 100% permanent and total was reduced in her Tier because she was asked if she would be willing to drive, not whether she could drive. She said she would be willing to drive, but that since she has no hands, she can’t drive. But the VA assessor remembered the Veteran had driven with a friend across country for a family event, where the friend drove, and had to reschedule a VA appointment. And the VA assessor indicated in the Veteran’s record that the Veteran had driven herself. took that as an answer that she’s able to drive, although driving is not one of the ADLs considered for Caregiver program eligibility. She was also asked if she had handrails in her shower. She said yes, but also told the assessor she cannot use them as she has no hands. The Veteran states nothing was asked about her specific disabilities injuries or specific capability to complete ADLs. But she states she needs continuous help bathing, eating, and toileting.

- One Veteran with diagnosed schizophrenia, TBI, PTSD, a history of dangerous behavior to self and others, and who needs constant reminders and redirection, who was Tier 3 under the prior regulation, will now be disenrolled because the VA says the Veteran can fully sustain themselves in society.

- Another double amputee Legacy Veteran wounded in Afghanistan rated Tier 3 under the prior regulation, and who failed three different ADL tests during the Caregiver team reassessment, and who needs daily assistance with toileting, bathing, and medication management, is being disenrolled because the assessor did not believe he would need such support for the next six continuous months.

- A Veteran suffering from Parkinson's, TBI, brain injury, and oxygen deprivation injuries, who was a Tier 3 under the prior regulation, and who was hospitalized for his disabilities twice in the last year, will be disenrolled because the assessor did not believe he would need such support for the next six continuous months.

- Another Veteran, completely blind due to an IED explosion, rated as 100% permanent and total, who has lost all sense of smell, taste, and touch, and some hearing loss, was reduced from Tier 3 under the prior regulation to Tier 1 under the new regulation because the VA believes he can perform all his own ADLs, and there is only a need for safety supervision.

- An OEF/OIF Veteran, a survivor of combat wounds, who attempted suicide, suffered multiple concussions, suffers post-concussion syndrome, vestibular disorder, multiple degenerative disks, has lost the use of his arm, suffers complications from VA surgery, and has PTSD, will be disenrolled from the program because the VA believes the Veteran can fully sustain himself in society.

- A single amputee Veteran with significant TBI, burns, and needed wound care, who was wounded in 2011, but initially denied eligibility for the Caregiver program because he was an activated Reservist when wounded, was recently advised he'd be disenrolled because the VA did not believe he would need continuous ADL support for the next six continuous months.

- Another double leg amputee was determined to be independent in lower body dressing because since he doesn't have legs, he doesn't need to put on shoes. But the Veteran uses prosthetics, needs to wear shoes with the prosthetics, and cannot put those shoes on his prosthetic feet. The VA assessment even said he needs supervision and assistance with this activity. The VA assessment also admitted he needs assistance prosthetic adjustment assistance. While the VA assessment says he needs assistance with almost all of the transfers, because the VA assessment does not believe he ever stands up, even though the assessment talks about his prosthetics and his crutches for walking, they don't even assess his ability to transfer from sitting to standing, for which he needs assistance every time. The VA assessment also determined he is unable to exercise the judgment and physical ability necessary to adjust to changing societal environments and avoid potentially harmful situations. The report even said he had a ramp at his home, which is not the case.

- A Veteran in a Western State was assessed in the function checks as at risk for dehydration, malnutrition, harm to self or others, impairment of memory, ability to reason, lack of judgment, and lacks the ability to manage medications. In this case there is disassociation disorder and cognitive decline due to an incident in which brain damage occurred from severe oxygen deprivation. The VA assessment also states the Veteran needs assistance with almost all his bathing and is a fall risk. The assessment says he's dependent for upper body dressing, dependent for footwear, needs assistance with lower body dressing, needs assistance with transfer out of the bed or to stand, assistance with transferring from the toilet, suffers delusion, needs daily redirection in sustaining himself in society, has a propensity for impulsive high risk behaviors, that he is incapable of managing medication to the point that he may threaten his own health or safety, and is incapable of managing their own health and safety. But then the final VA determination states he is not at risk for self-neglect.

- A southern Veteran, who was a Tier 3 (highest tier) under the prior regulation, is being reduced to Tier 1 under the new regulation. His VA assessment said he needs assistance dressing, bathing, adjusting prosthetics, and walking, and that he needs supervision, protection, or instruction to maintain his personal safety on a daily basis, is unable to self-sustain in the community, is blind in both eyes, lost use of his left hand, has hearing loss, cannot smell or taste, is a fall risk, and can never be left alone.

- We have heard at one VAMC, of the more than 40 Legacy Veterans in the program, all but one will be disenrolled.

The key issues appear to be one of two ways the VA looks at this: either with ADLs, where the VA appears to be applying extremely strict criteria to the requirement the Veteran will need continuous and significant assistance with completing their ADLs for at least six continuous months. Who can project anything like that out for six months? The Veteran could need 24/7 assistance for the next month or two, but unless the Caregiver evaluation team is absolutely sure the Veteran will need it for the next six months, the Veteran is denied eligibility to the Caregiver program. Does the VA believe the Veteran's need for ADL assistance which are very evident today are suddenly going to change in three months? That's preposterous.

