TESTIMONY

QUALITY OF LIFE FOUNDATION

FOR THE SPECIAL COMMITTEE

ON AGING AND VETERANS' AFFAIRS

HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS

JUNE 5, 2024

Chairmen Casey and Tester, Ranking Members Braun and Moran, and Committee Members, my name is Andrea Sawyer, and I am the Advocacy Director for the Quality of Life Foundation (QoLF), a national non-profit organization founded in 2008 to address the unmet needs of caregivers, children, and family members of wounded, ill, or injured veterans.

As you know, over the years, legislation, and policy with respect to caregivers has fortunately evolved. Congress passed the *VA MISSION Act of 2018* which made substantial changes to the original Program of Comprehensive Assistance for Family Caregivers (PCAFC). The changes include: (1) expanding PCAFC eligibility to caregivers of Pre-9/11 veterans and (2) expanding eligible care conditions to include illness and noncombat-related injuries.

Initially, the MISSION Act legislation was greeted with great fanfare. New generations of veterans and caregivers would now be eligible, and those who were ill or otherwise injured would have the option of having a loving family member care for them. By broadening eligibility, Congress acknowledged the argument caregivers had been making for years--by being present at the veteran's side, caregivers are able to facilitate growth, maintain progress that was made in therapies, and offer a more complete medical picture to the specialists who were not able to be with the veteran all the time. This led to improved outcomes for many warriors and cost- savings for the government.

## Congressional Intent vs. Implementation

Congress clearly expressed its intent that seriously injured veterans were to be served by the PCAFC program in the MISSION Act legislation. As it had done with the original legislation creating the program, Congress again made sure to leave no doubt that injuries other than physical injuries were to be considered, emphasizing on multiple occasions that, "serious injury (including traumatic brain injury, psychological trauma, or other mental disorder,)" be considered. It is important to note that Congress had the opportunity to change the eligibility requirement from seriously injured to the stricter "severely" injured, a term that was clearly in the lexicon at the time of the passage of the legislation. However, Congress chose to stay with the more inclusive "seriously injured."

As a result of this new legislation, the Department of Veterans Affairs drafted new implementing regulations, including revising the criteria for admission and developing new application, assessment/evaluation, and approval/denial processes. As a result, and due to the complexity of

the new evaluation and appeals processes, QoLF refocused its efforts and created educational resources for those applying for the program and assisted in the preparation of clinical appeals for those who have been denied. Through our work, our staff has developed a unique understanding of the operational and policy questions and challenges surrounding the roll-out and implementation of the post-MISSION Act PCAFC program. However, let me be clear QoLF is NOT offering any clinical judgement, we are simply assisting the caregiver and veteran to identify factual errors and omissions in the record, gather documents supporting their case, and articulate their arguments in clear, concise language.

As we assisted in the drafting of these clinical appeals, we found that although the new legislation broadened the program, the VA's implementing regulations and guidance have vastly narrowed the number of individuals who would qualify for PCAFC services, including the stipend. In many cases, it seemed the VA had exchanged a program intended for seriously injured to one only for those who were severely injured. BOTH categories of veterans often require a caregiver to achieve their maximum level of functionality and highest quality of life.

In March 2022, QoLF testified before the Senate Veterans Affairs Committee (SVAC) about the problems we found with the regulation and implementation of changes the VA made after the MISSION Act passage. At that time, VA had just paused the discharges of Legacy participants since their re-evaluations had just begun under the post-MISSION Act evaluations. While it was anticipated there would be some discharges among Legacy participants, far more were discharged than expected through the assessment process. Additionally, many older veterans from the first MISSION Act cohort, with needs anecdotally expected to qualify for the program, were not qualifying.

**Where We Were:**

At the time of March 2022 SVAC hearing, QoLF listed a multitude of issues with the assessment and evaluation process, some created from legislation, some from regulation, some from the assessment language, and some from the implementation process. The highlights of those stated issues were:

1. Language in the regulation requiring assistance "each and every time" an Activity of Daily Living (ADL) was completed;

2. Language in the regulation requiring "continuous daily care" for supervision, protection, and instruction;

3. Language of serious injury v. catastrophically injured;

4. Language surrounding the "ability to self-sustain in the community" with respect to tier determination;

5. The length of time of the history of the veteran's condition being evaluated in the record (past twelve months);

6. Gathering of the outside records and specialists' input; and

7. Lack of evidence provided by the CEAT (Clinical Eligibility Assessment Team) decision to understand the discharge or level decision rendered.

