S. HRG. 117–583

HONORING OUR COMMITMENT: IMPROVING VA'S PROGRAM OF COMPREHENSIVE ASSISTANCE FOR FAMILY CAREGIVERS

HEARING

BEFORE THE

COMMITTEE ON VETERANS' AFFAIRS
UNITED STATES SENATE

ONE HUNDRED SEVENTEENTH CONGRESS

SECOND SESSION

MARCH 23, 2022

Printed for the use of the Committee on Veterans' Affairs

Available via the World Wide Web: http://www.govinfo.gov

U.S. GOVERNMENT PUBLISHING OFFICE
50–935 PDF WASHINGTON : 2023

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HONORING OUR COMMITMENT: IMPROVING VA'S PROGRAM OF COMPREHENSIVE ASSISTANCE FOR FAMILY CAREGIVERS

WEDNESDAY, MARCH 23, 2022

U.S. SENATE,
COMMITTEE ON VETERANS' AFFAIRS,
Washington, DC.

The Committee met, pursuant to notice, at 3:01 p.m., via Webex and in Room SR–418, Russell Senate Office Building, Hon. Jon Tester, Chairman of the Committee, presiding.

Present: Senators Tester, Murray, Brown, Sinema, Hassan, Moran, and Boozman.

OPENING STATEMENT OF CHAIRMAN TESTER

Chairman TESTER. I am going to call this hearing to order.

Senator Moran will be here shortly and hopefully before I get done with my opening statement, but I want to wish everybody a good afternoon, and I want to thank you all for being here today to discuss VA's Program of Comprehensive Assistance for Family Caregivers.

Congress required VA to establish support for caregivers after seeing the need for at-home assistance for Iraq and Afghanistan veterans coming home with serious injuries. The success on life-changing assistance it provided led Congress to remove the disparity between pre- and post-9/11 caregivers by expanding the program to veterans of all eras in the VA MISSION Act.

However, under the Trump administration, VA implemented new regulations narrowing eligibility much more than Congress ever intended to do. VA narrowed eligibility to veterans with a 70 percent or higher service-connected disability rating and those with an inability to perform an activity of daily living without assistance each and every time the activity occurs. That resulted in a mere 14 percent acceptance rate into the program and thousands of legacy post-9/11 participants no longer qualified for the benefits that they need, that they have earned, and that they deserve. The veterans in my State and every State represented on this Committee received letters kicking them out of the program.

I expressed this concern to the Trump administration, and more recently to Secretary McDonough, that too many veterans and caregivers would be left without the critical assistance they needed because of VA's overly restrictive regulations, and I pressed them to reconsider. Many of these folks up here joined me in that effort.

Today, I am pleased that the Biden administration and Secretary McDonough have listened to the concerns raised by the people on this Committee and to the veterans and caregivers across our great country. Just yesterday, VA announced that it will be taking steps to change the restrictive Trump regulations that have been harmful to so many veterans and their caregivers. VA will immediately halt the discharge of legacy participants from the program, meaning that no caregivers who are already in the program will be removed in October. VA will also reevaluate the program's eligibility requirements to ensure they meet the intent of Congress.

I appreciate Secretary McDonough and Deputy Secretary Remy making this information public before the hearing so members of this Committee could have the latest of information.

We understand the VA witnesses here today will not be able to speak with great detail about some of these proposals, but I appreciate them being here to discuss the issue with this Committee. And we will hear from our second panel about their concerns with the program and how it is critically to veterans and caregivers nationwide.

I want to say a few things about our friend, Garry Augustine. I want to take a moment to recognize his life, a decorated veteran, a fierce advocate, and former Executive Director of the DAV, who passed away last week. As a member of this Committee for the last 15 years, I have had the honor of working closely with Garry on a host of issues critical to veterans and their families. One issue particularly close to his heart was the caregivers program that we are going to be talking about today, and he helped lead the fight to expand the program to veterans of all generations, including his fellow Vietnam veterans.

As we work to improve this program, we also should do this with Garry in mind and do our best to honor his lifetime of service as a soldier, as a veteran, and as a leader in the veterans advocacy community. His work for veterans and their families will certainly be felt for years to come, and he is somebody that I can tell you on a personal note I have missed since his retirement and continue to miss him.

We will give Senator Moran a minute or two, and then if he does not show we will go to the panel one.

[Pause.]

Chairman TESTER. I will now turn it over to Senator Moran for his opening statement.

OPENING STATEMENT OF SENATOR MORAN

Senator MORAN. Chairman, thank you for your delay. When my former colleague, Senator Roberts, announced his retirement from the Senate, people started congratulating me on being a senior Senator, and I did not know what it meant.

Chairman TESTER. It means you are a lot older.

Senator MORAN. That is not what I thought it meant. It meant I talk a lot more.

Chairman TESTER. Okay.

Senator MORAN. And I got caught.

Mr. Chairman, thank you, and I thank our witnesses for joining us today. This is a really important topic, and I am glad we are having this hearing.

The VA is expected to see a significant increase of veterans with long-term care needs within the near future. To prepare for this increasing trend, the Department has routinely told Congress and veterans that it is shifting the focus of its long-term care from institutional care settings to home- and community-based settings. And I applaud the Department's efforts to empower veterans by supporting their desires to stay at home and to remain in their communities as long as possible, surrounded by family and loved ones.

To that end, family caregivers play an integral role in making certain our veterans can remain at home and are central to the success of VA's efforts to shift care to home- and community-based settings. It is important to make certain that these frontline heroes are adequately supported in their work caring for our Nation's veterans.

This week, I was pleased to introduce, with Senator Hassan and Senator Tester of this Committee, the Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act to expand home-and community-based services for aging and home-bound veterans. The Elizabeth Dole Act will empower veterans and caregivers by increasing the spending cap for alternative care programs and expanding access to alternative care programs to veterans living in U.S. Territories and Native veterans enrolled in IHS or Tribal Health programs.

As we work toward enabling veterans to delay the need for institutional care through legislation like the Elizabeth Dole Act, it is important that we do not lose sight of making certain related laws we previously enacted are implemented properly. In recognition of the vital work that caregivers perform, Congress expanded the Program of Comprehensive Assistance for Family Caregivers in the VA MISSION Act to make certain that family caregivers of veterans from any era receive the support and resources necessary to keep the veteran at home.

The VA, however, is failing at implementing this expansion. From the two-year initial delay in implementing phase one to the inexcusably high denial rates, we continue to hear from advocates and caregivers alike about the real fear of being unfairly denied or discharged from the program because of how the VA runs it.

Today's hearing is both timely and necessary as we work to make certain the laws we pass are implemented in ways that work as Congress intended. We have a duty to see to it that the VA is faithfully executing these laws and investing resources as intended into family caregivers.

Thank you again, and I look forward to today's testimony.

Chairman TESTER. Thank you, Senator Moran.

Now we will start with the panelists on panel one. I would like to welcome Dr. Beth Taylor, who is the VA's Assistant Under Secretary for Health for Patient Care Services and the Chief Nursing Office, to our first panel.

You have got a big job, Dr. Taylor.

She is accompanied and supported by Dr. Colleen Richardson, Executive Director of the Caregiver Support Program.

You, too, have a big job.

I want to thank you both for being here, and Dr. Taylor, you may begin. We are going to give you five minutes. Hopefully, you can keep it to that, but please know that your entire written statement will be a part of the record.

PANEL I

STATEMENT OF BETH TAYLOR ACCOMPANIED BY COLLEEN RICHARDSON

Dr. TAYLOR. Thank you. Good afternoon, Chairman Tester, Ranking Member Moran, and members of the Committee. I appreciate your interest in the VA Caregiver Support Program and the opportunity to answer your questions today. I am accompanied by Dr. Colleen Richardson, Executive Director of our Caregiver Support Program.

The contributions of caregiving has an important impact in the lives of family members and an increasingly valuable role in our health care system today. Through our combined 37 years of VA clinical experience, Dr. Richardson and I have witnessed and recognized the impact of caregiving on the health and well-being of our veterans. The role of caregiving is not only time and energy intensive; it has an impact on one's physical, psychological, and financial health.

The VA Caregiver Support Program's mission is to provide resources, training, tools, and support services to the caregivers of our Nation's veterans. The VA Caregiver Support Program is breaking new ground and setting the standard on caregiving and the health care industry. By being a trailblazer, the program is in a dynamic state of evolution, and to evolve we must require a consistent feedback and partnership with all of you, our partners who are with us today, our veterans, our caregivers, and our many stakeholders that make our work possible. We are proud to be leading the country in providing a program which offers unmatched benefits, services, and support to caregivers of veterans to enable them to achieve their optimal level of independence and well-being.

In 2010, the VA established the Caregiver Support Program to administer the Program of Comprehensive Assistance for Family Caregivers, PCAFC, and the Program of General Caregiver Support Services, PGCSS, two programs which support caregivers of veterans in need of personal care services.

Initially, PCAFC was targeted toward caregivers of eligible veterans who incurred or aggravated a serious injury in the line of duty on or after September 11th, 2001.

Through the MISSION Act of 2018, VA was authorized to expand eligibility to veterans who incurred or aggravated a serious injury or illness in the line of duty for all eras in a phased approach: phase one, which occurred October 1st of 2020, and phase two, which will go live this October 1st. The adoption of the new MISSION Act regulations was to address issues in the lack of standardization, consistency, and equitability identified in PCAFC while expanding the program and making it more inclusive for veterans and caregivers of all service eras.

We have doubled the size of the program in the 16 months since expansion, quite an accomplishment, and credit is due to our CSP staff throughout the enterprise. Their work is particularly notable during the COVID era, where many clinicians also stepped forward to help with first and fourth mission assignments to ensure we could meet the care demands of our system and of our Nation and where the challenges of the new normal work environment required them to accomplish the expansion in new and untested ways. We recognize the hard work of our staff, yet we acknowledge there is so much more to be done.

To be clear, we were not able to fully anticipate the challenges COVID would present nor the impact the regulation would have on different eras of veterans. Through the evaluation of feedback from internal quality assessments, veterans, caregivers, and VSOs, along with other partners, we recognized the need to take a step back and assess. We have heard and understand the issues that have been raised about the rate of acceptance in PCAFC as well as the concerns regarding our legacy participants and the eligibility criteria. The Caregiver Support Program has taken efforts to closely examine program data, and as we gain increasing granularity with our data systems, we can better identify and define trends that help us and others understand the true performance of the program.

Now more than ever, veterans and caregivers have options available to appeal a PCAFC decision with which they disagree. A ruling by the U.S. Court of Appeals for Veterans Claims made available PCAFC decisions to be appealed to the Board of Veterans' Appeals. The Caregiver Support Program is actively implementing the necessary infrastructure and processes to offer the full spectrum of options available under the Appeals Modernization Act, which includes supplemental claims, higher level reviews, and appeals to the board.

As a VA nurse, a daughter, granddaughter and great granddaughter of veterans, and in partnership with Dr. Richardson, a psychologist, a combat veteran, and a former member of the Navy Medical Service Corps, you have our commitment to guide the Caregiver Support Program to be the preeminent program in the industry on caregiving. We welcome and invite you, this Committee, our partners, and our stakeholders to help us in achieving this mission.

I thank you for the opportunity to discuss the accomplishments and opportunities of our program, and we stand ready to respond to your questions.

[The prepared statement of Dr. Taylor appears on page 37 of the Appendix.]

Chairman TESTER. To the second. Good job. I will tell you that I do not know who is going to show up to this hearing. This is a very, very busy time right now. Do not make an assessment because Senator Moran and I are the only ones at this Committee that this is not an important issue. This is a very important issue.

And like I say, they may all show up; none may show up. Nonetheless, this is really important.

And by the way, I will just ask a question. Whoever wants to answer them can answer them. But the truth is I do look forward to working with you to develop new regulations to administer this program in a much more fair and much more efficient way.

I understand VA will be changing the current regulations for the caregivers program through its rulemaking process. So the question is: What is the process and timeline to get the proposed regulations so that we can get these restrictive criteria off the books?

Dr. TAYLOR. Thank you, Chairman, for that question. I think, most importantly, the process is going to involve our stakeholders; it is going to involve partnership with members of this Committee; it is going to involve our veterans and our caregivers. We need to look at the process holistically, and we need to anticipate what the impact of any changes in eligibility might be, especially as we have learned in the phase one rollout that different eras of veterans have different needs. So we must not only think about the veterans that we are serving now, but we must anticipate our phase two expansion and anticipate what needs that that cohort of veterans may have that we have not seen yet to date.

So in terms of the timeline, sir, we do not have that established, but I can tell you that tomorrow at 8:00 Dr. Richardson and myself have a meeting with the Acting Under Secretary and we will be initiating our efforts relative to the announcements that the Deputy Secretary had in the press conference yesterday.

Chairman TESTER. Okay. Very, very good. I think that it is going to be critically important that as you go through that process and announce that timeline that you set up that, as you said, in the process, the VSOs need to know where you are so that they know what to do within that timeline.

The number of post-9/11 veterans who were poised to be dropped from this program in October, not to mention all the veterans denied entry into the program in the first place, is concerning to all of us. For those notified that they would be removed from the program in October, is there anything that they need to do now?

Dr. TAYLOR. No, sir. There will be additional communications coming out to the veterans and caregivers, notifying them of the announcement yesterday and the impact that that will have. I am sure that our veterans and caregivers have many questions related to the announcement yesterday, and those details will be coming out imminently.

Chairman TESTER. For those that were denied access to the program under the current regulations, will they need to apply again?

Dr. TAYLOR. Dr. Richardson, can you take that one, please?

Dr. RICHARDSON. Sure. Good afternoon, Mr. Tester. So to answer that question, sir, I think there is still more to come on that. We have not figured out exactly the path that we want to go given yesterday's announcement, but rest assured that between Dr. Taylor and myself we will make sure that it is equitable and fair to all veterans as we move forward in this process. So, more to come, sir.

Chairman TESTER. I appreciate that. Look, I think that making it as user friendly as possible for the veterans is really important, especially as to what has happened now. So communication is going to be very, very important directly with the veterans, with the VSOs, so they can help you with communication is really important.

Now look, I have heard from caregivers around the country that the consistent reassessments of veterans and their caregivers take a mental and physical toll. And by the way, I would agree with that as you take a look at the challenges these folks have. Will these assessments continue even as the VA works to improve this program?

Dr. TAYLOR. Yes, sir, our current plan is for those assessments to continue and really for a couple reasons. One, we want to have a complete data set on the needs of our veterans in the different cohorts, and so we feel it is important to continue those assessments. However, we also feel it is important to be clear about the actions that we will not be taking as a result of those assessments as we have in the past.

And I want to—I think we want to ensure that we are very clear about our communications with those caregivers and families. We know historically that we have not done the best job in communicating. I think Dr. Richardson would agree. And we want to be very clear about our communications and what the purpose of the reassessments are and how we might use that information to better the program going forward.

Chairman TESTER. Yes. Look, in the end you guys have to make this program. And I do not work in the Agency, but it seems to me if the VA is reevaluating criteria right now I would just say make sure the evaluations you are doing are going to actually do you some good in the end with the criteria changing.

And then the other question is: How does the program support mental health needs of caregivers, or does it?

Dr. TAYLOR. Yes, an excellent, excellent question, sir, and one that we are particularly concerned about as recognizing that there is, as you just said, stressors associated with the assessments, the potential denials of the program, and so we are very cognizant of that. We want to make sure that our caregivers and our veterans have the support services that they need, and we partner very closely with the Office of Mental Health Services to ensure that we have wraparound support for our veterans who may need mental health support.

Chairman TESTER. Thank you.

Senator Moran.

Senator MORAN. Chairman, thank you. Again, thank you both for being here. It is a little bit more of a difficult hearing, maybe for you and us, with the announcement from yesterday.

Dr. TAYLOR. Yes, sir.

Senator MORAN. I mean, I think the correct answer will often be we do not yet know. But what do you expect, or what do you think, the changes in regulations will accomplish? And maybe your answer is that that is going to be determined by all those consultations that we think you should make. But what is the problem that is being solved, that is being attempted to be solved?