Further, the VA appears to be looking at a Veteran on their best day instead of their worst. Caregiver Support Office Director Dr. Colleen Richardson says we should celebrate the small victories Veterans and Caregivers have in their recovery. We could not agree more. But the Caregiver evaluation teams out in the field executing these policies seem to believe such small victories are all the proof they need to throw the Veteran out of the Caregiver program.

Clinical Determinations and Appeals

Alternatively, the VA appears to overstate the ability of Veterans to sustain themselves in society. While the regulation's criteria for self-sustainment in society are nebulous at best, we also have not seen any assessment scripts or decision-making documents the Caregiver assessment teams use which go into nearly the evaluation detail they do for ADLs. Given that, we can only assume such determinations are left to the discretion of the assessment team, seemingly without the direct input of the Primary Care Team, it appears the Caregiver assessment teams are making their own clinical assessments of the Veteran's personal care requirements despite the Primary Care Team engaging with that Veteran for their day-to-day medical care.

And this strikes to the issue of this program being run by the Veterans Health Administration and not the Veterans Benefit Administration. And that is also seen in the difficulty the VA is having in adapting this program to appeals that may now go to the Board of Veterans Appeals. Why did the court decide to mandate that route for appeals? Because they saw how inadequate the assessment process was and how limited the Veteran's rights were in the VHA clinical appeals process. While we are worried that turning this into a benefit instead of a health care provision, as it is now, will force Veterans to decide whether the risk of their disability rating being reduced in a new Compensation and Pension Exam likely, needed in applying for what would be a new benefit, is worth the benefits of the Caregiver program. But, such a change would require a change in law anyway, and your Committee could draft that law so that no new C&P Exams are allowed from the application for a Caregiver benefit. Otherwise, we are worried conversion to a Benefit will drive Veterans away from the Caregiver program.

Remedies

On February 7th of this year, The Independence Fund, joined by 21 other Veteran and Caregiver groups, submitted a Petition for Rulemaking to the VA to fix these problems with the current Caregiver regulation. A copy of that petition is attached. In that Petition, we stated the reasons for granting this petition is that the VA substantially deviated from Congressional intent in drastically restricting future access to the benefits offered Veterans and Caregivers, tightening the eligibility criteria substantially beyond that required by law. We also noted how the recent *Beaudette* court ruling found the VA's process of Caregiver program appeals problematic, which means that Veterans and Caregivers who are thrown out of the PCAFC have little chance of successfully appealing VA's procedures and decisions.

The Petition made the following recommendations:

1. Eliminate the prohibition on work and replace it with criteria of activities of daily living and/or the need for supervision, protection, and instruction. While the VA takes the position that although employment is not an automatic disqualifier for PCAFC, VA will still consider employment as one of the factors in determining eligibility for PCAFC. Further, while maintaining employment does not automatically disqualify a Veteran for PCAFC, VA considers employment and other pursuits, such as volunteer services and recreational activities, in evaluating an individual's PCAFC eligibility, ostensibly as a proxy for whether the Veteran can complete their activities of daily living, or as an external factor to weigh whether the Veteran truly needs supervision, protection, and instruction. VA declined to include language to state that employment is not an exclusionary factor for the PCAFC eligibility, and Caregivers are regularly asked as to their outside employment status, hours worked, and presence inside the home during their initial eligibility and re-eligibility interviews. The Petition provided specific language the VA could use to that such activities, "does not disqualify a person from being …eligible" to participate in the program, either as a Veteran or a Caregiver.

2. Eliminate the requirement for a Caregiver to engage 100% of their time to provide care. We note in our Petition the assessment evaluation, "practice in the field by the Centralized Eligibility and Appeals Team members conducting the assessments about

which the Petitioners have heard is that they regularly deem proposed Family Caregivers ineligible if they are not providing 100% of the personal care services at all times." Given that, we recommended that the Caregiver roles and responsibilities text be changed to read, "Whether the applicant will be capable of ensuring the performance of the required personal care services without supervision, in adherence with the eligible Veteran's treatment plan in support of the needs of the eligible Veteran."

3. Relax the strict requirement for a Veteran to fail 100% of their activities of daily living. In both the regulation and the execution in the field, if an ADL has nine steps, and they fail one or two of them, they are deemed to still be able to complete the ADL, even though VA says those steps are necessary elements of the ADL. Further, the regulations criteria require failure, "each time he or she completes" the ADL. By a strict reading of the current regulation, if a Veteran needs assistance performing the activity of daily living 99% of the time, but one time out of every 100 times attempted, they are able to perform the activity of daily living on their own, they must be deemed ineligible for the program. The Caregiver Support Office calls for "small victories of Veterans in the program to be celebrated," but a small victory on one day out of a hundred could mean being kicked out of the Caregiver program. I do not believe that was the intent of Congress.