Additionally, two court decisions, the *Beaudette* and the *Veteran-Warriors* decisions, created new issues surrounding PCAFC. The decisions meant the Caregiver Support Program (CSP) had to develop and implement plans to resolve existing issues within PCAFC, some of which QoLF had mentioned in our March 2022 SVAC testimony.

In the months after the March 2022 SVAC hearing on VA's PCAFC, VA Central Office (VACO) CSP leadership wisely engaged with Veteran Service Organizations (VSOs), CSP staff, and caregivers across the country to learn about challenges, identify additional issues, and discuss ideas for resolution. As a result of those engagements, VACO CSP has resolved some of the original issues, identified potential regulation changes, and developed and implemented staff trainings for a program that had not existed previously within VACO CSP, and, in some areas, VHA. While we do not always agree, QoLF wants to commend Dr. Colleen Richardson and her staff for their willingness to engage in these very complex issues and seek appropriate policy solutions.

Unfortunately, in the late fall of 2022, VA Office of General Counsel ceased to allow the VACO CSP team led by Dr. Richardson to interact with and continue the active listening sessions with VSOs on policy and implementation language surrounding the remaking of the regulation for the VA CSP, including the PCAFC. Since that time, the entire Veteran Caregiver Community, as well as the VSO Community, has awaited the new pending regulation for the VA CSP, hoping that the problems we testified to in the past, and will testify to today, will be addressed in that new regulation.

On May 13, 2024, QoLF and Military Officers Association of America (MOAA) held a Caregiver and Veteran Experience: A Community's Response to the Pending VA Caregiver Support Program Regulations 2024 Roundtable. At that time, we hosted legislative representatives from many prominent VSOs, several Congressional staffers, including SVAC staffers from both sides, and caregivers, researchers, and governmental representatives. The purpose of the roundtable was to identify problems with the post-MISSION Act regulation and propose actionable solutions to improve VA PCAFC. Some of those solutions are incorporated our testimony today.

## **Where We Are:**

While much work has been done, much still remains to make this an effective and fair program for veterans and caregivers. Below, please see a summary of remaining issues:

1. *"Each and Every Time":* The legality of the requirement that a caregiver must assist a veteran with an Activity of Daily Living (ADL) "each and every time" it is completed for eligibility in the program has been reviewed. The *Sheets* decision ruled that this strict interpretation of assistance with ADL's under VA's regulation was allowed under the legislation creating the PCAFC. However, VACO CSP has acknowledged that this strict interpretation is keeping veterans, especially older veterans, out of the program and penalizing veterans for being able to

do anything for themselves, impeding progress in rehabilitation and potentially causing harm. Changing the ADL language to "regular assistance" would align the language with the frequency of assistance under other VA programs, as well as allow veterans to function at their highest potential when able to without fear of losing their caregiver. Changing this language will require a regulation change.

**QoLF feels a change to "regular assistance with an ADL" will resolve the issue. HOWEVER, to prevent any backsliding we would prefer this language be legislated as otherwise the regulation can be re-interpreted as was done in 2015, 2017, and 2020, necessitating constant pauses.**

*2. "Continuous Daily Care":* The requirement that a caregiver must assist a veteran with supervision, protection, and instruction (SPI) continuously throughout the day excluded some conditions for which the legislation had been expanded. For example, under the original regulation for the MISSION Act, a veteran with Alzheimer's who only sundowned would not be eligible for the program because the veteran would not always need "continuous daily care." While the veteran would have needed daily care, the veteran was independent during some daytime hours, and therefore care was not continuous. The *Sheets* decision actually rectified this issue by stating that the "continuous daily care" standard under the MISSION Act regulation was stricter than the PCAFC legislation allowed. As a result, the regulation reverted back to the definition found in the legislation which was "regular or extensive instruction."