Dr. TAYLOR. Yes, excellent question, Senator. Thank you. I think what we do know by the experience with the phase one expansion is, as I said a few minutes ago, that different eras of veterans have different needs. We have also found that some veterans, while they need support services, may need them intermittently and not as narrowly as was originally described in the regulation.

So for example, there may be a veteran that is receiving radiology or oncologic chemotherapy procedures and may have periods of time where they need a caregiver over a long period while they are in that, whenever they are receiving that treatment. Or, there may be a veteran who has had a very significant surgery and for a period of time they may need caregiver support but it is not indefinite. It is not for their lifetime. So I think those are two examples that give us an opportunity to reflect on what we have written in our regulations and what clarifications, or what minor shifts, we might be able to make to capture men and women like I just described and others who may have intermittent or periodic needs.

Senator MORAN. I was not sure when you answered Senator Tester's question about timeframe. So is the Department proposing new regulations that will be written and then submitting them for comments or commentary by the groups that you described?

Dr. TAYLOR. Yes, sir.

Senator MORAN. As compared to getting the input first and then drafting the regulations. The regulations will be something we can see soon?

Dr. TAYLOR. We are certainly hoping that. I think we are planning a summit in the month of April, so coming up obviously very soon. And we really want to get input. You know, our thought is we will help—we will need that help in co-creating the way forward and ensuring that we have it right because we recognize that as the Chairman suggested, that the original intent—the first regulation we missed the mark on that, and so we want to get it right. But we also recognize that we can only do that through partnerships with our VSOs, our stakeholders.

Senator MORAN. So regulations drafted and then submitted for commentary.

Dr. TAYLOR. Yes, sir.

Senator MORAN. At what point in time did you realize the mark had been missed?

Dr. TAYLOR. I think as we gathered data, especially with the expansion of caregiver support. You know, with the phase one expansion. I think as we got additional information about what the era, that particular era, of veterans needed and also thinking that the experience with legacy and applying the new criteria against men and women who had been in this program for many years, that is how we came to the conclusion internally that we have missed the mark.

Senator MORAN. Dr. Richardson, the centralized teams, team reviews and the final eligibility determination for all legacy participant reassessments, I want to spend a minute on that. These teams make the determination based on an assessment done by the local VA medical center and through telehealth visits. Have I got that right?

Dr. RICHARDSON. Yes, sir, that is accurate.

Senator MORAN. That is my premise. And my question is: Does the VA think that this centralized process ensures consistent, appropriate application of the eligibility criteria, including mental health determinations?

Dr. RICHARDSON. Sir, that is an excellent question. I think we had the opportunity to remove decision-making from the medical facilities. There is over 140 medical facilities. So that is 140, at least 140, different decisions.

So we have these specialized, Centralized Eligibility and Appeals Teams which are specifically trained to look at the assessments that the medical facility staff have completed and objectively, as a team, look at the holistic picture of the veteran and render a decision based on those assessments. We feel like having it removed from the medical facilities offers a more objective perspective on the chart.

As far as consistency goes, we are seeing consistency amongst decision-making within the CEA Teams. However, I think, as Dr. Taylor has alluded to, we are seeing some gaps with the ability to expand regulations further to capture more veterans as we move forward. But as far as consistency in decision-making, we are seeing that across the teams.

Senator MORAN. So the result to date would be different, broadly different, from one hospital to another?

Dr. RICHARDSON. They should not be, sir.

Senator MORAN. But they are?

Dr. RICHARDSON. So we have done consistency and standardization exercises, and we are only seeing that there are about three facilities or three visits——

Senator MORAN. Three outliers.

Dr. RICHARDSON. Three outliers, yes, sir.

Senator MORAN. Any of them in Kansas?

Dr. RICHARDSON. No, sir.

Senator MORAN. Of course, an outlier could be, in my mind, a good thing or a bad thing. I do not know which way that cuts.

Dr. RICHARDSON. That is right.

Senator MORAN. How is information from the VA provider or other providers taken into account during the reassessment process? And most importantly, well equally important, is in mental health providers in particular, was—their commentary, their notes, their description of their patient, how was it considered?

Dr. RICHARDSON. Great question, sir. So it is taken into consideration. I do think that is another opportunity for training and education and another opportunity to partner with our primary care physicians. We have heard concerns about that as well, that those things are not being taken into consideration. So I think that is another opportunity to expand upon and do better on.

Senator MORAN. Let me conclude with kind of a series of questions. What percentage of the decisions were overturned through the appeals process?

Dr. RICHARDSON. Great question, sir. It is 13 percent.

Senator MORAN. And what is at least an estimate of how long the process takes through the VHA clinical appeals process, through the Board of Veterans' Appeals for supplemental claims and higher level reviews? What is the extent of all that?

Dr. RICHARDSON. Sure. So the median days for decision with VHA, the VHA clinical appeals process, is around 17 days for a decision. It is yet to be determined what that will be with the Board as we continue to work through those processes?

Senator MORAN. What resources has the VA dedicated to processing the appeals that have been generated by the legacy participant reassessment process and the program expansion?

Dr. RICHARDSON. Sure. So we have dedicated resources already getting ready to hire for phase two expansion. We are getting ready to hire an additional 362 staff. We had 80 percent of that hired to date. So we have roughly about 2,200 staff within the Caregiver Support Program across the country; 80 percent of that is currently hired.

In regards to the appeals to the Board of Veterans' Appeals, we have staff detailed into the program office with an org chart of an additional 70-plus staff getting ready to come on board as well.

Senator MORAN. Quite a team.

Dr. RICHARDSON. Yes, sir.

Senator MORAN. While Senator Tester sneezes, I will ask one more question. What VA resources have been dedicated to making certain that they are appropriately adjudicated? So in addition to personnel, any other thing that I should know about what the VA is doing to make certain they get it right?

Dr. RICHARDSON. That is a great question, sir. So we are working closely with the VBA and BVA as we move forward. VBA has the expertise in this area. So we are leveraging some of their automated processing, and they are teaching and educating us along the way. It has been a process, and we are thankful for their partnership as we move forward.

Senator MORAN. Thank you both.

Chairman TESTER. Yes, thank you very much, Senator Moran.

And I want to thank you also both for your testimony today and the answers to the questions, very concise, and I appreciate that very much. We will release you. You are welcome to stay and hear the second panel if you would like, and we will go to our second panel.

And I will introduce the second panel as we are getting set up. We have multiple veterans service and advocacy organizations who represent and assist veterans and caregivers across our country. Our second panel will include Steve Schwab, who is Chief Executive Officer of the Elizabeth Dole Foundation; Caira Benson, a caregiver for a husband who is a post-9/11 Army veteran. We have Jim Marszalek, the National Service Director for the Disabled American Veterans; Andrea Sawyer, Advocacy Navigator for the Quality of Life Foundation. And even though this is not a virtual hearing for the members, it is virtual hearing for one of our folks that are testifying. This is Sarah Verardo, Chief Executive Officer of the Independence Fund, and as I said, she will be joining us virtually.

Steve, Mr. Schwab, we will start with your opening statement.

PANEL II

STATEMENT OF STEVE SCHWAB

Mr. SCHWAB. Thank you so much, Mr. Chairman. Chairman Tester, Ranking Member Moran, and members of the Committee, the Elizabeth Dole Foundation is pleased to testify today on the VA's Program of Comprehensive Assistance for Family Caregivers. We are also deeply appreciative to you, Senator Moran, Chairman Tester, and others who have offered bipartisan support to the Elizabeth Dole Foundation Act.

As you might suspect, I had a very different testimony planned until yesterday's announcement from the VA, but I am very pleased to be with the Committee today to ensure that we do right by our veterans and their caregivers. The Dole Foundation applauds Secretary McDonough and Deputy Secretary Remy and the program staff for announcing a reversal of all legacy caregiver dismissals and for planning to reevaluate the program. This was a vitally important decision, and we thank VA leadership for listening to our community and taking this very necessary step.

As a result, we now need to shift our focus to building a new, inclusive, and realistic eligibility formula and regulations and a customer serviced-focused evaluation process. Yesterday's decision proves that the voices of our MSOs and VSOs and our caregivers and veterans are vital in shaping the destiny of VA's support for our community, but there is still more that needs to be done.

While we are looking forward to engaging in a process to formulate new regulations, there is one aspect I want to ensure is discussed today, and I believe you both referenced this, the outsized emphasis on the activities of daily living, which stacks the deck against those caring for veterans with TBI or PTSD. Many of these veterans require 24-hour care due to violent flashbacks, mood swings, confusion, and the inability to use their phone or even to prepare a meal. However, because they are capable of performing ADLs, they were less likely to be eligible for PCAFC under the previous regulations. We must ensure this inequity, among others, is addressed in the new regulations.

Recognizing that my time is limited, I am honored to turn it over to one of our caregiver fellows, Caira Benson, whose story illustrates why yesterday's announcement was so important and the path forward to getting this right is so vital.

Thank you, Mr. Chairman.

[The prepared statement of Mr. Schwab appears on page 41 of the Appendix.]

Chairman TESTER. Caira.

STATEMENT OF CAIRA BENSON

Ms. BENSON. Thank you, Steve.

Chairman Tester, Ranking Member Moran, and members of the Committee, thank you for inviting me to share my story.

I am a full-time caregiver to my husband, Eric, an Army combat veteran who lives with traumatic brain injury, chronic pain, and a degenerative neurological condition. I have been a wife staring at their comatose spouse, being told it is time to say goodbye, only to feel relief when he defied all expectations.

Today, Eric is considered permanently and totally disabled and unable to work. He is wheelchair-dependent, struggles cognitively, suffers migraines and blackouts, and is losing his vision. He is 41.

Congress created the Program of Comprehensive Assistance for Family Caregivers to assist caregivers like me, whose spouse needs substantial care. The program should have been a blessing. However, the program has become unpredictable, stressful, and frankly, dehumanizing. My husband grows more dependent on my care every day. Yet, I was accepted to the caregiver program in 2017, dropped in 2018, denied in 2019, and readmitted in 2020 but only after 2 hard-fought appeals.

The assessments are demoralizing. My husband is only capable of 30 minutes of sustained cognitive activity. I had to watch him answer questions until he was doubled over and drooling on himself in exhaustion because the assessor would not allow me to help him respond. There is no reason to ignore medical accommodations and cause medical distress to prove what was already well documented.

Despite all of Eric's care needs, we were only approved for level one. His need for supervision, protection, and instruction, even though clearly documented in both his assessment and medical records, was never even taken into consideration by the CEAT.

Before I was a caregiver, I was a nonprofit executive and a college professor. We are a one-income household, not by choice but by forced circumstance. The cost of caregiving is crushing, and my family should not have to fear that an annual assessment or a policy change will threaten our financial stability.

To the members of this Committee, please know that I speak for every caregiver when I say our ability to provide holistic care for our veterans is hampered by frequent and intrusive assessments which are not properly reflective of clinical records or weighed accurately in CEAT decisions. Congress must ensure that any new regulations require a veteran's needs to be documented accurately, evaluated thoroughly, so that our Nation can better serve our veterans and their caregivers.

Thank you. I look forward to your questions.

[The prepared statement of Ms. Benson appears on page 46 of the Appendix.]

Chairman TESTER. Appreciate your testimony.

Jim, please proceed.

STATEMENT OF JIM MARSZALEK

Mr. MARSZALEK. Chairman Tester, Ranking Member Moran, thank you for inviting DAV to testify on ways to fix and strengthen VA's comprehensive caregiver program.

Mr. Chairman, six years ago, DAV launched the Unsung Heroes Initiative to honor family caregivers, to extend the program to veterans of all eras, and to include veterans disabled due to illnesses, not just injuries. In 2018, we were pleased when Congress passed the VA MISSION Act, which expanded the caregiver program to veterans of all eras. And in 2020, we applauded when VA adopted new rules that extended eligibility to cover illnesses. These new regulations also attempted to fix longstanding problems with eligibility, reassessments, and appeals.

Unfortunately, almost two years later, it is clear many of the same problems remain. For example, the regulations changed how

VA measures a veteran's need for assistance with activities of daily living or ADLs. According to VA's new definition, the veteran must require help each time they complete an ADL. Under this standard, a paralyzed veteran who finds the strength to transfer from their wheelchair just one time in a day would not meet this each-time standard for mobility. What is worse, VA does not even explain how they determine an ADL meets the each time standard. Mr. Chairman, it has become clear that these new regulations are not working as the law intended.

Let me share a story of a veteran and caregiver that illustrates problems with the current regulations. In 1969, Dennis Joyner was gravely wounded in Vietnam by a landmine, resulting in the amputation of both his legs and his left arm. He spent months recovering in hospitals and years rebuilding his life. But Dennis was blessed to marry Donna, who gave up her career and became his full-time caregiver.

When the program was expanded to include Vietnam veterans, they were thrilled to be approved at the highest level of support. But just one year later, VA conducted a reassessment and notified them that their caregiver benefits would be reduced. They, and we, cannot understand how VA could find that Dennis needed less caregiver support since his injuries have not and will never improve, and the only change was they are both a year older.

Mr. Chairman, VA's caregiver program was created precisely for people like Dennis and Donna.

We were pleased to hear VA yesterday announce a plan to review and change the regulations and to protect caregiver benefits during the process. Unless VA prioritizes getting veterans and caregivers into the program and not out of it, the problems will persist.

Here is a few of DAV's recommendations. First, VA must replace the current eligibility regulations, particularly the each-time ADL rule, and create new standards that are clear, consistent, and equitable.

Second, VA must provide detailed explanations on how standards will be measured and applied in each decision notification it sends to veterans and caregivers.

Third, eligibility decisions for veterans should be shifted to VBA, allowing VHA to focus on qualifying, training, and supporting family caregivers. VBA already has the experience and infrastructure necessary to process these claims.

Fourth, VA should only require annual reassessments when a veteran's disabilities and need for caregiver services are likely to have changed. A 70-year-old veteran who is paralyzed or missing multiple limbs is extremely unlikely to need less caregiver support one year later.

Finally, the Administration should withdraw its appeal in the *Beaudette* case that provided veterans the right to appeal caregiver decisions to the board. Veterans must have all of their due process rights protected, including full appeal rights.

Mr. Chairman, that concludes my statement. I am happy to answer any questions you may have.

[The prepared statement of Mr. Marszalek appears on page 51 of the Appendix.]

Chairman TESTER. Thank you, Jim, and I appreciate your recommendations.

Andrea?

STATEMENT OF ANDREA SAWYER

Ms. SAWYER. Mr. Chairman and Ranking Member Moran, thank you for holding this hearing.

I work for the Quality of Foundation which was created to serve the families of seriously wounded veterans. We have created educational resources and are one of the few organizations that assist with clinical appeals, one of which was the Bensons' appeal.

Over the years, legislation and policy surrounding caregivers have evolved. Congress passed the VA MISSION Act which expanded eligibility to the program. By broadening eligibility, Congress acknowledged caregiver involvement led to improved outcomes. Congress included traumatic brain injury, psychological trauma, and other mental disorders, and identified seriously injured as the level of severity to be considered.

As a result of the new legislation, the VA drafted new regulations. We have found that while the legislation created a program for seriously injured, VA has created a program for the catastrophically injured. Under the new regulation, a veteran must now require assistance with an ADL each and every time it is completed. Under the new supervision standard, the veteran must need continuous daily care.

Quality of Life has requested information on the decision-making process SOPs and training documents to inform our efforts, but we have been denied access to that information.

We would like to applaud the VA for taking steps to pause the dropping of caregivers to review the process.

Now it is even more relevant to highlight the challenges faced by families as they navigate the PCAFC. We have noticed the following issues.

Number one, information that should be correct in the VA medical records is not. Ratings information, documentation of guardianships and fiduciaries are wrong. These documents indicate an already established need for assistance or supervision.