   VA takes the position that it did not define the inability to perform an ADL using "most or majority of the time" language because VA believes that such terms are too vague and subjective, leading to inconsistencies in interpretation and application. Also, VA believes that using "most or majority of the time" instead of "each time" would be difficult to quantify and would require VA to establish an arbitrary threshold. By this, the VA has now established that it cannot perform qualitative analyses of the extent to which an eligible Veteran's disability impacts their ability to perform an ADL, and must therefore operate under a clear criterion.

   To resolve this problem, the petition proposes to replace the phrase "each time" with "any time when." The full ADL definition will then read "a Veteran or servicemember requires personal care services any time when he or she completes one or more of the following [activities]." Given VA's admitted inability to perform qualitative analysis, the proposed "any time" language is not vague and subjective—it clearly means that the Veteran must be unable to perform any of the activities listed in the ADL definition all the time.

4. Allow for the extended period for the reassessment of catastrophically disabled Veterans. The law says nothing about how often the VA needs to conduct a reassessment for eligibility. That is completely VA's desire to make it annual. While the regulation does allow for reassessments to occur, "on a less than annual basis if a determination is made and documented by VA that an annual reassessment is unnecessary," the practice in the field by the Centralized Eligibility Assessment Team members conducting the assessments about which we have heard is that they uniformly require even the most catastrophically disabled Veterans to go through an annual reassessment and that many of the most catastrophically disabled Veterans are being advised they will be disenrolled from the program once the grace period ends on October 1, 2022, as I discussed before.

To resolve this, the petition provides language to reduce reassessments to five years for catastrophically disabled Veterans, and to stop reassessments for permanently and totally disabled Veterans except when specifically ordered for the Veteran in question by the Director of the VISN.

5. <u>Eliminate the unnecessary and arbitrary minimum 70% disability rating</u>. The VA's arguments for imposing a minimum 70% disability rating is based upon its interpretation of the legislation's eligibility requirement for the Veteran to have suffered a "serious injury." But by the VA's own discussion in the Final Rule, it recognizes "illness" is not the same as "injury," yet includes it in the disabilities which will qualify in meeting the "serious injury" definition. Further, the VA states they've modified the requirements so that the inability to perform the ADLs does not have to be related to the serious injury which renders the eligible Veteran in need of the personal care services. The VA has therefore admitted its broad definition of "serious injury" is arbitrary, and so, therefore, is the minimum 70% disability rating arbitrary and unnecessary as well.

   The other personal service care eligibility requirements are sufficient to ensure only those eligible Veterans in need of personal care services are admitted to the program. The 70% minimum service-connected disability rating requirement is, as the VA admits, immaterial to the eligible Veteran's need for personal care services. It serves no purpose other than to exclude eligible Veterans arbitrarily and for no discernable public policy purpose. Therefore, to resolve this problem, we proposed to change the definition of "serious injury" to any service-connected disability. It's time to stop this madness and bring some sanity back to the process.

<u>Negotiated Rulemaking</u>
Finally, the petition proposed the VA use the "Negotiated Rulemaking" process to fix the Caregiver program. While negotiated rulemaking is regularly used by the Departments of Education (in their case on Veterans education issues), Interior, Energy, and the EPA, the VA does not appear to have used them in the past. But the petition spelled out for the VA how it can follow the other agencies' example and engage in negotiated rulemaking. For the Committee, given the traditional rulemaking process did not result in VA adapting any of the changes proposed by the stakeholder Veteran and military serving organizations, despite their near unanimous opposition, and because the interested Veterans and Caregivers recognize the urgent need to review and revise the PCAFC regulations, we think it is judicious for VA to engage in negotiated rulemaking as soon as possible.

Conclusion

Again, Mr. Chairman, Ranking Senator Moran, and Members of this Committee, I and the Independence Fund deeply appreciate your allowing me to testify before you today. We've welcomed the opportunity to work with your staffs, and believe you are committed to ensuring Veterans get the Caregiver assistance they rate and need, when and where they need it, and that Caregivers are adequately supported. For that, we thank you.

We've done everything we can to engage the VA on this issue – we were deeply engaged in the regulation development process, commented extensively on the proposed regulation,

have communicated repeatedly and consistently on detailed steps the VA can take to fix these problems (problems your Committee has previously noted), but to date, it appears nothing is going to change. We are still awaiting the Department's response to our Petition for Rulemaking, but unless we see substantial changes proposed by the VA, we believe you, Senators, will need to legislate the necessary changes and force the VA to take the action you originally intended with passage of the MISSION Act. It is unfortunate the Department is this unresponsive to the Veterans and Caregivers who live with these rules every day, but that's the reality as we see it now.

I will end my discussion today with one offer and one plea – **tell us the things I and The Independence Fund can do for and with you and your Committee to best address the needs you've identified for the VA and community to better address the Caregiver program**. We remain as committed as you to address these issues fully and quickly and look forward to working with you to do so today and tomorrow. On a personal note – being a caregiver and watching a man that I have known for 23 years – since high school – decline in front of me and then be cross examined by VA in a contentious and hostile program that was created to be a haven for Caregivers – is cruel and adds another layer to a life that is already devoid of any margin. On behalf of my fellow Caregivers, I ask you to do the right thing with immediate intervention into this program – those that have spent decades advocating and caring for their loved ones are begging you to help us shoulder this war at home.