**The guidance for VA CSP SPI was rewritten, nationwide staff was retrained, and QoLF has seen a significant improvement in qualifying under this requirement.**

**3.** *"Seriously vs. Catastrophically Injured":* Both the Omnibus Act of 2010 and the MISSION Act used the term "seriously injured." At the time of the original legislation the term "Seriously Injured" existed in the DOD lexicon as a person who would need at least six months to recover from injury and would not return to a state of fitness for duty. Because of the number of joint commissions that existed at the time, media interest, and public scrutiny that lexicon was understood at the time. By 2018, the passage of the MISSION Act, withdrawal from Iraq, and downsizing of the force in Afghanistan lowered the number of recently injured veterans and attention to this population waned, allowing the term and its definition to fall out of the common lexicon surrounding the legislation. Transition of staff in Congress and in the VA also created a vacuum of knowledge around this term.

The term "catastrophically injured" was created by the VA in 1996 with the expansion of VA priority groups and the realization that there were veterans who needed primary care from VA, but whose severely disabling injuries/conditions were NOT service-connected. For example, a veteran who became a quadriplegic from a car accident AFTER his service, would qualify under the designation of "catastrophically injured" so as to be eligible for VA healthcare even though his severely disabling injury was not a service-connected injury. Additionally, catastrophically injured" focuses more on injuries impacting the performance of ADL's and less on a need for conditions that require SPI, although PCAFC allows for qualification due to a severe need for SPI.

DOD used "catastrophically disabled" as a term to discuss an injury category that was unlikely to ever be able to return to fitness to duty after injury, allowing for a service member's consideration for medical retirement during their recovery process, but there was no adoption of DOD's term "catastrophically disabled" in the original or MISSION Act legislation surrounding PCAFC. Thus, VA never adopted the DOD's definition of "catastrophically disabled" and instead used their own previously existing definition.

Somehow, in the discussion of the PCAFC program through the years since the MISSION Act, the understanding of these terms has been confused by some organizations, veterans, and staff leading to a misinterpretation of the intent of the program. "Catastrophically injured" does NOT describe the injury severity for PCAFC services in either the law or the VA regulation. It was an "insurance" term created by VA to designate a priority care and payment group for VA outpatient healthcare services.

**QoLF believes the issue surrounding the definition of VA's term "catastrophically disabled" has brought to light why VA did not use its own definition of "catastrophically disabled". However, since the catastrophically disabled, as designated by the VA, need high levels of assistance with ADL's and/or SPI functioning, Congress could expand the eligibility to "seriously injured and those designated as qualifying for VHA services under VHA's definition of catastrophically disabled." This would allow veterans who were severely disabled after service, in non-service connected accidents or by non-service connected illnesses, to be able to reap the benefits of VHA's PCAFC.**

4. *"Unable to self-sustain in the community":* For purposes of determining the tier level of the veteran, the Caregiver Eligibility Team (CEAT) has to answer the question, "Is the veteran UNABLE to self-sustain in the community?" Due to the confusing wording of the question, QoLF identified that this was keeping many significantly injured veterans (quadriplegics, triple amputees, and veterans missing parts of their brains) from being placed in the highest tier for their caregiver stipends. These denials were not because these veterans did not qualify for that level of caregiving; it was because CEAT staff often read the question backwards. QoLF addressed this issue in our March 2022 SVAC testimony and addressed it with CSP leadership afterward. VACO CSP set up a Quality Management (QM) review team who did a random sampling of cases for the "unable to self-sustain in the community" question. Upon that first review, and with multiple errors documented, the field staff was retrained. Once the retrained field staff had time to make more decisions, another review was conducted. Despite many retrainings and examples being added to the form where the answer has to be given on this question, there still seem to be many errors regarding the interpretation of that specific question. This is not a legislative issue, it is a regulatory issue.

**QoLF believes that the VA regulation and assessments should reframe the question to: Is the veteran able to function in the community without a caregiver?**

**5.** *Review of past twelve months of records' review*: In our March 2022 SVAC testimony, we addressed that a review of twelve months' worth of records may not accurately capture the veteran's needs, especially during and immediately after the COVID restrictions often kept patients from being seen in clinic. Additionally, if veterans and their practitioners have long-standing relationships, doctors may not take the time to restate a veteran's needs in every record.