Number two, the collaboration with the veteran's primary care manager is rarely filled out by the veteran's doctor, and that information is limited to very generic information and only includes the last 12 months of records. The program is supposed to gather outside medical records. This rarely happens.

We do not have any idea if the new assessment has been validated against other industry standard validated instruments or how it is scored to make decisions on whether a veteran qualifies for a caregiver.

And lastly, during the assessment process, the veteran must list his deficits and then the caregiver must describe all assistance provided in front of the veteran, repeatedly, taking an emotional and mental health toll.

There is a large denial rate for applicants. Legacy review denials are high.

Given the information presented above, we respectfully ask the Committee to work with the VA and nonprofit organizations on the following items and additional items in our testimony: to realign the program with congressional intent; to increase transparency related to the decision-making process, VA needs to make the full criteria available; to change the requirements so a veteran does not have to be present for the caregiver's interview and lengthen the timeframe for check-ins and reassessments to lessen the burden on caregivers and veterans; and, to require the VA to honor its duty to assist the veterans to help collect their records.

We would like to thank the Secretary for preemptively granting our request to place a moratorium on drops and reassessments, which was our number one ask.

To leave you with an appeal from a caregiver on her thoughts about this program, one caregiver stated, "We have spent the last 15 years focusing on every improvement our son has made. The PCAFC reassessment process wipes that out. I had to recount everything he could not do in front of him. My son, who was a nuclear engineer, now struggles to put Legos together. He wept during the assessment. I asked if he could leave and was told, no. As a mother, it broke my heart. When he starts to recover mentally, we have to go through it all again for the quarterly assessment." And we have similar letters to offer for the record.

[The letters referred to appear on pages 139–144 of the Appendix.]

Mr. Chairman, the Quality of Life Foundation thanks you for holding this hearing, and we look forward to answering any questions you may have.

[The prepared statement of Ms. Sawyer appears on page 63 of the Appendix.]

Chairman TESTER. Thank you, Andrea.

Next, virtually, we have Sarah Verardo.

STATEMENT OF SARAH VERARDO

Ms. VERARDO. Chairman Tester, Senator Moran, thank you for inviting me today to testify in front of you.

I hope you and your staff have had the opportunity to review my written testimony submitted on Monday, and I hope you see that our organization, along with many other organizations, has made every effort possible to warn the VA that this new regulation does not honor the commitment Congress set with veterans and caregivers through the MISSION Act. It is a dramatic step back in the support it provides disabled veterans and the caregivers who support them and places every veteran and the caregivers in support, that are supporting them, in real danger of falling through the cracks of what has turned into a senseless, compassionless, bureaucratic nightmare.

I am a caregiver myself to my catastrophically wounded husband, Sergeant Michael Verardo, U.S. Army, Retired. Michael was twice wounded in Afghanistan in 2010, imminent death status, his arm and leg blown off, and 120 surgeries later. As his recent annual reassessment for the caregiver program noted, Mike requires constant assistance to complete the basic activities of daily living and needs my constant support to navigate life and society.

But just last week, we were notified that Mike will be demoted to the lowest tier in the new caregiver ratings. Why? Apparently, because someone on the Centralized Evaluation and Assessment Team, the CEAT, saw videos from 2016 and 2017 where Mike was advocating for reform in VA health care programs. While I was with him at every one of those events to provide the assistance he needed even then, those five and six-year-old videos were apparently enough to determine Mike did not need as much support anymore. The rest of his assessment explicitly said otherwise, and his VA records note that the declines have been devastating and he requires the equivalent of full-time nursing home care. But this one statement about an internet search, which by the way is nowhere in the regulation, was enough to reduce Mike's rating.

When did Google become a clinical evaluation tool? How is this even allowable, ethical, or legal? And most importantly, Senators, what are you going to do about it?

What is even more incredible is that I am relatively one of the lucky ones, if you can call it that. Over the last five and a half months, we have been inundated with pleas of veterans and caregivers being told they will be disenrolled come October 1st, 2022. After years of being at the highest tier ratings in the prior caregiver program, now these catastrophically disabled veterans, many of whose cases I have detailed in my written testimony, are being told they are somehow miraculously cured, can complete their activities of daily living or ADLs, and no longer need any supervision.

The assessment documents in these cases detail how these veterans fail their ADLs and need supervision for their own safety. But because the regulation requires the assessment teams to make the impossible prediction the veteran will require continuous moderate to significant levels of personal care services for the next six months, the assessment teams realize they cannot, that likely no one can, so they say the veteran must be disenrolled.

And The Independence Fund and many of the other organizations who have joined in on this crusade have warned the VA, Congress, and even this Committee that exactly this would happen. We made these warnings during the lead-up to the new regulation, during the public comment period on that regulation, in our letter to the Committee in 2020, in my comments before the Caregiver Advisory Committee in 2021, and in a letter that we and 21 other organizations sent to the Secretary last November.

We have detailed in the written testimony how each element of the new regulation was unnecessary and counterproductive, but the real tragedy is that it was unnecessary. By the law you passed, VA could have simply certified the caregiver IT tracking system and used the old regulation. But as you said, Chairman Tester, it appears the VA took the opportunity of the congressionally mandated expansion of the caregiver program to pre-9/11 veterans to also make it tougher to get into the program.

We are cautiously optimistic with VA's announcement yesterday regarding the suspension of disenrollments and demotions for legacy caregivers. But, Senators, this is the third time since 2017 the VA has been forced to pause these actions because of the systemic lack of consistency in these evaluations. This time it is because the regulation is so poorly written.

And we will fully engage in the stakeholder summit we hope that VA holds as soon as possible. We will support such changes like the one we recommended in our petition for rulemaking and letters, and we ask Congress to make the necessary legislative changes.

[The letter and petition referred to appear on pages 105–120 of the Appendix.]

But, Senators, we have been down this road before, and it has failed before. Bureaucratic delays to protect the systems and processes has consistently proven stronger than the desire to help veterans and caregivers.

So, Senators, we ask you if we are not all here together by the end of April or May at the very latest then we ask you to please take action to fix this legislatively. Thousands of caregivers across this country are counting on you.

We have stepped up to take on the unimaginable. We have fought longer and harder than any one person is meant to fight. And we live lives without margin while fighting against the very institution and the very program meant to help us all while navigating heartbreaking declines and loss in our own homes. So we are counting on you, and we need your help.

Thank you.

[The prepared statement of Ms. Verardo appears on page 88 of the Appendix.]

Chairman TESTER. Sarah, thank you for your testimony. I want to thank everybody for their testimony.

And please know that I do not think there is anybody on this Committee that is happy with what has happened. I remember talking to Assistant Secretary Remy while he was being confirmed and said we have got, I believe, an 86 percent denial rate in this program. I do not think that is what Congress intended.

And then when I hear the stories of assessment and reassessment, it is something that makes you wonder why. That is all. Just, why.

And I am going to focus most of my questions with you, Caira. I could focus it with anybody who testified today, but—I think you have talked about the fact that your husband is a triple amputee, correct?

Ms. BENSON. No. My husband has all his limbs.

Chairman TESTER. He has what?

Ms. BENSON. He has all his limbs.

Chairman TESTER. He has all his limbs. And so the injury that he has is with TBI and PTSD?

Ms. BENSON. No. He has a TBI, and the TBI was significant enough that he has toxic encephalopathy as well. So his brain, for lack of a better term, is dying.

Chairman TESTER. Gotcha. And so when you first got accepted into the program and then you were reevaluated, did the person who did the assessment—as was pointed out I think by Jim, that you know, he was a year older. Did they give you any reason why?

Ms. BENSON. No. So our first entry into the program was ’17. We were dropped in ’18 because we wintered in the South and they considered us nonpermanent address. By ’19, we had won——

Chairman TESTER. So, stop for a second.

Ms. BENSON. Yes.

Chairman TESTER. You were dropped from the program because you had a different address in the winter than you did in the summer?

Ms. BENSON. Correct.

Chairman TESTER. I assume that must be part of the regs?

Ms. BENSON. No.

Chairman TESTER. I mean, you lived in this country, right?

Ms. BENSON. Correct.

Chairman TESTER. You fought for this country, right?

Ms. BENSON. He did.

Chairman TESTER. That is an interesting twist. Keep going.

Ms. BENSON. So in '19, we applied again, but because we had finally won a correct diagnosis of traumatic brain injury—my husband was injured in 2000 and 2003. He was not diagnosed with TBI and encephalopathy until 2018. Because he had that on board, we were considered ineligible for the program because it was not service-connected. And the filing in VBA to get that service-connected has been active since 2016.

When the regulations changed in 2020, it no longer had to be service-connected, and we were ecstatic. My husband was home based primary care at that point. They encouraged us to apply yet again, and we did. We were accepted in at level one. At that point in time, he had one ADL and he was given intermittent supervision, protection, and instruction.

We reassessed in 2020, January of this year. He had just been released from the hospital for COVID. He had five ADLs that were hands-on and needed continuous daily care, as is evidenced by three doctors saying he could not be left alone. We still attained level one.

The VA only counted—or the CEAT, I should say, counted two of the ADLs because the other three ADLs, even though he needed anywhere from 25 to 75 percent help during those ADLs, were not entirely dependent. We were told in order for an ADL to count it had to be 100 percent caregiver effort. They did not include supervision, protection, and instruction even though three of his doctors had asked us never to leave him alone. And we were issued level one.

We decided not to appeal at that point. We were exhausted.

Chairman TESTER. I have got you. Just curious, did the TBI happen in service to the country?

Ms. BENSON. It did.

Chairman TESTER. Was he in theater?

Ms. BENSON. He was in—his first TBI was a parachute malfunction during basic airborne course.

Chairman TESTER. Yep.

Ms. BENSON. His second was a double car bomb in Baqubah.

Chairman TESTER. And did the Department of Defense—did they diagnose him as having traumatic brain injury?

Ms. BENSON. No. He was never screened under the DOD. The VA diagnosed him.

Chairman TESTER. Okay. I will kick it over to you, Senator Moran.

Senator MORAN. I do not how to respond. I mean, I appreciate your circumstance, the stories that you tell. I do not know how you are capable of doing what you are doing, and I do not understand why the process that is designed to help you ends up harming you. And I apologize for that, and we continue to work to try to care of veterans, in the process, make the VA perform its duties as it should.

And it is true for all of our witnesses and advocates here today. Thank you for what you do to care for those who have been harmed so greatly.

I do not know who to ask this question to, but—how do you explain what Caira just described? Steve, you brought Caira to us. Obviously, Caira has the capability of telling a story that is so compelling, and it sounds like there is just so many other circumstances in which there is a compelling reason to get this right.

How did it—why did it go so wrong? What went on that precipitates this kind of circumstance?

Mr. SCHWAB. Well, Senator Moran, thanks for that question. And you can see why we wanted to bring Caira here to bear witness to what she has been going through. Andrea mentioned that she has got letters from countless other caregivers who have experienced similar circumstances. You heard compellingly from Sarah what she and Michael have faced in their own situation. And unfortunately, that is happening too much and too often.

And, Senator Tester, I believe you asked a really important question to the VA earlier around consistency. I think it was you that asked that question. And it was suggested, and perhaps it is true, that the VA said that there are three hospitals that they deem outside of the consistency that they have seen across other institutions in executing evaluations. We have not seen that.

The inconsistency on the experience that caregivers have faced across the country is unbelievable, and going into these evaluations it seems that the standard all too often is how do we get to "no" versus how do we get to "yes." And if we cannot get to "yes" or we have got to get somewhere in the middle, there is not a clear path given to that caregiver and that veteran. There is not a warm handoff.

I do not want to say that happens in every situation. There are certainly great people at the VA at every level doing good work. But there is far too many stories like Caira's and Sarah's and Andrea's that are happening, and that points to some real root issues. And we think it is because there is 160 facilities that are executing this program in different ways.

As hard as—and Colleen has been a great new leader for the program, but as hard as we put forward new issues around consistency it does not seem to be changing what we have been experiencing.

Senator MORAN. Mr. Schwab, I mean, that suggests that in a sense that is luck of the draw or where you live, just circumstances, not that the program is—the program may be fine, but it is implemented differently in different places.

Mr. SCHWAB. That is correct.

Senator MORAN. So some people have an appropriate response, and others have a tragic response.

Mr. SCHWAB. That is correct.

Senator MORAN. What was announced yesterday by the Deputy Secretary, I think as I looked at what was said, it is enacting a moratorium on discharging legacy participants from the program, reviewing eligibility requirements to ensure they meet congressional intent, and explore shifting some responsibility to VBA. Could you each, or any of you who feel that this is a question that you could answer well, tell me what you think this means for veterans and caregivers? Did you hear what you wanted to hear even though it is now not in the beginning?

Jim, you look like you were ready to speak.

Mr. MARSZALEK. Sure. Thank you, Senator. I am optimistic. I was glad to hear, VA say that there is going to be a summit in April because that is news to me. But I think that is what needs to happen, to get people together to talk about these different issues. And I was glad to hear they are working with VBA already because they have been through these processes before.

The transparency is the biggest issue here. Every caregiver we have talked to—and I am sure everybody at the table can attest it. You are not getting any information as to how they made their decision. They are not sharing any of it, and we do not know how they have made the decision and how they have come to the conclusion.

The case I talked about, about Denny, he got a year older. Nothing has changed. His level of caregiver support that his wife provided has never changed at all in the past year although he was reduced and not told why. The letter just said, you are being reduced to the lower level effective this date. That is all the letter says.

So I think you have to go back to the drawing board and figure out what should the regulations be, but I think you have to do it with everybody. And I will refer back to the appeals modernization. That took everybody in a room months to figure out a good appeal process for VBA. We are in the same situation right here. We have tried. The process is broken. It is not working. It is not how anybody intended it to be.

So we have got to go back to the drawing board and figure out how do we do this together, and you have got to have everybody at the table. And I think caregiver families at the table, talking about what their experiencing is very, very important.

The reassessments, going through those so frequently, and requiring the veteran to be part of some of these quarterly calls as well is damaging to the veteran. It is doing more harm than good. I mean, we are hearing that across the board.

Senator MORAN. Thank you.

Chairman TESTER. Go ahead.

Ms. SAWYER. Thank you. I would like to say I am optimistic that the VA is willing to look at this regulation and assessment. One of the things that we have found as we are reviewing the clinical decisions that we can find in the record is that there are issues surrounding the fact that outside medical records are very often not included. They (veterans and caregivers) are not given time to gather outside medical records and have them included.

In a lot of cases, and the Bensons' case was one, from the time she was notified that she was being reassessed until the time she had a CEAT decision was like three weeks. So she did not have time to gather a lot of the outside medical records. And then there is a whole process to get the records scanned into the VA, and a decision had already been made.

In addition, the PCM is not asked very specific questions. They are basically asked: Does the veteran understand the treatment plan? Does the caregiver understand the treatment plan? Can the care be provided in the home? And, has the veteran ever been considered for institutionalization?

Well, why not ask them whether or not the veteran can perform the ADLs, or whether or not they can meet the standard, whether or not they think the veteran is able to meet the standards for supervision, protection, and instruction, rather than relying on a self-report from the veteran and caregiver that then they (the VA) can disregard as a self-report.

The third thing in that decision is that there is a question that CEAT considers, or the decision-making body considers, that is worded in a very strange way. The question is: Is the individual unable to self-sustain in the community? And the answer to that single question determines whether or not a veteran is tiered at a tier one or a tier two.

The question itself is worded in a backward manner. So if you answer, is the individual unable to self-sustain in the community and you say "no," that means the veteran is able to self-sustain in the community. If they would simply change the question, is the individual able to self-sustain in the community, that would overturn about 75 percent of the tiering errors between level one and level two that we see.

Thank you.

Chairman TESTER. Great point.

Senator MORAN. Thank you, Ms. Sawyer.

Chairman TESTER. Senator Murray.

SENATOR PATTY MURRAY

Senator MURRAY. Well, thank you so much to all of you. Thank you for being here. Thank you for continuing to stay on this. And I certainly think when we first passed this, Senator Tester and others know who worked on this, we never expected these kinds of challenges this far into this.