Conversely, due to the high turnover of VA physicians, a veteran and his primary care physician may have only met together once before an evaluation for PCAFC was completed by the physician.

Most VA physicians and practitioners do not have sufficient time with patients during a visit to make required documentation (screenings, etc.). Due to their limited time, and these requirements, many practitioners simply copy and paste many of the same notes visit to visit so that they can pay attention to the patient. Thus, notes may not capture the complete condition of the veteran due to the large amount of information that must be collected in the very short amount of time that the VA allots physicians to meet with patients. ADL needs are neither required nor routinely documented during a visit with a primary care doctor, nor are the needs of supervision, protection, and instruction.

**This issue is NOT resolved, but this issue involves much more than the CSP.** It is dependent upon the amount of general information that physicians are required to collect, the short period of time that VA physicians have to talk with their patients and record notes in the record (in some clinics this is 20 minutes— 10 mins with the patient, 10 minutes for documentation), the shortage and turnover of physicians, and COVID which limited in person interaction between the veteran, caregiver, and physician. Recall that many VA clinics refused to allow caregivers in with veterans during COVID so physicians may or may not have known if a caregiver was even involved. We will further address this issue in our recommendations at the end of our testimony.

6. *"Gathering of outside records and specialists' input"*: While the PCAFC assessment asks if the veteran sees outside physicians, and the assessment notes the answer, there is difficulty in getting the veteran's outside records into the VA PCAFC process. Two reasons account for the difficulty: VHA's understanding of their "duty to assist" and each facility's policy for how records are placed in the system at each VA. Caregiver Support Program (CSP) leadership has done a significant amount of training with the CSP staff on assisting veterans and caregivers with gathering outside records and giving the records time to arrive at the VA, while also keeping an eye on the timeline for the PCAFC assessment process. This "duty to assist" in the process is a new process within VHA CSP. While this principle should have been understood because it exists within Veterans Benefits Administration (VBA), it was not at many Veterans Health Administration facilities, so "duty to assist" was formalized by training. **QoLF believes the training in "duty to assist" in gathering outside records for local CSP staffs will help to resolve this issue, but the language could be legislated to insure that VHA honors its "duty to assist" veterans, as VBA is already required to do.**

The second issue with a veteran's outside records is the placement of the records in a veteran's medical records. This is true for services provided through Community Care or through other insurance, TRICARE, or MEDICARE. The records must be received and uploaded into the VA medical records system in order to be considered as part of the PCAFC application. However, EACH Veterans Affairs Medical Center (VAMC) Information Technology (IT) Office determines who has the ability to upload these records—leading to variations in procedures and the time needed to complete the process. Some facilities allow the CSP office to directly upload the records into the system, while others require the Primary Care Manager (PCM) to first go through the records to determine what needs to be scanned in and then send it to VA Records at the facility for scanning. Other facilities require that outside records be taken directly to a VA

Records office. Further, none of these circumstances allow the veteran or caregiver to see the uploaded records, as they do not have access to the system where the records are placed. Some CSP teams do notate in MyHealtheVet (MHV) that records are in another system, but others do not.

**QoLF believes that VA CSP and VA IT need to coordinate and create a directive standardizing this process to minimize the variations in outcome and promote the timely inclusion of outside medical records in the decision making process. This is outside the sole scope of VACO CSP. Some medical records and community care records coordination and standardization improvements are listed in H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act.**

Additionally, a veteran's specialists such as mental health practitioners, neurologists, neuropsychologists, and orthopedists, do not routinely have the ability to directly offer their opinions on the functional capacity of a veteran during the PCAFC process. Only PCMs are consulted. As with the Primary Care concerns mentioned above, specialists have little time to document a veteran's needs. As such, much information about very specific treatment or assistance needs may not be found in the record. PCMs are asked to answer questions about treatment plans and institutionalization, but we know that they rarely answer these questions in the CSP-PCM PCAFC Collaboration document. The PCMs do not have time to review all specialists' treatment plans and, therefore, may answer in a way that disagrees with a specialist who treats a specific, debilitating condition. Local CSP staff normally answer the document assigned to the PCM's.