So you know, I am glad the VA made some announcements yesterday. We are going to be following up on this. Your testimony today is extremely important. And I know I am not going to give up, and I know Senator Tester is not going to give up, Senator Brown, Senator Moran. We want this to work.

Senator BOOZMAN. What about me?

Senator MURRAY. Well, I did not see you over there. All of us. I do not know anybody that wants this program to work like this. I think we are in this, and we want you to know that, and we are going to continue to work to make sure that this program is instituted the way we envisioned it when we first passed it. So thank you all very much for being here and I appreciate the responses so far.

I do want to ask Ms. Sawyer a question a little bit differently. And it is great to see you again. Thank you for your steadfast leadership advocating for veterans and their caregivers.

As you know, we made changes in the last caregiver bill to make VA better account for the invisible wounds of war for which a veteran may need a caregiver. Tell me, has the VA done a better job with invisible wounds, and what would you like to see them do as part of this new look at regulations?

Ms. SAWYER. So I do believe they have expanded the areas of criteria that they look for in adding self-protection, self-direction, self-neglect, safety inside and outside the home, delusions, hallucinations.

Unfortunately—and I think some of this has to do with COVID and how they (VA) have changed things with COVID—it becomes a self-report. They ask the veterans and caregivers about these things themselves.

They do not ask for the input of any specialist. The input of any specialist is not required—only five questions from the PCM, those very generic questions that I listed, which do not really get to the heart of the matter and whether or not anyone feels that this veteran has a mental health need or a psychological need or a traumatic brain injury for supervision.

Senator MURRAY. I think that is what Caira was referring to when you said you had three doctors that said he needed somebody with him.

Ms. BENSON. Correct.

Ms. SAWYER. Yes.

Senator MURRAY. But that did not count.

Ms. SAWYER. Yes. They (specialists) are not even asked for—they are not required to be asked for their input. Only the PCM is required to be asked for his input. And then like I said, those questions are very generic.

Why wouldn't you ask the specialist for their input? What is the purpose of not allowing them to weigh in?

Our organization, in working with appeals, has taken those areas of supervision, protection, and instruction and actually asked the specialist to weigh in on those. And in some cases, we have actually received notes back that say they (the specialists) are not allowed to answer those questions because it would give too much information on the needs of the veteran. Well, isn't that the entire purpose of this evaluation, to inform the decision-making body about the needs of the veteran?

The other thing that I think misses the mark is in the development of these assessments and in their administration. These are 90-minute to 120-minute assessments, where the veteran has to sit and list on multiple occasions all of the things he or she can no longer do. And then he has to sit there while the caregiver then recounts everything the veteran cannot do for himself or herself and everything that they (the caregiver) then have to do as a result either to provide the veteran assistance or just do because the veteran is no longer able to do that. What we hear repeatedly is that takes an emotional toll. For some of these folks who have very severe brain injuries, sometimes they forget that they have these deficits.

We have been told for the last several years: "Build up your veteran; focus on their independence." And then we have an exam that does nothing but tears them down. And as soon as you get them built back up, it is time for a quarterly assessment that goes over the same thing.

And so there is really no other disability program that you qualify for that you have to requalify for or have a check-in on such a frequent basis, and we are wondering why VA does that.

And then we hear VA say that there is a lot of wraparound VA mental health services, but I do not see that in practice. And I especially do not see anyone checking in after these reassessments, when basically the home is in mental and emotional tatters. I mean, what we hear about this assessment is it takes weeks to get people back to their standard and even with the quarterly assessments.

I mean, I can tell you from my own household. After a quarterly assessment, it would take two to three days to get him to be able to say, gosh, I feel like I am worthless.

And so I think they attempted to expand the areas they were looking at, but I do not think that it has been implemented as they intended for it to be implemented.

Senator MURRAY. Okay. Well, my time is out. But I really appreciate all the work, all you are doing, and your testimony really means a lot to all of us. Thank you.

Ms. SAWYER. Thank you.

Chairman TESTER. Senator Boozman.

SENATOR JOHN BOOZMAN

Senator BOOZMAN. Well, thank you all for being here, and you really are making a big difference. This is a mess, and I know that we are all committed to helping get it straightened out.

We say these things all the time, but the answers need to come from the ground-up. Okay? And you all are certainly on the front lines and doing a tremendous job, and we really do appreciate that. And like you say, you are making a difference.

So, Steve, we can agree on the transparency thing. You know? What else do we agree on that we need to—what other changes? I mean, these real-life—you know, all of the—you know, why we do not have the specialists involved and this and that. I mean, none of that makes any sense. Where do we start?

You mentioned a—you know, that we are going to have a summit. Who needs to be at the summit? You know?

Mr. SCHWAB. Senator Boozman, thank you for that question. I think we need to start over. I think that VA, Congress, the major stakeholder groups need to be put in a room for as many days as it takes us to bring these stories forward, to bring these experiences forward, to bring the advocacy and the regulatory experience that the VSOs and MSOs have, alongside our friends and partners at the VA.

I will say, Senator, you know, there are good folks. These are good folks in the VA——

Senator BOOZMAN. No, no. For sure.

Mr. SCHWAB [continuing]. Who want to get this right. But to Sarah's point in her testimony, we have now paused the program three or four times, and we have made temporary solutions. It is time to go back to the fundamentals——

Senator BOOZMAN. Right.

Mr. SCHWAB [continuing]. And redraw the lines.

Senator BOOZMAN. Right. Very good. Anybody else comment on—again, like you say, you have given us a lot of really good information.

And it is just something we are going to have to figure out, Mr. Chairman, and you are going to have a lot of support in doing it. But it is going to be something that we are going to have to—you know, we—one of the things that Congress does not do a very good job of—we are so blessed, you know, in the sense that for the last several years we have been able to do a lot for veterans. And that is our veterans service organizations, that is you all, pressing things forward.

Sometimes we do not do as good a job on the oversight as we—and that is nobody's fault. I mean, it is our fault. You know, in the sense that we have got to do a better job. But this is one of the things I think we are all committed to, to rolling up our sleeves and getting the stakeholders involved, getting you all involved, and see how we can come up with some policies that are, you know, user friendly.

And as you point out, Steve, these are not bad people. These are people that are trying to do the right thing. They are handicapped by the bureaucracy, and sometimes you are not able to even use good common sense.

So thank you all for being here. We do appreciate it. And I know it is hard to talk about these things, but you have done a tremendous job expressing the problems you go through and your loved ones. So that is really what it is all about.

Thank you.

Chairman TESTER. Senator Brown.

SENATOR SHERROD BROWN

Senator BROWN. Thanks, Mr. Chairman. And thank you all for your testimony and the pain that you have gone through and the advocacy that you do for others, including your loved ones but people you do not know, too.

Before talking about specifically AIR Commission, I want to just raise concerns, and I will do this—I am doing this personally with the Secretary, but want to raise concerns about his recommendation to the AIR Commission to close down the Chillicothe. It is a veterans hospital center south of Columbus and serving Appalachia. And the plans that VA has announced to close it down, it is a long process. We will have other opportunities to weigh in.

But I know already veterans are scared. The hundreds of workers there are scared. It is in Appalachia. It is a poor part of Ohio. They will have to drive to either—some will drive to West Virginia. Some will drive to Dayton. Some will drive to Cincinnati. There are long drives to get the kind of care that they are used to getting. And so I wanted to put that just so my colleagues would hear that, about Chillicothe. I know that Senator Tester, in his State, has a lot of those same concerns.

I want to concur with what Senator Murray. I thought she said it really well, as you all did, about the caregivers program, that we did not intend to change how VA decided who would be let into the program or have people removed. We voted, and we wanted to expand it.

I had a roundtable with caregivers and hearing the same kinds of stories you told. I know that Senators Boozman and Moran and Tester have had the same kinds of discussions. My staff has reached out to a number of caregivers, too, and heard directly about what happens if they are kicked off of the caregiver program in September. They told me, without this program, they expect even more veterans suicides. The hopelessness you could see in their eyes, speaking for the person whom they are caring for, their husband, their sister, their whomever it is in each case.

I applaud the steps VA took this week to ensure those in the program could remain, but it does not solve the problem.

So I want to start with you, Mr. Schwab, and thanks for what the Dole Foundation is doing. You have been so important in this process.

Yesterday, the VA announced, as you know, convening an external stakeholder event to get input for its new regulation. Many of us raised concerns. All of us up here raised concerns, specifically that veterans needed to have a 70 percent service connected disability rating or the inability to perform an activity of daily living without assistance.

What recommendations would you give to VA, Mr. Schwab, when drafting the new regulations? How many caregivers are going through the appeals process that you know of?

Mr. SCHWAB. Thanks, Senator. That is a great question. The appeals side, I will tell you that way too many caregivers are so frustrated. And this is a big concern of ours by the way. The appeals processes exist for a reason. Gives folks their right to appeal a decision to our government. In droves, folks are not appealing because they are exhausted and they feel like——

Senator BROWN. What Ms. Benson said, yes.

Mr. SCHWAB. Yes. They feel like—and I think Andrea is seeing this. I think our friends at DAV are seeing this. We are certainly seeing this at EDF. The Independence Fund, I know is as well. With a 13 percent, you know, "yes" rate on appeals is a pretty low yield, which discourages appeals altogether. So I think there is a lot of work we have to do around appeals.

Senator BROWN. So they are exhausted. I am sorry to interrupt. They are exhausted because they have gone through so much already. They are also not very hopeful that their appeal—that they will win their appeal.

Mr. SCHWAB. That is right, Senator.

Senator BROWN. Okay.

Mr. SCHWAB. And their exhaustion comes from the arduous evaluative process that you have heard a lot about today.

Senator BROWN. Okay. So what is your most important recommendation when drafting the new regulations? Ms. Benson, do you want to? Yes.

Ms. BENSON. If that is allowed, thank you. I think some of the exhaustion—these assessments are six to eight hours over four assessments. Some of them are in the home. We are exhausted just to get through the process.

And for like my husband, we are dealing with some of the most catastrophically worst of the worst. These are exhausting for them. It can take us weeks and days to get back on track and into a normal rhythm. And they are non-accommodative. We are dealing with veterans with severe disabilities and not able to accommodate those disabilities in assessment. It seems entirely backward.

Senator BROWN. Give me an example.

Ms. BENSON. My husband——

Senator BROWN. Either with your husband or somebody else, yes. Sure.

Ms. BENSON. A prime example, my husband has a 30-minute cognitive—sustained cognitive task limit set by his provision team, by his HBPC team. After 30 minutes of sustained cognitive activity, my husband's brain gets tired. His left side of his face starts to droop. He has trouble with aphasia or finding words. He gets to the point where he cannot swallow. And it is all due to exhaustion. Yet, he has to be there for an hour and a half of questioning.

Mr. SCHWAB. Senator, if I could just address your really important question, just piggybacking on Caira's compelling comments there, our biggest concern to get right on the eligibility front, excuse me, on the formula front is parity between physical and mental and emotional conditions. President Biden, in the State of the Union, said we need to call for parity on mental health across this country. That needs to translate down into our agencies. And we are seeing huge disparities between caregivers who are caring for veterans with physical wounds and those that are caring for veterans with invisible wounds. That needs to change.

Senator BROWN. So I am sorry, Mr. Chair, if I could do one more quick question.

Mr. Schwab, if you would, here is my request. Just because you are so well connected and do this so well and you know so many people, directly or indirectly, like Ms. Benson's husband, would you sort of collect for the Committee what your—I assume you are doing this—what recommendations you would give to the VA?

Mr. SCHWAB. Yes.

Senator BROWN. Because we are—all of us—we are all singing off the same page, and we all want to fix this. We have all talked to caregivers who are struggling in the hardest times in their lives, forgetting even the pandemic, but struggling in the hardest times of their lives. And we need to know specifically how we guide them to do the right thing.

Mr. SCHWAB. We are happy to do that, Senator Brown. We work really closely with DAV and Quality of Life and The Independence Fund, Wounded Warrior Project. We will work together on that, and we will bring that back to the Committee.

Senator BROWN. Okay. Thanks.

Chairman TESTER. Thank you.

Sarah, are you still online?

Ms. VERARDO. Yes, sir, I am. Hello.

Chairman TESTER. Well, I did not want to leave you out of this. I will tell you all your testimony was, by the way, outstanding. Sarah, you did something that normally would make somebody like me angry, but I think it absolutely was the right thing to do, and that is you put it on me as much as you put it on the VA. You put it on this Committee and Congress as much as you put it on the VA. And I want to thank you for that because the truth is this is everybody's problem that we need to work together to solve. And if we do not do it this way, it will not get solved.

You heard the previous panel, I assume. If you did not, this is an unfair—no, it is not either. You can answer this question. They talked about the process they were going through. The timeline was not definite at this moment in time. So I get to ask you, if we were going to have a timeline for this, to fix this program, what do you think a reasonable timeline would be?

Ms. VERARDO. Thank you so much and for your support and I know your advocacy for veterans and caregivers across the country.

This program needs to be fixed immediately. We are all—what Steve just said about people are not appealing because they are exhausted, I could not—I was here silently saying, yes, agree, co-sign, because I am an advocate and I am used to being an advocate. When my husband just got dropped a level, my first thought was I do not have the fight in me anymore. I just cannot do it. I have been fighting to keep him alive going forward and to advocate for more than a decade. The fight, they won; VA won. And this needs to be fixed immediately from a morale standpoint for the veterans and caregivers that are in this program and relying on it.

And also, as everyone has said today, what we go through in our households with the veterans for whom we provide care, our loved ones, after these assessments, during the assessments, it is dehumanizing. It is demoralizing. It is embarrassing.

My husband—and for a long time, I did not want to say this part out loud, and now I have widely shared this. But my husband does not control bowel or bladder function. My husband had his arm and leg blown off. He is burned over more than 30 percent of his body. He has had 120 surgeries.

Many of you have been so amazing to us in this 10-year-plus long journey, and VA is forcing us to relive why he cannot—now he is on catheter care, bowel and bladder care, through VA. He is on a home-based oxygen program. I keep 100 percent of his care at the VA because I believe in the VA system and having a cohesive system where the right and left hands speak to each other, but clearly, that is not happening.

As we are going through these assessments—and this is true for thousands of caregivers. I have outlined 15 in my written testimony. As we are going through this process and having to relive all these things, and then in front of my husband I am having to explain: Well, yes, he does have a shower chair. But, no, his bottom is actually very burnt. And because, you know, of all the bladder issues, he has a recurring diaper rash. But, oh, sir, examiner, could you please check his VA medical files that actually detail all of this so that, at 37 years old, my husband is sitting next to me hearing about this.

And so that is why I am here begging you to help fight for all of us because we have been fighting for each other and for our veterans for a long time and we are exhausted.

So I hope that right now, immediately in fact, we are going to hear news that we are going to reverse the poor decisions. We are going to ensure national consistency. And I already feel encouraged knowing that you all are taking this issue and continuing to look at it so seriously, as all of our partner organizations are that are there today. So thank you.

Chairman TESTER. Thank you.

Senator Sinema.

SENATOR KYRSTEN SINEMA

Senator SINEMA. Thank you, Chairman Tester. I want to thank our panelists for being here and for the service that your organizations do for our veterans.

I know some of you, like us, are still reviewing the VA's announcement yesterday that they are halting discharge of legacy participants in the family caregivers program. I am encouraged to see that the VA is changing course after feedback from veterans, caregivers, and members of Congress for over a decade.

The caregivers program has been a critical lifeline for those seriously wounded in the Global War on Terror. The caregivers program was designed to support veterans and does so by providing flexibility to their loved ones who provide hours of daily care. For many of the Arizonans I hear from, caregiving has become a full-time job, a job that despite the VA's announcement yesterday now feels like it has little job security.

My first question is for any on the panel who would like to answer. My office has been hearing from Arizona veterans and caregivers with concerns about how they will get by if they are removed from the program. What can we do to ease this transition if caregivers are removed from the program in the future and need to reenter the workforce?

Mr. Schwab?

Mr. SCHWAB. Senator, thanks for that question. It is an important one. And thanks for your support of your Arizona caregivers. We know that you are a big advocate for those families.

I will say the first thing we ought to do when we relook at the program and start over, which we are all discussing is necessary, is we have got to move VA towards a warm handoff. If someone is decreased in services or dropped from a program, they need to be walked through what other services and supports are available for them right now at VA.

And beyond VA, a lot of our organizations provide support that fills in the gap for these families when they are not eligible for a certain program. And many of us have been challenged and struggle to work with VA, to help them facilitate a warm handoff to our organizations so that we can step in and provide community support to the great families in Arizona and elsewhere.

I think those two things are really, really important when we all come together and talk about what are the program goals. And I am sure my colleagues have other thoughts.

Ms. SAWYER. Hi, Senator. So when we get a family that has received a denial, before we start the clinical appeal, one of the first things we do is to have them reach out to their PCM for a referral to HHA and, if necessary, to skilled nursing also because by doing that, we actually document the care need that VA says the veteran has. By dismissing the family from the PCAFC program and then doing the HHA evaluation, we are actually documenting the need that the veteran actually does need that care according to the—according to another VA program.

And by doing that, we have started the process of getting a support in place for a caregiver to begin looking for work, whether or not they choose to appeal or whether or not they choose to accept those services and move back into the workplace.

We then talk about, you know, if those services are offered, then you need to start taking advantage of those services. Even if what you are doing it for that falls outside of the respite hours, you need to start using those hours, that as a caregiver you should not do the VA's job for free because we feel like VA is relying upon caregivers to do is that they (VA) are going to take the caregiving supports away from caregivers and yet no caregiver will leave their post of caregiving. So basically, the VA is getting us to do our job for free.

I was an original 2009 caregiver that was put on the Hill by an organization to come and advocate for the original legislation, and what Congress—what many of the members that we met with—said that they wanted to do was to help us, help support us so we could stay home, which meant that we gave up our jobs and our skills. We gave up our retirement. We gave up our contributions to Social Security because as a caregiver, if there is no earned income in the home, you cannot contribute to Social Security. And the safeguard was that we would have this stipend with which we could have at least a little spending money that was our money for us to figure out what to do with.

Basically, we feel like we have been in a reversal. So we are having to tell caregivers to find job training that, by the way, since you are receiving your caregiver pay, you need to be able to do in the home while you are still doing this, while you are still receiving the caregiver stipend, but have it completed so you can return to work when the caregiver stipend runs out. And, go ahead and get your supports in place so that when the day you do need to return to work they are already set up.

Senator SINEMA. Mr. Chairman, I know my time is expired. Are there others who wanted to respond, and might I have . . .

Mr. MARSZALEK. Thank you, Senator. I think they put it elegantly that, the warm handoff is so important because there are other resources out there that are available to folks so if they are getting, disenrolled from the program, that they are aware of those other resources and they are able to seek those out very easily and then we are able to connect them with them very easily.

Senator SINEMA. Thanks. Mr. Chairman, if I might, thank you. The caregivers program is supposed to include financial planning services, and I wanted to ask about the effectiveness of the benefit. Are caregivers and their veterans prepared financially for the long term, including major changes to the program?

And, Ms. Benson, if you have anything from a personal experience to share, I would love to hear that.

Ms. BENSON. Thank you, Senator. That is a far more recent addition. In the VISN we are in, to my knowledge, they do not have that support in place yet. We are asked if we would like a referral. That is something that many of us do not step into. I know there are several with fiduciaries who already have some planning in place.

For me, especially when I advocate with other caregivers, I talk a lot about making sure you have a secondary plan in place. If you have Chapter 35 benefits, make sure you use them before they expire. Talking about something as simple as health insurance and making sure that you understand the process for DIC and that it takes a while. All of those things are things we talk about in caregiver advocacy, but I have not heard personally that anyone is hearing that from VA or the VISN I am in.

Senator SINEMA. Has anyone else heard?

Ms. Sawyer?

Ms. SAWYER. I have not actually heard whether or not those programs are functional as of yet. But in bringing that up with health insurance, one of my concerns about the changes in this program and the drops that we have is this program provides health insurance for some of our caregivers. And one of the concerns that I have is how are we transitioning these caregivers who are going to be removed from the program and rely on this program for their health insurance. How are we transitioning them to health insurance in other ways?

Senator SINEMA. Ms. Sawyer, if I might, that was actually my last question.

Ms. SAWYER. Okay.

Senator SINEMA. My question for all of you is: What, if anything, should Congress do to help caregivers who have relied on the program for so long and may need to provide for their own health care insurance if they are disenrolled?

Mr. SCHWAB. Senator, I think that is one of the most important questions that has not been asked yet. And your colleague, Senator Brown, asked if the Elizabeth Dole Foundation would work with our partners to come up with some solutions to recast the program. I think at the same time we need to come back to the Committee with some recommendations for support for families that are eligible, to your question, Senator. And I think that is some work that we can do together as organizations and report back to the Committee because it is an essential question.

Senator SINEMA. Mr. Chairman, if I might, I would like to request that we ask for that information back and get it as quickly as possible to figure out what, if anything, can Congress do, what action can we take, to help people prepare for the fact that they may be disenrolled and losing their health insurance.

Chairman TESTER. Absolutely, we will get that information, and then we will also distribute it not only to everybody on this Committee but back to the VA. I think that is part of the process conversation that we have had, and that is that in the end we have the oversight responsibility, but the bottom line is the VA needs to step up. And so any recommendations we appreciate so we can take a look and see, if implementable, how quickly we can get them done.

Senator SINEMA. Thank you. Thank you, Mr. Chairman.

Chairman TESTER. Thank you. Look, we have a lot of work to do. It is pretty obvious by the testimony here today. I have been on this Committee for 15 years, and I do not know that we have ever had a committee hearing that is as gut-wrenching as this hearing is.

As Ranking Member Moran and I were talking, we passed a caregivers component that we thought was going to make it better, and obviously, it has made it worse. That was not the congressional intent, but it is pretty obvious what has transpired here.

And I think it is really important that we continue with more oversight than we began in this program in the past and make sure that the changes that the Administration makes actually benefit the veterans because that was the congressional intent from the beginning. It was not to make it more bureaucratic. It was not to kick people off the program. It was not to put veterans through hell in assessments. It was about making sure that we were doing right by the people who served our country and gave a lot to this country with their service to this country.

And so I look forward to continuing to work with the folks that are here today and the other VSOs out there that are listening and the other veterans that are out there listening and the caregivers that are out there listening, to make sure that we make the right improvements to this program so it serves our veterans in a way that I think Congress intended for it to be all along.

Once again, I want to express my appreciation for the witnesses, for being here today. I want to express my appreciation for the folks from the VA, Dr. Taylor and Dr. Richardson, for you staying and listening because I think it is very, very important that we really roll up our sleeves and we do not take a long time doing this. We gather the information, as much as we can, and I think it is out there, and go to work and solve the problem in a timely manner.

With that, we will keep the record open for a week, and this hearing is adjourned.

[Whereupon, at 4:35 p.m., the Committee was adjourned.]

APPENDIX

Prepared Statements

STATEMENT OF
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BEFORE THE
SENATE COMMITTEE ON VETERANS' AFFAIRS

March 23, 2022

Good afternoon, Chairman Tester, Ranking Member Moran, and Members of the Committee. I appreciate your interest in the VA's Caregiver Support Program and the opportunity to answer your questions today. I am accompanied by Dr. Colleen Richardson, Executive Director, Caregiver Support Program.

The contribution of caregiving has an important impact in the lives of family members and an increasingly valuable role in our health care system today. Through our combined 37 years of VA clinical experience, Dr. Richardson and I, have witnessed, and recognized the impact of caregiving on the health and well-being of our Veterans. The role of caregiving is not only time and energy intensive, it has an impact on one's physical, psychological, and financial health. The VA Caregiver Support Program's (CSP) mission is to provide resources, training, tools and support services to the caregivers of our Nation's Veterans. The VA's CSP is breaking new ground and setting the standard on caregiving in the health care industry. By being a trailblazer, the program is in a dynamic state of evolution and to evolve, we require consistent feedback and partnership with all of you, our partners who are with us today, Veterans, caregivers, and our many stakeholders that make our work possible. We are proud to be leading the country in providing a program which offers unmatched benefits, services and supports to caregivers of Veterans to enable them to achieve their optimal level of independence and well-being.

In 2010, the VA established the CSP to administer the Program of Comprehensive Assistance for Family Caregivers (PCAFC) and the Program of General Caregiver Support Services (PGCSS), two programs which support caregivers of Veterans in need of personal care services. Initially, PCAFC was targeted towards caregivers of eligible Veterans who incurred or aggravated a serious injury, in the line of duty on or after September 11, 2001. Through the MISSION Act of 2018, VA was authorized to expand eligibility to Veterans who incurred or aggravated a serious injury or illness in the line of duty for all eras in a phased approach (Phase I, which occurred October 1, 2020 and Phase II, which will go into effect October 1, 2022).

The adoption of the new MISSION Act regulations was to address issues in the lack of standardization, consistency, and equitability identified in PCAFC while expanding the program and making it more inclusive for Veterans and caregivers of all service eras. We have doubled the size of the program in 16 months since expansion – quite an accomplishment and credit is due to our CSP staff throughout the enterprise. Their work is particularly notable during the COVID era where many clinicians also stepped forward to help with first and fourth mission assignments to ensure we could meet the care demands placed on our system and our nation. nation. And, where the challenges of the new normal work environment required them to accomplish the expansion and in new and untested ways. We recognize the hard work of our staff yet we acknowledge that there is so much more to be done.

To be clear, we were not able to fully anticipate the challenges COVID would present nor the impact the regulation would have on different eras of Veterans when drafting the modified regulations. Through the evaluation of feedback from internal quality assessments, Veterans, caregivers, and VSOs, along with other partners, including those with us today, we recognize the need to take a step back and reassess.

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We have heard and understand the issues that have been raised about the rate of acceptance in PCAFC as well as the concerns regarding our legacy participants and eligibility criteria. CSP has taken efforts to closely examine program data and as we gain increasing granularity with our data systems, we can better identify and define trends that help us and others understand the true performance of this program.

Now, more than ever, Veterans and caregivers have more options available to appeal a PCAFC decision with which they disagree. A ruling by the U.S. Court of Appeals for Veterans Claims, makes available PCAFC decisions to be appealed to the Board of Veterans Appeals (Board). CSP is actively implementing the necessary infrastructure and processes to offer the full spectrum of options available under the Appeals Modernization Act (AMA), which include: Supplemental Claim, Higher-Level Review, and appeals to the Board.

As a VA nurse, a daughter, granddaughter, and great-granddaughter of Veterans and in partnership with the Dr. Richardson, a psychologist, combat Veteran and former member of the Navy Medical Service Corps, you have our commitment to guide CSP to be the preeminent program in the industry on caregiving. We welcome and invite you, this committee, our partners and stakeholders to help us in achieving our mission. I thank you again for this opportunity to discuss the accomplishments and opportunities of our program and we stand ready to respond to your questions.

WRITTEN TESTIMONY OF STEVE SCHWAB, CHIEF EXECUTIVE OFFICER OF THE ELIZABETH DOLE FOUNDATION BEFORE THE SENATE COMMITTEE ON VETERANS' AFFAIRS UNITED STATES SENATE ON THE VA'S PROGRAM OF COMPREHENSIVE ASSISTANCE FOR FAMILY CAREGIVERS

March 23, 2022

Chairman Tester, Ranking Member Moran, and Members of the Committee, the Elizabeth Dole Foundation is pleased to testify today on the VA Program of Comprehensive Assistance for Family Caregivers (PCAFC).

As the preeminent organization empowering, supporting, and honoring our nation's military caregivers, the Elizabeth Dole Foundation seeks to strengthen and empower American military caregivers and their families. In 2014, the RAND Corporation released *Hidden Heroes: America's Military Caregivers*[1], commissioned by EDF. This was the first comprehensive, evidence-based national study of military and veteran caregivers. This report gave us the first scientific count of military and veteran caregivers – 5.5 million. The report also revealed that these 5.5 million caregivers provide more than $15 billion in uncompensated care every year. Additionally, almost two-thirds of post-9/11 military caregivers reported financial strain because of caregiving responsibilities, with many stating that they have taken unpaid leave or stopped working temporarily (48%); cut back on the number of hours worked (39%); took early retirement (11%); quit work entirely (28%); or cut back on educational activities (26%).[2]

In 2009, the Caregivers and Veterans Omnibus Health Services Act, establishing PCAFC, passed the Senate unanimously. In 2018, The MISSION Act expanded this program to all eras of service. This also unanimously passed the Senate. In both instances, caregivers took to Capitol Hill to share their stories and fought for the passage of this legislation after having their work hidden for so long. They traveled into DC, visited their congressional offices, and spoke of their challenges with complete strangers in the hope that their vulnerability and activism would impact policy that would touch millions.

In the past six months, our community has reached out to their lawmakers once again. During the current reassessment process, thousands of caregivers are being informed that they will be

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[1] Ramchand, Rajeev, Terri Tanielian, Michael P. Fisher, Christine Anne Vaughan, Thomas E. Trail, Caroline Batka, Phoenix Voorhies, Michael W. Robbins, Eric Robinson, and Bonnie Ghosh-Dastidar, Hidden Heroes: America's Military Caregivers. Santa Monica, CA: RAND Corporation, 2014. https://www.rand.org/pubs/research_reports/RR499.html. Also available in print form.

[2] Ibid

transitioned out of the program. This includes caregivers who are unable to work because their veteran needs around-the-clock supervision. Caregivers who left careers and their educational endeavors to assist with their veteran's Activities of Daily Living (ADLs). Caregivers who are the sole reason their veteran is alive today. Since the start of the reassessment process, thousands of caregivers in PCAFC have been informed that they will transition from the program. With an overall denial rate of 88%, there is no way that what we are seeing today was the intention of Congress in 2010.[3]

On May 6, 2020, the Elizabeth Dole Foundation submitted comments on the new proposed regulations for PCAFC. We submitted these comments with the support of our partners at AARP, the Air Force Sergeants Association, Caring Across Generations, National Alliance for Caregiving, National Military Family Association, Paralyzed Veterans of America, the Rosalynn Carter Institute for Caregiving, and most importantly, nearly seventy caregivers from across the country. The VA received 271 comments, 86% of which expressed opposition to the proposed regulations.[4] Despite opposition from multiple veteran service organizations and Congress, these regulations were adopted with little change in July of 2020. It is not a surprise that this hearing is occurring two years later.

Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs):
At the Elizabeth Dole Foundation, our network of caregivers who care for a wounded, ill, or injured post-9/11 veteran have voiced concern that the care provided under Instrumental Activities of Daily Living (IADLs) is not recognized as relevant or important to their veteran's health as Activities of Daily Living (ADLs). ADLs include tasks such as eating or bathing and are often seen in cases of visible wounds. IADLs include tasks like ensuring veteran safety or medication management, and are often seen in veterans with invisible wounds, such as PTSD or Traumatic Brain Injury (TBI). IADL assistance can also mean monitoring daily triggers that would place the veteran at a greater risk of suicide. In the assessment, IADLs are framed as a need for Supervision, Protection, and Instruction (SPI). Given the high rate of invisible injuries among our post-9/11 caregivers, IADL support is the most frequent intervention and oftentimes the most emotionally challenging for caregivers given the unpredictable nature of PTSD and TBI.