**QoLF has recommendations for this issue later in our testimony.**

7. *Lack of evidence provided by CEAT for admission/discharge*: VHA has conducted clinical appeals for many years for various programs and services. As a clinical support program, VHA rules apply to CSP. Previously, VHA required very little documentation as to why a specific treatment or program was approved or denied and this model continued with PCAFC. Thus, PCAFC decision-makers at the VAMC, Veterans Integrated Service Network (VISN), and CEAT levels did not have to do more than post the answers to the eligibility questions and whether or not they admitted or discharged the veteran. The VHA Clinical Appeals Directive 1041 governing appeals within the program did not require that the CEAT provide what evidence was considered or how the CEAT came to their decision with the specificity that is required in VBA decisions. The CEAT was also not required to share what information was lacking for admission, discharge, or to achieve a higher level of care.

Under the *Beaudette* decision, VHA was forced to change this process with the notification of each level of VHA decision-making and VHA clinical appeals for the PCAFC. The courts also granted a right to appeal this decision to the Board of Veterans Appeals.

This was a LARGE ask of the PCAFC program as it was different than any other VHA program and these processes did not exist previously within VHA. Since the *Beaudette* decision, the PCAFC program had to create a more robust VHA clinical appeals process, get feedback on that process from VSOs and other stakeholder groups, and get training on the existing 8 point letters used by VBA. PCAFC then had to develop a model, have it approved by Office of General

Counsel, develop the IT template, develop training on how to implement and complete the letter, field test it, adjust it, and then train and implement this enterprise wide at each VISN.

PCAFC/VACO CSP have implemented a form that replicates all of the information in a VBA 8 point letter documenting the CEAT decision-making process. That form is required to be uploaded to the veteran's medical record so that it is visible within the record. Those forms are operational, and QoLF has seen them in the record. These forms provide the needed information to assure veterans, caregivers, providers, and VSOs that the decision-making process is impartial and to clarify what evidence was considered during the decision process. If important evidence was viewed but not considered, or if information was missing, veterans and caregivers now know exactly what needs to be considered or included for any of the three types of VHA clinical appeals that are now offered. **QoLF believes development of a CEAT decision-making form and 8 point letter has solved the issue of being able to determine how a decision was made by CEAT, what information was considered, and if that decision complied with PCAFC guidelines.**

**Where we need to be:**

While many PCAFC issues existing prior to the March 2022 SVAC hearing have been resolved or are in the process of resolution, some issues still remain, and, with closer scrutiny, new issues have emerged. These issues include:

***1.*** Lack of Congressional intent behind the expansion of PCAFC to older generations;

***2.*** PCAFC participant re-employment and retirement needs;

***3.*** Aging caregivers and Caregiver-GEC interaction or non-interaction;

***4.*** The recommendation by some to move the program to the VBA;

***5.*** Interaction of IT policy and CSP at local facilities regarding outside medical records' entry; and

***6.*** PCM and Specialty Care Provider input in the assessment and evaluation process.

As these issues have arisen, the issues have been discussed with the VACO CSP and during the VA CSP Summits with VSOs and stakeholders. The issues will require further efforts to resolve, either within VACO CSP/PCAFC or through regulation or legislation.

*Lack of Understanding of Congressional Intent Regarding Expansion of PCAFC*: While QoLF agrees that every seriously injured, service-connected veteran should be eligible to apply for a caregiver, QoLF does recognize that the PCAFC was originally created to recognize young, working-aged caregivers leaving the workplace and not earning a wage or having the benefit of health insurance. In expanding this program to earlier generations, Congress did not clearly change this intention.

While the program was never created to be a dollar-for-dollar replacement for wages a caregiver had earned or could earn in the workplace, it was considered a recognition of the caregiver being

unable to work due to the needs of the veteran. With the expansion of PCAFC, older veterans with service-connected ratings who had non-service connected serious conditions creating a need for assistance, were rightfully included in the program. And in all fairness, this was a necessity as proving whether or not a WWII veteran's dementia or diminishing ability to complete ADL's was related to a seventy year old injury would be virtually impossible and not the type of clinical decision VHA makes. However, if the caregiver was older, retired, and Medicare eligible, then the original intent of PCAFC did not apply. If the MISSION Act changed the intent of the program to compensate a caregiver for a service that would otherwise be provided by the VA, then the intent is changed, but there is no clear record of this change of intent for expansion. This means that the VA has had to guess at the intention of the MISSION Act expansion, making it difficult to figure out how to merge an existing program intended for a younger generation with generations of older veterans for whom the original intent does not apply.