Even though ADLs and SPI are supposed to be given equal weight, the assessment process has a heavy focus on ADLs. According to the Caregiver Support Program at the VA in 2021, 43% of denials are based on an "inability to perform an activity of daily living or a need for supervision,

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[3] "Veterans' Family, Caregiver, and Survivor Advisory Committee", VA.gov, 23 September 2021, https://www.va.gov/ADVISORY/MINUTES/Minutes-VFCSACSep2021.pdf
[4] "Program of Comprehensive Assistance for Family Caregivers Improvements and Amendments Under the VA MISSION Act of 2018", federalregister.gov, 31 July 2020, www.federalregister.gov/d/2020-15931

protection, or instruction" for a minimum of six months.[5] This new rule disproportionately impacts caregivers who care for veterans with severe mental health diagnoses and was strongly opposed by multiple veteran service organizations.

In 2020, we highlighted this issue in our public comments.[6] Not only does this prioritization of ADLs fail to capture the full picture, but it also inadvertently creates an inequity between injuries that are seen and those that are not. Any disparity between physical and mental injury or illness is unacceptable and feeds into the already pervasive stigma in our military and veteran community.

Below are a few examples of how this has impacted caregivers:

- One caregiver recounted that during her assessment, VA staff did not inquire about how the caregiver keeps their veteran safe and only focused on ADLs.
- Another caregiver informed us that they were not asked about IADLs, and that staff were "not interested" in hearing about the veteran's mental health concerns.
- Despite Supervision, Protection, and Instruction being a qualifying factor, another caregiver reports that this was not prioritized, and the majority of the assessment focused on ADLs.
- A caregiver who cares for a veteran with PTSD noted that though the veteran can do many ADLs on their own, evaluating this aspect is limiting in scope and does not accurately portray the reality of their quality of life.

Veterans make a lot of choices; to serve their country, sacrifice time with their family, and to represent their branch with honor. If they are injured, they do not get to choose how their injury impacts their lives and their caregivers do not get to choose what type of care their veteran needs. The Elizabeth Dole Foundation will continue to push for this gap to be closed and for more support to be provided to our constituency.

"Each and Every Time" Standard:

According to the Final Rule, assistance with ADLs is only considered if the caregiver assists their veteran "each and every time" it occurs for a minimum of six months. This means that even if a caregiver helps their veteran with an ADL daily, it still does not reach the level of assistance that the regulations stipulate. Put simply, this standard is overly restrictive and does not match the reality of caregiving. In our public comments, we underscored that "the level of caregiver support needed can vary over time and we are concerned about how the revised criteria may impact caregivers who are applying for enrollment into PCAFC."[7] The comments went on to

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[5] "Veterans' Family, Caregiver, and Survivor Advisory Committee", VA.gov, 23 September 2021, https://www.va.gov/ADVISORY/MINUTES/Minutes-VFCSACSep2021.pdf

[6] "Comment Letter on Proposed PCAFC Regulations", hiddenheroes.org, 6 May 2020, www.hiddenheroes.org/news/pcafcletter/

[7] Ibid

provide the following example: "One day, a caregiver may need to wash a veteran during a shower, however on the next day, that same veteran may only require assistance getting in and out of the shower to bathe. By day three, the same veteran may only require setting the water to an appropriate temperature." The level of caregiver support needed can vary over time, and it is critical that this fluidity is recognized.

Not only is the "each and every time" standard overly restrictive, but we are also finding that it is having a negative impact on the mental and emotional health of veterans and their caregivers:

- One Pennsylvania caregiver shared with us that, "I have to sit and watch him cry while I'm listing the things, he is unable to do for himself."
- Another caregiver wrote, "The constant having to relive and retell your story is triggering for the veteran and caregiver. The constant talking about how broken your veteran is and what he cannot do when we are repeatedly being told in therapy to focus on what he can do...The stress from this program is starting to cause more harm than good. It's unfortunate and disheartening."
- When asked about the impact of the assessments, one caregiver noted that "stress from upcoming check-ins and reassessments builds in the days and weeks leading up them followed by complete disastrous meltdowns the caregivers and families must then endure."

Caregivers frequently report that this process is dehumanizing and demoralizing. This is worsened when a veteran and caregiver spend hours recounting injuries and limitations, only for that vulnerability and openness to be punished with notification that they will be transition from PCAFC. At a time when we are deeply urging our community to ask for help when they need it, we cannot be pushing them away in this manner. These regulations are overly restrictive and do not match the reality of the daily life experience for so many caregivers. We strongly encourage Congress to address this issue and make the appropriate changes.

Documentation Challenges:

Medical records play a critical role in assessing eligibility for PCAFC. Medical records capture the veteran's need for a caregiver, as well as their complex medical history. Per current regulations, the evaluation team is only able to consider the past 12 months of the veteran's records with the VA. This creates an incomplete picture of the veteran's needs, as many have not been to their local VA due to the pandemic. This arbitrary timeline limits the scope of records to consider and does not capture the full needs of the veteran. For veterans with chronic PTSD and suicidal ideation, looking past 12 months of records is imperative as oftentimes the review team will see a pattern of in-patient stays that occur for several years.

After their assessment, caregivers are overwhelmingly reporting that the evaluation notes made by VA staff are not consistent or accurate. Notes are often electronically copied and pasted into the medical record leading to egregious errors in the documentation. This almost always leads to a decision by the VA to transition the veteran and caregiver from the program. This is unacceptable.

The following are examples directly from our community:

- One caregiver from Delaware shared with us, “they base their decision on [doctor’s] notes and in their notes, no one put the caregiver role. The documents that prove need for care from other providers were not uploaded to the file and PCP denied the submission."
- One caregiver reported that “the specific reason for discharge was that ‘The medical record was absent for a neurocognitive disorder, psychosis, delusion, impulsivity or elevated risk that would impair the veteran's ability to manage his self-preservation, identify his needs or provide or arrange for his health and safety and it then pages later states they were not able to collaborate with his care team and “the veteran’s chart was reviewed for information within the last twelve (12) months from…reassessment date.” The caregiver expressed disappointment that their veteran’s documentation that qualified them for medical retirement, disability rating, and unemployment was not considered in this assessment. Additionally, the denial letter states, “he is unable to maintain safety,” a clear qualification for the program.
- Another caregiver spoke with the head of the Caregiver program in Mississippi when they confirmed that for the program to consider medical records from outside of the VA Network, the caregiver must bring them. The head of the program confirmed that the digital system is unable to view outside medical records, and the few that they can see are limited in scope.
- Despite the veteran’s PCP affirming that the caregiver assists with all ADLs daily, they were denied due to records stating that the veteran does not need assistance with ADLs.

While we opened this testimony by detailing the overly restrictive nature of regulations, the Elizabeth Dole Foundation is equally concerned with the ongoing structural and administrative issues with PCAFC. This program has been available for ten years, how is it that documentation errors in a veteran’s medical record have not been addressed? How can a veteran check every box per the new regulations but still be denied from the program due to documentation errors and a lack of provider documentation on the need of a caregiver?

Our nation’s military and veteran caregivers deserve our support and they deserve us to get this program right. I am calling on VA to listen to caregivers and bring solutions to the table to address these issues, and if not addressed, I am calling on Congress to conduct the appropriate oversight and ensure that this program is meeting the needs of our veteran and caregiving community. That is what this expansion was designed to do, and what we advocated that it would do.

WRITTEN TESTIMONY OF CAIRA BENSON, MILITARY CAREGIVER AND DOLE CAREGIVER FELLOW WITH THE ELIZABETH DOLE FOUNDATION BEFORE THE SENATE COMMITTEE ON VETERANS' AFFAIRS UNITED STATES SENATE ON THE VA'S PROGRAM OF COMPREHENSIVE ASSISTANCE FOR FAMILY CAREGIVERS

March 23, 2022

Chairman Tester, Ranking Member Moran, and Members of the Committee, I am pleased to testify today alongside Steve Schwab of the Elizabeth Dole Foundation on the VA's Program of Comprehensive Assistance for Family Caregivers.

When I first met my husband, Eric, in 2005, I never imagined what would lie ahead. I saw us raising a family together, thriving in our respective careers, and traveling the world together in our retirement. But after returning home from the frontlines of the Iraq War, Eric and I found ourselves preparing for a very different kind of battle.

Eric was a combat engineer officer in the Army. His overall plan was to serve for as long as he could and make a career of it, but his major injuries in the early 2000's would end that dream. I still remember him returning from Iraq in 2006, after continually being exposed to explosions and chemicals, and knowing things were "off." When he discussed this with his doctors, they would brush it off as "reintegration stress." No one would listen, even when my husband started experiencing numbness in his legs when he went running. Every symptom and complaint was ignored when no clear cause could immediately be found, even though both of his post-deployment screenings showed what I now know to be clear signs of a Traumatic Brain Injury (TBI).

It would take us a multitude of specialty clinics and countless doctor's appointments until he was formally diagnosed with a TBI in 2018. He was also formally diagnosed with Toxic Encephalopathy[1] the same year. This meant he was also facing a progressive neurological decline that was very likely caused by continuous blast and chemical exposures. By the time of diagnosis, my husband was using a wheelchair for long distances, blacking out, suffering from continuous headaches, and had been removed from all work due to employers being unable to accommodate his disabilities. He was only 38.

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[1] According to the National Institute of Health, toxic encephalopathy is "used to indicate brain dysfunction caused by toxic exposure. Toxic encephalopathy includes a spectrum of symptomatology ranging from subclinical deficits to overt clinical disorders. The clinical manifestations of toxic encephalopathy are related to the affected brain regions and cell types."

Today, Eric is considered wheelchair bound without hands-on assistance.[2] His daily life is interrupted by loss of fine and gross motor control, migraines, blackouts triggered by lights and scents, photophobia, and chronic regional pain syndrome. In addition to all of this, his current neurological degradation has begun to impact his eyesight and his ability to read. His level of disability and care needs qualifies him to be enrolled in Home Based Primary Care (HBPC) at the VA, in addition to seeing specialized neurologists.

Every day I, alongside our five children, watch him decline slowly from his TBI. Watching him understand his condition and coming to terms with the future is heartbreaking.

When we heard of the Program of Comprehensive Assistance for Family Caregivers in 2017, we were elated that there was finally a program that could support me with the new challenges we were facing. We were enrolled in PCAFC in 2017, but were discharged by the spring of 2018 because we spent winters with family to accommodate Eric's medical conditions. Despite having set addresses in both locations, we were discharged due to a "non-permanent address."

In October of 2020, the Final Rule for PCAFC was published. At first, I was delighted that the regulations had shifted to begin considering illnesses that were not service connected. Eric has been considered permanent and totally disabled since 2017, but since we were still struggling to service connect his TBI and Encephalopathy, I was optimistic this change would be able to help families like mine.

We applied the moment the new regulation went into effect. In fact, we were the first veteran/caregiver team to go through the new process at Lake Nona VA Medical Center in Orlando. Our HBPC team, and even the initial assessor, considered our case to be an "easy approval." Eric had a Katz score of zero, meaning he needed help with every single Activity of Daily Living (ADL), functional assessments documenting his ADL needs, and three providers on record saying he should not be left alone due to his blackouts, his confusion afterwards, and his newest symptom — a facial droop that caused difficulties with speech and swallowing.

Considering the plethora of documentation for his caregiving needs, his care team was shocked when our case was denied by the Centralized Eligibility and Appeals Team (CEAT) within days, and without even allowing the veteran's primary care physician to weigh in on the case.

I was livid. The reasoning of the CEAT's denial was that the RN who did Eric's functional assessment rated him as independent across the board—a direct contradiction to what we stated to the RN during that assessment and what was clinically documented. I assumed this would be easy to correct and immediately filed an appeal with the help of a patient advocate.

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[2] Hands-on assistance is defined as the physical assistance of another person without which a person would be unable to perform one or more of the Activities of Daily Living (ADLs).

We were denied again. I enlisted help in drafting our second appeal from the Quality of Life Foundation, and in doing so, unearthed even more discrepancies in our case. I filed the new appeal and was contacted by the Caregiver Support Program (CSP) to discuss the review. When I returned the call, I was shocked to discover that no one at the facility, local or VAMC, knew who the person who had called me even was.

I called the number on the appeals form and connected with the Program Manager of VISN 8 Caregiver Support who helped us track down our appeal letter. After digging into our case, she agreed our case had an "egregious oversight," that Eric's Functional Assessment was indeed "negligent." She couldn't override our denial at the local level, but she would help us by ordering a new assessment so it would reflect the medical record. In addition, she documented in his medical records that there had been a significant mistake in our assessments, as well as in our decision, and that those assessments had been redone to be consistent with the medical record.

After months of work and discussion with the VA, the Atlanta CEAT finally approved our enrollment within PCAFC. Despite Eric's doctor's requests to be placed higher, we were placed at Level One of the program. We should have easily qualified for Level Two, but we were tired of fighting the system and did not appeal the decision.

We stayed current in the program, conducted wellness checks, and continued to meet the parameters of the PCAFC program. Eric continued with his therapies and HBPC care. We had other battles we needed to tackle and were ecstatic that PCAFC was no longer one.

In December of 2021, we were called and told it was time for our annual reassessment. I was also informed that we would be going through the entire application process again, including an intake questionnaire. I was baffled. We did our check-ins and regularly met with his care team, so we were unsure as to why we needed to complete the entire process again.

On January 14th, we completed the first portion of our yearly assessment. Before we began, I made the assessor aware that my husband had medical accommodations in place due to his TBI. If Eric spends more than 30 minutes engaging in sustained cognitive tasks, his left face starts to droop, he starts to slur words, and he loses the ability to swallow. Eric also had just been discharged from the hospital due to complications from COVID-19, and the assessor and I both agreed on the importance of not pushing Eric to exhaustion.

Despite this, the assessor continued the assessment beyond his accommodative limit and Eric's face began to droop. I began to help answer questions surrounding his history in order to give him a break, but the assessor insisted she needed the answers from him and if I didn't stop interjecting, she would make me leave the room. I reiterated his need for a shortened assessment to accommodate his condition, but she told me she was unable to split up the assessment.

After nearly an hour of questioning, I decided Eric needed to stop. He was losing the ability to speak, had a migraine, was short of breath, and even had drool coming out of his mouth from his inability to swallow. He had become so exhausted that he couldn't hold himself up in his wheelchair, and his entire left side was unresponsive. I helped lift him into bed, gave him much needed migraine medication, and continued the assessment alone as he slept.

We went on to thoroughly discuss Eric's ADL and IADL[3] needs. Despite these needs being recorded in detail in his record by his HBPC team and despite everything that the assessor had just witnessed, it seemed as though the assessor did not believe me and challenged me on why he needed assistance. However, nothing could have prepared me for what I was asked next.

The accessor then asked if I had "any concerns about [my] intimate relationship." I was stunned. When I clarified to see if she was asking about intimate partner violence, the assessor reiterated that she was specifically asking about intimacy issues. Not only did this have no relevance to his condition or caregiving needs, but it was also humiliating and demeaning.

After a little over two hours, the assessment concluded. This was followed up with three more assessments the next week, all of which took no less than an hour, and were scheduled around his nine regularly scheduled appointments and therapies. We were approved to remain at the lower level within the program for assistance with two ADLs, despite his care team documenting him needing assistance with five ADLs and his inability to be left alone. It is especially worth noting that he was not approved under Safety, Protection, and Instruction. This qualification is part of the new regulations, and is supposed to help caregivers who assist with mental health, neurological residuals, and IADL needs qualify for the program. Eric's need for non-ADL support, even though clearly documented in assessment and medical records, was never even taken into consideration during CEAT decision.

When I first heard about this program, I was so thankful there was finally assistance for caregiving teams like Eric and me. I needed someone to be a resource for us and to support our unique needs. Sadly, I was let down. I am disheartened and dismayed at what this program has become.

Unlike thousands of caregivers going through the same process, we are still in the program. However, the past five years we have spent interacting with the program have been

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[3] According to the VA, Instrumental Activities of Daily Living (IADLs) are defined as "a series of more complex tasks or functions that help maintain one's personal life and environment, for example: shopping for food, cooking, doing laundry, housecleaning, managing money, managing medications, driving/using public transportation, or using the phone."

demoralizing, humiliating, and exhausting. Those years have also taught me that this support can be taken away at any time. A truth validated by watching so many other deserving families being discharged right now.