Additionally, older cohorts of veterans may have older caregivers. The expansion without an official change of understood intent creates the dilemma of whether or not the caregiver is able to care for the veteran to the extent that is necessary to safely keep the veteran at home. If a veteran is deemed eligible and in need of a caregiver, the proposed caregiver may be trying to do the job of caregiver, but PCAFC may find that for the best health outcomes, the assistance the veteran needs should be completed by someone other than the person who is now filling that role. Then the question is: Who fills that role?

**QoLF believes Congress needs to define the intent of the expansion of PCAFC to clarify that the mission of the program is to "recognize the sacrifice of caregivers for providing services that would otherwise be required to be provided by the VA." Additionally, a clarification would assist in the standardization of the program between generations and VISNs across the country.**

*Retirement needs of PCAFC Caregivers:* When Congress created PCAFC, as discussed the intent was to serve a younger veteran population, the vast majority of caregivers were spouses or siblings of young veterans or middle-aged parents of young, injured veterans. Many of those caregivers, referred to as Legacy caregivers, had short work histories due to their age at the time of becoming caregivers. Their injured veteran also had little time in the work world.

While PCAFC was never meant to be a dollar-for-dollar replacement for wages lost, designating the stipend as unearned income has created a growing concern as these caregivers age and have no way to contribute to either Social Security or a retirement fund. Some caregivers will exit PCAFC when their veterans pass away, years before they are eligible to draw from retirement plans, but they will have expired employment certifications or will need to prove their worth in a new workplace after having been out of their professional fields while they were caregiving. In addition, due to the nature of the veteran injuries, these survivors will not receive any significant life insurance making the survivor financial outlook bleak.

Department of Defense programs exist for military spouses as they move duty station to duty station so that they can re-certify their employment certificates or receive new training. The Department of Labor has a model for returnship programs for older workers who return to the workplace after an absence. VA should develop models to help caregivers return to the workplace and save for retirement so that caregivers do not pass from PCAFC into poverty with

the passage of their veterans. Also, in light of this, employment that does not interfere with the duties of caregiving should not be held against a caregiver's suitability.

**QoLF believes that Congress should assist caregivers to renew their employment certifications that lapsed due to caregiving responsibilities and to re-enter the workplace through returnship programs. Congress should study creating a mechanism for which PCAFC caregivers earning the stipend would be allowed to contribute to retirement accounts to secure their financial futures into retirement as is outlined in S. 3885 the Veteran Caregiver Re-education, Re-employment, and Retirement Act of 2024.**

*Aging caregivers and PCAFC-GEC interaction*: When PCAFC finds a veteran in need of assistance, but the caregiver is not able to safely provide the care the veteran needs, an alternate caregiver needs to be found. In addition, some veterans have such significant needs that they need a combination of support services to stay safely in their homes. Sometimes, another family member is available, but Geriatrics and Extended Care (GEC) programs through the VA, including Homemaker/Home Health Aide (HHA) and Veteran Directed Care (VDC), are also an option to fill those caregiving needs. However, a number of problems exist with the assumption that other GEC programs will automatically replace a caregiver:

1. Until recently, PCAFC did not track referrals to GEC from PCAFC, allowing for loss of PCAFC to create a vacuum in the assistance for the veteran because GEC did not initiate an evaluation of the veteran for services.
   **QoLF does believe PCAFC has implemented a request that a veteran and caregiver will be connected to GEC for evaluation for GEC programs in the absence of a qualifying caregiver, but QoLF remains concerned that the GEC programs may not be able to fill the need in a timely manner. This is addressed in H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act.**

2. There is a GEC case mix tool that determines the number of hours that a veteran may receive care from both GEC and CSP programs. While GEC leadership says that the hours that are recommended for levels of care are suggested numbers of hours, many VA facilities and local GEC programs take these hours as hard limits. As a result, caregivers who live in the home and provide care 24 hours a day, seven days a week, are replaced by VA GEC programs that offer hard limits of either 32, or with an exception 56, hours a week. Please understand, that means a caregiver is still doing 112 hours of caregiving each week as those veterans with the most significant needs often require care at night as well. VA has simply taken away the stipend and provided some help, if GEC providers are available.

   **QoLF believes the case mix tool needs to be reviewed to acknowledge that some veterans require more care than is currently allotted. The program and the GEC case mix tool need to be flexible to accommodate the varying care needs of veterans and not be hard limits. QoLF believes Congress needs to further examine the interaction of GEC programs and services. This is addressed in H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act.**

3. GEC providers are unavailable. In many areas, agencies and providers who are contracted to provide care through HHA and Respite programs are unable to find workers to fill the required number of hours on the contract. Many times this is due to low compensation rates offered by the VA, and while the VA does have mechanisms to increase compensation to meet the market demand, it is extremely underutilized. In addition, due in part to low wages, providers often do not show up at their assigned time, and there is no way for caregivers and veterans to directly report this information to the VA. They can report it to the contracted agency, but the agency may or may not find a replacement aide, once again leaving caregivers and veterans without help. In a few cases of older caregivers, we do know that some used their PCAFC stipends to pay for private providers. When their PCAFC stipends were taken away, they could no longer private pay for aides and VA programs were unable to find agencies to fulfill contracts for HHAs and Respite, creating greater health issues for caregivers and veterans. In one of our recent cases, a caregiver was discharged from the program, specifically so she could be given more HHA hours. Of the 32 hours she was granted for HHA care through an agency, fewer than half of them were being filled by the agency due to staffing shortages. She was having to call EMS repeatedly to help her get the veteran up to bathe and change him, which is what the HHA contracted care was supposed to help her do.

   **QoLF recommends that a mechanism be created for local VAMCs to be trained in how to raise reimbursement rates quickly when rates drop below competitive area rates for Home Health workers. In addition, the VA needs to better track when providers are not showing up for shifts and develop options to address this problem to potentially include paying family caregivers who are providing care for a veteran when a contracted agent is supposed to be doing so. VA should also not be able to discharge a veteran or caregiver from PCAFC, except in cases of fraud or abuse, without GEC care being in place if the reason for dismissal is that the caregiver is deemed unable to fulfill the assistance needs of the veteran. This is addressed in H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act.**

4. The Veteran Directed Care Program (VDC) is an invaluable tool within the VA that allows veterans to create flexible budgets to provide for their own clinical support needs, including caregiving. While we have understood that some have suggested that the VDC program replace CSP, QoLF does not agree. Currently, many VAMC's do not offer VDC, and even those that do often do not have a dedicated staff member to administer the program. In addition, Medical Center Directors are hesitant to implement the program because they are paid by reimbursement and the VAMC must provide the funding up front. Furthermore, the problems with finding providers for VDC are often the same as HHA and Respite. Lastly, while sometimes preferred, VDC places a significant paperwork and accounting burden on the veteran or family member which can be especially difficult for older veterans and caregivers. In some cases, due to the case mix matrix mentioned above, that family member now performing these administrative duties may be a former caregiver who is no longer allowed to participate in the caregiver program, but still has to provide all the caregiving services except for the limited hours that are now provided by a VDC caregiver.

   **QoLF believes that the VDC program can be a good option for some caregivers, but**

**the CSP program provides a much more comprehensive host of services and is administratively less burdensome to the caregiver.**

*The recommendation to move PCAFC eligibility from VHA to VBA*: Some have recommended that VBA has a better evaluation process to decide if veterans qualify for programs based on disabilities than VHA. While QoLF acknowledges that VBA does make eligibility decisions for benefits, PCAFC is a **clinical** support program as defined by statute, an area in which VBA has no experience. The purposes are different and not comparable, and VBA has no viable way to determine eligibility for a clinical program. If PCAFC eligibility were shifted to VBA, why wouldn't the eligibility for Homemaker/Home Health Aide, Veteran Directed Care, or Home-Based Primary Care (HBPC), all clinical support programs, be made through VBA?