This yearly process takes hours from our lives—hours I need to support Eric. Eric has felt so demoralized by the program and the processes involved. The VA's mission is to care for those who shall have borne the battle, yet Eric feels they are ignoring a crucial part of that mission and his healthcare if VA is not fully supporting the caregiver. Given everything we have gone through, and Eric's feelings of betrayal, we are currently weighing if the benefits of this program are worth the physical and emotional toll it takes on our family. This cannot have been the intention of Congress when it was passed unanimously years ago.

I am not alone in this experience. Across the country, there are thousands of Cairas and Erics fighting for support from the VA. The PCAFC process needs to be simplified and the assessments need to be less frequent, intrusive, dehumanizing. Our HBPC doctors already document much of what is asked by the caregiver support program during assessment. VA doctors should have templates ready to document what is needed for the CEAT during appointments. Neurological impairments and IADLS should be properly weighed under the supervision, protection, and instruction qualifier. Progressive or long-term cases, like Eric's, should be allowed a respite from yearly assessments as long as his HBPC team verifies there is no significant improvement. It is time for the Caregiver Support Program to truly accommodate their participants.

It is my privilege and honor to be Eric's caregiver, and my worth as a caregiver is not defined by my acceptance into, nor my participation in, any program, especially including PCAFC. However, the quality of my husband's care at VA is, and should be, judged by how VA treats, supports, and deals with veteran caregivers.

Chairman Tester and Ranking Member Moran, thank you for holding a hearing on this critical issue and allowing me to share my story. I am happy to answer any questions you may have.

KEEPING OUR PROMISE TO
AMERICA'S VETERANS

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STATEMENT OF
JIM MARSZALEK
NATIONAL SERVICE DIRECTOR

COMMITTEE ON VETERANS' AFFAIRS
UNITED STATES SENATE
MARCH 23, 2022

FIXING AND STRENGTHING VA'S CAREGIVER SUPPORT PROGRAM

Chairman Tester, Ranking Member Moran, and members of the Committee:

Thank you for inviting DAV (Disabled American Veterans) to testify about the Department of Veterans Affairs (VA) Caregiver Support Program (CSP) – specifically the Program of Comprehensive Assistance for Family Caregivers (PCAFC) – the challenges it faces and how best to move the program forward to properly support seriously injured, ill and disabled veterans and their family caregivers.

As you know, DAV is a non-profit veterans service organization (VSO) comprised of more than one million wartime service-disabled veterans that is dedicated to a single purpose: empowering veterans to lead high-quality lives with respect and dignity. Tens of thousands of our members and Auxiliary are themselves caregivers, many of them in the PCAFC. These men and women have selflessly dedicated years or decades to provide loving care for a seriously disabled veteran family member who would otherwise have required institutional or non-institutional care from VA. These unsung heroes deserve our thanks and our full support, and we appreciate the opportunity to share DAV's perspectives and recommendations with the Committee.

BACKGROUND

Mr. Chairman, May 5, 2010, was a historic day. Following unanimous congressional approval of the *Caregivers and Veterans Omnibus Health Services Act of 2010* (P.L. 111-163), President Obama signed this landmark legislation that formally recognized the critical role family caregivers play in keeping our promise to America's veterans, and for the first time, provided meaningful support directly to family caregivers. The new law created a comprehensive program (PCAFC) to support these caregivers through the payment of a stipend, provision of health insurance, guaranteed respite care, and mental health services, along with training and counseling to support them. The law also created a program that offered a lower level of support, known as the Program of General Caregiver Support Services (PGCSS), offering family caregivers ineligible for PCAFC with access to training, coaching, educational materials, and peer support.

In July 2011, the first approved family caregivers entered the PCAFC; by the end of the year more than 2,000 family caregivers were enrolled and by 2014, there were over 20,000 deserving family caregivers receiving desperately needed support. However, the law only provided eligibility for the PCAFC to veterans whose injuries had occurred on or after September 11, 2001, leaving behind tens of thousands of veterans from World War II, the Korean, Vietnam, and Persian Gulf War eras. In addition, the regulations promulgated by VA left out thousands of veterans whose severe disabilities were the result of illnesses, rather than injuries.

In 2016, DAV launched The Unsung Heroes Initiative, an advocacy and awareness campaign to change the law to include veterans of all eras and veterans whose disabilities were caused by illnesses. The initiative helped generate significant new media coverage of the problems and additional congressional focus. Together with our VSO partners, we delivered a national petition to Congress signed by hundreds of thousands of supportive Americans, calling for comprehensive caregiver benefits for severely disabled veterans of all eras.

CAREGIVER EXPANSION

With a growing consensus on the need for change, and strong bipartisan, bicameral congressional support, Congress included provisions in the VA MISSION Act of 2018 (P.L. 115-182) to expand PCAFC eligibility to veterans from all eras in a two-part phase-in. Unfortunately, VA failed to deliver the required new caregiver IT system (Caregiver Records Management Application, or “CARMA”) on-time, and as a result the first phase of the expansion – covering WWII, Korean and Vietnam War veterans—was delayed until October 1, 2020, a year later than mandated by Congress. Consequently, the second phase (post-Vietnam thru 9/11) was also delayed by a year and is now scheduled to begin October 1, 2022.

Concurrent with expansion of the program to pre-9/11 veterans, VA proposed and promulgated new PCAFC regulations to address persistent problems with the program’s eligibility and reassessment rules. In April 2017, then-VA Secretary Shulkin had suspended removals from PCAFC based on VA reassessments due to concerns about inconsistency, transparency, and equity of the decisions. After an internal review of the program, the reassessments were restarted in September 2017, but it soon became apparent that the problems had not been resolved. In December 2018, then-VA Secretary Wilkie also temporarily suspended removals from the PCAFC citing the same recurring issues with reassessments and removals.

NEW CAREGIVER REGULATIONS

In an effort to address these recurring problems, VA began working on changes to the PCAFC regulations, formally proposing new eligibility rules in March 2020, which following a short public comment period, were adopted on July 31, 2020, and became effective on October 1, 2020, the same day that the first phase of the expansion took place. In addition to providing details necessary to implement the mandated expansion of eligibility to pre-9/11 veterans, the legislation made some significant changes to key definitions impacting eligibility.

The new regulation changed the definition of “serious injury” to cover “any service-connected disability” that was rated at 70% or more, or that when combined with other service-connected disabilities resulted in a combined rating of 70% or more. This definition had two major consequences: first, veterans whose disabilities resulted from serious illnesses would now have the same eligibility as those with serious injuries. Second, veterans rated less than 70%, including thousands currently receiving caregiver benefits, would no longer be eligible for the PCAFC. In our formal comments on the proposed rule submitted to the Federal Register in May 2020, DAV expressed support for expanding this definition to cover illnesses; however, we cautioned that the new 70% requirement could negatively impact thousands of family caregivers whose needs were moderate to severe.

Another major change was the new definition of “inability to perform an activity of daily living (ADL),” which now required a veteran to need assistance “each time” they completed an ADL. In our Federal Register comments, DAV expressed serious concerns about whether this new “each time” standard could be consistently assessed and applied, and whether it would be an equitable standard for veterans across the full spectrum of disabilities. We questioned whether it was logical or equitable for VA to assess a veteran who could complete an ADL one time each week or month as not requiring assistance “each time” they perform that ADL.

The new “each time” ADL standard became even more important because the new regulation changed the requirements for caregivers to receive the highest level of stipend support. Under the new rule, a veteran must have at least three qualifying ADLs meeting the “each time” standard to be eligible for the higher tier of stipend support. As I will describe below, and I’m certain you have heard and will hear again today from other witnesses, these new rules are resulting in far too many veterans being found ineligible for the PCAFC, and thousands have already been notified they will soon be removed from the program.

PERSISTANT ROBLEMS WITH THE CAREGIVER PROGRAM

Since October 1, 2021, well over 125,000 veterans have applied to the PCAFC, mostly pre-9/11 veterans who had been waiting more than a decade to finally become eligible. However, many of the same problems that caused two different VA Secretaries to halt reassessments and removals, continue to plague the caregiver program under the new regulations. The latest statistics received from the Veterans Health Administration (VHA) indicated that out of approximately 116,000 applications since the phase one expansion began in October 2021 through January 2022, only about 16,000 were approved; that’s greater than an 85% denial rate.

More troubling, the CSP has been unable or unwilling to provide complete and meaningful details regarding the categories, reasons, and bases of these denials.

Similarly, despite completing more than half of all the legacy reassessments for veterans and their caregivers in the program before the new regulations took effect, the CSP has yet to provide VSOs and other stakeholders with relevant data on how many will be removed or reduced to a lower tier, and a breakdown of the reasons for these changes. Considering the time, resources and delays involved in developing and deploying the new CARMA IT system, it would be concerning if VHA was unable to retrieve and share such data.

As discussed above, perhaps the most significant concerns about the PCAFC eligibility process is the near total lack of transparency for veterans, caregivers, and their authorized representatives regarding how and why VHA is making its decisions. The notification letters disseminated to date have offered no details of the evidence or findings that were used in making eligibility decisions. Typically, the notification letters failed to cite evidence or findings to justify the inclusion or exclusion of certain ADLs in the decision. We understand that the CSP is currently developing new models for decision notification letters that will comply with the AMA's requirement under 38 USC 5104 to provide specific categories of information, often referred to as an "8-point letter." We look forward to seeing this requirement fully and faithfully implemented as intended by Congress in the near future.

Pursuant to the problems discussed above, DAV has serious concerns whether the "each time" standard in the regulation could ever be consistently and equitably assessed and applied. In conversations with the CSP, we have raised the question of whether a veteran who is able to complete an ADL only one time in a month would fail to meet the "each time" standard; we were told that it is not the intention of VHA to 'penalize a veteran for a moment of independence.' We agree with that intention; however, we are unable to verify if that statement is accurate until we can review the assessments of veterans we represent. Despite repeated requests, we have yet to be provided explanations of how the CSP uses and scores its current assessment tools. Without such basic transparency, it is impossible to determine whether the new eligibility regulations are being properly administered, or whether they are faithfully fulfilling the intention of the law.

The same problems exist for reassessments. Thousands of legacy veterans and caregivers have undergone reassessments of their eligibility over the past year, and we are increasingly hearing from many who are unhappy about both the process and the outcomes. VHA's notifications, whether verbal or in writing, provide little or no meaningful explanation for why a reassessment resulted in a reduction or removal of a caregiver from PCAFC. We have heard anecdotal stories of reassessments, both virtual and telephone conversations, that were aggressive or hostile, and within days resulted in reductions or removals. While VA had projected that thousands of veterans would be removed from the PCAFC under the new eligibility regulations, without full and comprehensive data from VHA, it is impossible to determine if the reports we have heard represent merely anecdotal information or broader systemic problems. Moreover, complete statistical data is necessary to determine the accuracy of VHA's projection that 98% of former tier one caregivers would be removed from the program based on the new eligibility regulations, but only 2% of former tier two and three caregivers. We urge the Committee to request and make public all such data.

THE *BEAUDETTE* DECISION

Mr. Chairman, in addition to new regulations, another major change to the PCAFC occurred last year when the Court of Appeals for Veterans Claims (CAVC) issued a ruling in the *Beaudette v. McDonough* case on April 19, 2021. The Court held that VA's interpretation that the original caregiver law (P.L. 109-461) precluded veterans from appealing unfavorable decisions to the Board of Veterans' Appeals ("the Board")—as is allowed for all other VA benefits under the Veterans Judicial Review Act (P.L. 100-687)—was incorrect. The CAVC held that not only would Mr. Beaudette be allowed the right to appeal his removal from the caregiver program to the Board, but that VA's error was so grave that VA would be required to notify every veteran and caregiver who had ever applied for the caregiver program and received a decision of their new options to appeal to the Board or utilize the appellate provisions of the 'Veterans Appeals Improvement and Modernization Act of 2017 (P.L. 115-55), commonly referred to as the "AMA."

On August 5, 2021, VA formally agreed to implement the *Beaudette* decision, even though the Administration would later file an appeal to overturn that decision with the U.S. Court of Appeals for the Federal Circuit in December 2021. However, more than seven months after agreeing to implement *Beaudette*, VA has yet to fully establish and fully operationalize new appellate processes. While veterans and caregivers have already filed almost a thousand appeals to the Board and an unknown number of AMA supplemental claims and higher level reviews with VHA, there is no process for veterans or their authorized representatives to confirm if their appeals have been received, whether power-of-attorney authorizations have been received and recognized, or when the next steps on those appeals will take place, including requests for hearings and informal conferences.

THREE VETERANS AND THEIR FAMILY CAREGIVERS

Mr. Chairman, to better illustrate the problems we have observed with the new PCAFC regulations, below are three stories from veterans and their family caregivers, each of whom has given DAV permission share their recent experiences.

Brad and Donna Barton

In 1968, during the battle of Khe Sanh, a Marine named Brad Barton was hit by shrapnel from a North Vietnamese mortar round, which severed his spinal cord and instantly paralyzed and confined him to a wheelchair for the rest of his life. Like others who suffered such catastrophic injuries, Brad required tremendous support in his recovery and rehabilitation. Brad was lucky to meet and later marry Donna, who has been by his side supporting him since 1974. While Brad worked hard throughout his life to develop as much independence as possible, he relies increasingly on Donna.

Although disappointed in 2010 when the new VA caregiver program excluded pre-9/11 veterans, Brad and Donna were excited when the *VA MISSION Act of 2018* authorized the program to expand to include Vietnam era veterans. After a further unnecessary year-long delay caused by VA's failure to field the new CARMA IT system on time, Brad and Donna were among the first to apply for the PCAFC when the first phase of the expansion took place in October 2021. Within a couple months, Brad and Donna received notification from VHA that she was approved into the PCAFC. However, according to the VHA notification, Brad was found to only have two ADLs that qualified under the new regulations; VHA did not qualify him for the mobility ADL, which would have been the third ADL necessary for the higher tier of the program. Instead, Donna was admitted into the lower tier of the program.

Brad and Donna are at a loss to understand how his mobility challenges did not meet the new ADL standard, since Brad needs assistance every day maneuvering his environment, whether transferring from his bed to his wheelchair or to another chair or in some other way. Neither the letter notifying them of the decision nor the summary of the assessment he was able to obtain provided any explanation of why he did not qualify for the mobility ADL. Brad requested but was unable to get a copy of the complete assessment to understand VHA's rationale nor to obtain all the other evidence used by VHA to make this decision. He filed two clinical appeals with VHA as allowed under the new regulations (pre-*Beaudette*), both of which were unsuccessful and neither of which provided any additional explanation. Following the CAVC ruling in the *Beaudette* case, Brad asked DAV to represent him in filing a new appeal allowed by the CAVC decision, and DAV subsequently filed a higher level review with VA and requested an informal conference. To date, we have heard nothing further from VHA on when, how or who will conduct the higher level review. Furthermore, we have not been able to obtain the evidence used by VHA – a basic right under the Veterans Judicial Review Act. Brad, like thousands of others, is once again left waiting for support he and his family caregiver need.

Dennis and Donna Joyner

In the summer of 1969, just 32 days after arriving in Vietnam, 20-year old Dennis Joyner was on patrol in the Mekong Delta with his Army unit when he was catastrophically wounded by a landmine explosion that resulted in the amputation of both of his legs above the knees and his left arm below the elbow. Dennis almost died right there on the battlefield, but thanks to heroic actions by his fellow soldiers, he survived. After numerous surgeries and months of recovery, with indispensable support from the VA and his family, he was slowly able to begin building a new and meaningful life. In 1981, Dennis married Donna, and they have been together ever since. Donna knew she would be taking on a permanent role as caregiver and eventually gave up her own job to care for Dennis full time. As Dennis and Donna enter their twilight years, he requires more and more support, even for activities that he was able to do on his own in his younger years.