Additionally, some have argued that veteran service officers did not have access to PCAFC records. To resolve this, VSO's simply needed to ask veterans and caregivers to provide a copy of the veteran's medical records. All of the PCAFC documentation was in the medical record, and VHA has now created an online portal where VSOs have access to view documentation for VHA Supplemental Claims and VHA Higher Level Reviews. The Board of Veterans Appeals works in concert with PCAFC to obtain all documentation related to cases submitted to the Board. That documentation is and always has been available to the VSOs.

**QoLF feels this issue has been resolved by the developments in PCAFC after the *Beaudette* decision implementation. However, QoLF believes that the VA should explore the opportunity to establish a "pathway to advocacy" through VHA where organizations, traditional VSOs and other nonprofit organizations, can be trained on the services and programs available to veterans through VHA, be given points of contact for those program to connect veterans, and create a release of information that is recognized throughout the VA so qualified organizations can advocate on a veteran's behalf. "Pathway to Advocacy" is included in H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act.**

*Interaction between PCAFC and IT*: **As discussed earlier, QoLF believes VACO CSP and VA IT/ VA Medical Records need to create a unified policy for how a veteran's outside provider records (whether CCN or private pay) are uploaded to the VHA medical record and PCAFC application to be viewed. This important issue should not be left to a facility by facility decision.**

*PCM and specialists' input in the assessment and evaluation process:* Because VA PCMs and specialty care providers have little time to document needs for assistance in the medical records leaving an absence in the record of documentation of the veteran's need(s) for assistance, a uniform way to document these needs becomes necessary. While we understand that clinicians may not want to weigh in directly through a questionnaire in the assessment process, it is important that these practitioners are able to document the needs of the veteran in both ADLs and SPI.

**QoLF would offer some suggestions to see that PCMs' and specialty care providers' input is provided:**
**1) Congress should remove the language "to the maximum extent possible" when**

**describing the input of the physician in the MISSION Act;**
**2) VA creates a form that is filled out once a year where the PCM documents a discussion of a veteran's ADL's and makes a decision to refer to Occupational Therapy(OT) /Physical Medicine and Rehab for a Functional Independence Measurement and Functional Assessment Measurement score (FIM-FAMs) or full OT exam. Mental Health Providers and/or neurologists would be required to complete a SLUMS (or similar mental status) score yearly and decide if further evaluations or service referrals were needed; and**
**3) VHA should develop a training for all medical providers within VA to address why documenting current needs, even if takes time and is repetitive, is needed for the PCAFC evaluation, as well as other clinical support services that VHA provides.**

**QoLF does not believe that there is any ill intent, simply a lack of time, on the part of providers to document all the needs of a veteran carefully. Requiring a veteran's medical specialists, not just the PCM, to participate in PCAFC, is included in H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act.**

## Conclusion

QoLF appreciates the opportunity to offer feedback in the form of updates and recommendations on the state of PCAFC. We would like to again offer praise for Dr. Richardson and her VACO CSP team. Since Dr. Richardson's tenure in the VA CSP began in February 2021, she was tasked with continuing to implement a program that had a regulation, directive, and assessment developed prior to her arrival. When confronted with the challenges created by the processes established prior to her arrival to the program, Dr. Richardson and her team have acknowledged these issues and made a concerted effort to conduct quality management reviews; to rectify what they can within the program themselves through training and guidance to the locals, VISNs, or national program; to engage with stakeholders about changes that are needed and should be proposed; and she has taken action on all feedback she has been given. While we feel PCAFC has had many stops and starts, QoLF feels that the Program, which has not before existed in any medical setting in the United States, is today on a footing to work out the final problems and be the extremely successful program that veterans and caregivers need it to be and the program Congress intended it to be.

We urge the passage of H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act to codify important changes within PCAFC to codify important changes to PCAFC. Additionally we request the passage of S. 3885 the Veteran Caregiver Re-education, Re-employment, and Retirement Act of 2024 which would create pathways for caregivers to return to employment when they are finished with their caregiving duties and allow them to save for retirement while they are fulfilling their caregivers duties so they do not wind up destitute in their later years. Thank you for the opportunity to present our testimony to you today.