Like Brad and others, Dennis has waited and worked for more than a decade to get Congress to expand the PCAFC to seriously disabled veterans of all eras. After waiting an additional year due to VA's IT failure, Dennis and Donna woke up early on October 1st of 2020 to apply for the caregiver benefits she so richly deserved. Within weeks, they had begun the interview and assessment process, and within a couple of months, he was found eligible and she was admitted to the program at the higher tier. Both were thrilled to finally receive the same support as post-9/11 veterans already in the program, and relieved to know that as they continued to age, VA would be giving Donna its maximum support to enable them both to continue living at home for as long as possible.

A couple of months ago, almost exactly one year from the date Dennis and Donna began to receive full caregiver benefits, the CSP initiated a "reassessment" of his condition and her caregiving. After what they found to be an aggressive interview and follow up by CSP staff, Dennis and Donna were notified that she was being downgraded to the lower tier of the PCAFC because VA had determined that Dennis required less caregiver support. No specific explanation or additional information was provided, other than links to forms explaining how they could appeal this decision under the new *Beaudette* appeals regime. For Dennis and Donna, it was unfathomable that VA could have determined he needed less support since his injuries have not and will never improve, and the only difference was that they were both a year older. Dennis asked DAV to represent him in his appeal and we have requested a hearing on the proposed reduction in caregiver benefits. Like others in the same situation, neither Dennis nor DAV, his authorized representative, have been permitted access to the evidence and assessments used to make this decision.

Dave and Yvonne Riley

Dave Riley served both in the Army and in the Coast Guard, where he became an elite helicopter rescue swimmer. While on active duty in 1997 at the Coast Guard Aviation Training Center in Mobile, Alabama, Dave contracted a rare bacterial infection that quickly began destroying his organs and limbs, threating his life. While in a medically-induced coma, his wife Yvonne had to make the gut-wrenching decision to allow his doctors to amputate both his legs below the knees and both his arms below the elbows in an attempt to save his life. Dave did survive but his life was forever changed. He was, however, blessed to have a wife who committed to care for him, to allow him to live as fulfilling a life as they could build together. From his return home and for the next 25 years, Yvonne has been the person who takes care of him: from attaching his four prosthetic limbs in the morning, to meeting his basic needs throughout the day.

With the love and daily support of his wife, Dave has been able to raise a family and have a successful life. But he realizes that none of it would have been possible without Yvonne. That's why Dave was dedicated to supporting DAV's Unsung Heroes Initiative, and why he traveled to Capitol Hill numerous times over the years to advocate for expanding the caregiver program to veterans of all eras, and to include those disabled by illnesses. Dave knows that the challenges that he and Yvonne face today will only get harder as they grow older. Dave has been waiting for years for Yvonne to get the recognition and support she needs and deserves, and they are both anxiously waiting for VA to implement the second phase of the PCAFC expansion this October, without any further delays.

DAV RECOMMENDATIONS

Mr. Chairman, for Brad, Dennis and Dave, the caregiver program is not just about meeting their needs, it is also about providing the honor, respect, and tangible support that Donna, Donna, and Yvonne—and many other caregivers—have earned and deserve. The expansion of the PCAFC to veterans of all eras, and the inclusion of severe disabilities resulting from illnesses, are both overdue changes that will benefit tens of thousands of veterans and caregivers for decades to come. The support provided by the PCAFC has been a lifeline for so many, and the dedicated staff of the Caregiver Support Program deserve great credit and thanks for helping improve so many lives. However, the new regulations adopted in 2020 have not fixed longstanding problems with the eligibility and reassessment process, and VA has failed to implement the new Court-ordered appeals process. VA, Congress, VSOs, and other key stakeholders must work together to improve the eligibility, reassessment, and appeals processes. We must develop a consensus for the best path forward, and then modify the statute, regulations, and administrative processes so that VA prioritizes getting veterans and caregivers into, not out of the caregiver program. To that end, DAV offers the following recommendations.

1. **VA must complete the phase two expansion of the PCAFC to all eras of veterans on October 1, 2022, as scheduled without any further delays.**

   After already waiting a decade for the expansion of eligibility to all eras, and then an additional year due to VA's IT failure, it would be unconscionable to force severely disabled veterans and their caregivers to continue waiting. Congress must take every action necessary, including providing additional resources to the CSP if required, to ensure that phase two of the caregiver expansion takes place as currently scheduled on October 1, 2022.

2. **VA must prioritize the processing of PCAFC applications and appeals, not reassessments, reductions, or removals.**

   The primary focus of VA now must be to admit veterans into the caregiver program or to elevate them into a higher tier of assistance, not to conduct reassessments that would remove or reduce caregivers into a lower tier unless there is reason to be believe that removal or reduction would be in the veteran's best interest. This is particularly true for those newly-approved veterans and caregivers who became eligible with the phase one expansion. It is hard to understand why the CSP, which is overwhelmed with work from a higher-than-expected number of applications, as well as new appeals work due to the *Beaudette* decision, would divert resources to conduct reassessments leading to removals and reductions. The CSP has indicated its central ethos is now focused on "getting to yes," the prioritization of its time and resources should be reordered to reflect that goal.

3. **VA should not require annual reassessments of a veteran's qualifying ADLs if they are based on disabilities unlikely to improve.**

   While the statute requires VA to "...monitor the well-being of each eligible veteran receiving personal care services under the program..." [38 USC 1720G(a)(9)(A)], it does not mandate an annual reassessment. Furthermore, even though the new regulations call for annual reassessments, they also allow that, "Reassessments may occur on a less than annual basis if a determination is made and documented by VA that an annual reassessment is unnecessary." [38 CFR 71.30]

   We understand and agree with the program's interest in regularly checking and monitoring the needs, health, and well-being of all caregivers; that is a strength of the program. However, VHA should take into consideration whether the underlying conditions for a qualifying ADL are likely to improve in determining when to reassess a veteran's need for caregiver assistance, similar to how the Veterans Benefits Administration (VBA) administers regulations related to routine future disability compensation reexaminations. [38 CFR 3.327]

   The optimal frequency of reassessing a severely disabled veteran's need for caregiver support depends on the type of injury, illness, and disability, as well as age and other factors. For example, a 60-year old veteran in the PCAFC who is paralyzed or missing multiple limbs is extremely unlikely to have less need for caregiver support one year after the initial assessment; whereas a young and recently-disabled veteran may not yet have reached their full potential for recovery, rehabilitation, and independence.

4. **The Administration should withdraw its appeal of the *Beaudette* decision and immediately and fully implement it and all AMA requirements.**

   As discussed above, the CAVC in *Beaudette* ruled that VA must provide every veteran and caregiver who received a decision since inception of the PCAFC in 2011 with the right to appeal any unfavorable decision to the Board of Veterans' Appeals, along with the right to choose AMA options and receive full due process rights contained in the Veterans Judicial Review Act (VJRA). Notwithstanding VA's settlement in the *Beaudette* case, its acceptance and implementation of the class action ruling by the CAVC, and the preliminary actions taken to establish new appellate procedures for the CSP, the Administration last December appealed the *Beaudette* decision to the Court of Appeals for the Federal Circuit.

   We believe that Board and CAVC oversight would help address the systemic problems in providing consistent, equitable and transparent decisions. Regardless of what the language of the original statute, or the intent of some or all of its authors, allowing VA to provide only a "clinical appeals" process has been and would continue preventing too many veterans from receiving caregiver benefits and therefore should be rejected. VA has already conceded in the *Beaudette* case that its caregiver benefits are "benefits" within the scope of the VJRA, and thus should have all VJRA due process rights. Moreover, the lack of confidence in the process by veterans and caregivers undermines the integrity of the law and the program, which judicial review can bolster.

5. **Congress should enact legislation to separate PCAFC eligibility determinations for veterans from eligibility determinations for family caregivers; and require VBA to make veterans' eligibility decisions while continuing to have VHA make caregiver eligibility decisions.**

To improve accuracy and consistency of PCAFC eligibility decisions, we recommend separating the determination of a veteran's eligibility for PCAFC from that of their designated family caregiver. For veterans applying to the PCAFC, the determination of their eligibility is based on specific criteria in the regulations, as applied to clinical and other relevant evidence assembled by VHA. In most respects, the adjudication process for determining eligibility for PCAFC benefits is not materially different than what VBA uses for making disability compensation determinations, particularly when assigning rating levels. For example, in the disability claims process, a VBA rating specialist reviews primarily clinical evidence and medical opinions, and then adjudicates based on how it aligns with the appropriate regulatory standards. Now that caregiver decisions must contain the same elements as VBA claims notifications, and veterans must be provided the same AMA and VJRA rights as all other benefit claimants, it makes even more sense to use VBA's established experience and expertise to adjudicate veteran eligibility for the PCAFC.

Under this concept, the VHA CSP would continue to have responsibility for all other aspects of the program's administration as it does today, including determining caregiver eligibility; providing caregiver education, training, and counseling support; delivering and coordinating all PCAFC benefits; conducting assessments, reassessments and making "best interest" determinations; and overseeing and making recommendations for how to better achieve the purposes of the program. While clinical assessments, medical opinions and other relevant evidence would continue to be assembled by VHA, it would be forwarded to VBA to adjudicate a veteran's eligibility for the PCAFC based on the existing law and regulations.

We recognize that this change would increase the workload of VBA, which is already facing a rising number of benefit claims. However, the work required to adjudicate veterans' eligibility for PCAFC benefits would be more easily accomplished inside VBA where similar work, processes and IT infrastructure already exists, rather than in VHA, where it would be necessary to re-create a parallel level of expertise and infrastructure.

6. **Congress or VA should replace the "each time" standard for qualifying ADLs with a more realistic, measurable, and equitable standard.**

As discussed above, the new regulatory standard that a veteran must require assistance "each time" they complete an ADL has proven unworkable. Contrary to the plain meaning of the phrase "each time," VHA has openly stated that if a veteran completes an ADL one time in a week or month, that ADL is not disqualified from consideration on that basis alone. As such, the "each time" standard is not being strictly enforced, raising questions about whether PCAFC assessments and eligibility determinations are arbitrary.

On the other hand, if a literal "each time" standard was strictly applied, it would mean that a veteran who could not complete each of the seven ADLs without assistance 99 of 100 times a week, but who could muster the physical energy and mental acuity to complete each ADL one time a week, would not even qualify for the lower tier of the PCAFC. DAV had warned during consideration of the new caregiver regulation that establishing a new ADL standard without first determining if it can be objectively, consistently, and equitably assessed and administered would lead to problems, as have clearly manifested.

7. **VHA must provide full transparency for all assessment tools, questionnaires and methodologies used to make PCAFC decisions, and must provide veterans and their representatives full access to all evidence, information and deliberations used to make eligibility decisions.**

Despite repeated requests over the past two years, VHA has not provided transparency of the assessment tools, questionnaires and methodologies used to make eligibility determinations for the PCAFC. Preventing veterans and their advocates from understanding how caregiver eligibility decisions are made does not benefit veterans, caregivers or ultimately, VHA itself.

Moreover, now that the CAVC has ruled, and VA has agreed to accept the *Beaudette* ruling (notwithstanding the Administration's subsequent appeal of that ruling), there is no reason for VHA to prevent veterans and their authorized representatives from having full access to all evidence, information and deliberations related to their decisions. The fact that veterans and caregivers now have a right to file an appeal with the Board or through additional AMA options, requires full access to all evidence used in making the decisions being appealed. As such, the Board of Veterans' Appeals would require VHA to present all evidence—including clinical evidence, assessments, and opinions during consideration an appeal; and the Board would then make all such evidence fully available to veteran appellants and their authorized representatives. VHA's continued failure to provide such access in contravention of accepted AMA and VJRA principles serves only to delay and deny veterans their due process rights.

8. **Congress must require VA to regularly publish all relevant data on PCAFC applications, approvals, denials, admissions, reassessments, and appeals – including details on the specific reasons for each decision.**

> Just as individual veterans must have full access to all the facts and evidence related to their caregiver claims and appeals, VA must also make fully and openly available all the program data and statistics to Congress, veteran stakeholders, and the public. Since the phase one expansion of the PCAFC, the CSP has only intermittently provided meaningful data requested by Congress and VSOs. Such information is essential for stakeholders to assess whether the PCAFC is operating as Congress intended and as the law and regulations require.
>
> Further, without complete and timely data, it is impossible to determine if the new caregiver regulations promulgated in 2020 are achieving the goals identified by VA during rulemaking. As discussed above, until VHA releases detailed information on the number of legacy veterans and caregivers removed from the program due to new eligibility regulations, Congress cannot determine whether the regulation is working as VA intended, or whether Congress is satisfied with the outcome. VHA must provide the same level of transparency for caregiver benefits that VBA provides for benefit claims, which includes regular reporting, such as its weekly "Monday morning" workload reports.

Mr. Chairman, VA's Caregiver Support Program, both the comprehensive (PCAFC) and the general (PGCSS) programs, provide much-needed and deserved assistance to severely disabled veterans and their family caregivers. For those admitted into these programs, this support is beneficial and life-changing, and veteran and caregiver satisfaction is very high. Unfortunately, the eligibility, reassessment and appeals processes are not and have not been functioning properly from the beginning of the program. We urge the Committee to continue aggressive oversight of VA's caregiver program, carefully consider the recommendations that DAV and our colleagues have proposed, and work together with all interested stakeholders to fix the identified problems and strengthen this invaluable program.

That concludes my testimony, and I would be happy to answer any questions you or members of the Committee may have.

"HONORING OUR COMMITMENT: IMPROVING VA'S PROGRAM OF COMPREHENSIVE ASSISTANCE FOR FAMILY CAREGIVERS"

STATEMENT OF ANDREA SAWYER

QUALIFY OF LIFE FOUNDATION'S WOUNDED VETERAN FAMILY CARE PROGAM

BEFORE THE

COMMITTEE ON VETERAN'S AFFAIRS

UNITED STATES SENATE

MARCH 23, 2022

Mr. Chairman, Members of the Committee, my name is Andrea Sawyer, and I am an Advocacy Navigator 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 those who have been wounded, ill, or injured serving this nation.

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 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 at their side. By broadening eligibility, Congress acknowledged the argument caregivers had been making for years--by being present at the veteran's side, caregivers were 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 a cost-savings for the government.

Congressional Intent vs. Implementation

Congress clearly expressed its intent in the new 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 "catastrophically" injured, a term which had been very 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 both educational resources for those applying for the program, as well assisting 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 this program. Let me be clear, however, 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 and concise language.

As we have assisted in the drafting of these clinical appeals, we have found that while the legislation as passed broadened the program, the VA's implementing regulations and guidance have vastly narrowed the number of individuals who would qualify for the stipend and other PCAFC services. In many cases, it seems the VA has exchanged a program intended for seriously injured to one only for those who were catastrophically injured. BOTH categories of veterans often require a caregiver to achieve their maximum level of functionality and highest quality of life. For example, under the original program, the veteran and caregiver simply needed to prove that the veteran required assistance with defined Activities of Daily Living (ADLs). These include bathing, toileting, dressing, transferring, eating, and incontinence. Once that need for assistance was established, then the amount of time that the caregiver was required to assist the veteran with the established ADLs was calculated. This amount of time and number of areas of assistance determined the caregiver's stipend level.

Under the new regulation, however, a veteran must now require assistance with an ADL "each and every time" it is completed to qualify. Such a strict application of the rules within PCAFC inhibits even low levels of independence for those who may be able to perform an ADL infrequently by excluding them from the program. One caregiver offered, "The constant reminder of 'we will end this benefit any time there might be a hint of recovery or improvement,' does not encourage improvement." The strict interpretation of the regulation particularly disadvantages those with dementia, severe illness, traumatic brain injury, and other conditions that are relapsing and remitting and does not serve the best interest of the veteran.

Furthermore, when testifying before Congress on February 6, 2018, Secretary Shulkin stated that the Department wanted to make this change to standardize and align the PCAFC program with other VA programs such as Aid and Attendance(A&A). However, even A&A does not have such strict standards. Its standards simply state that the veteran must require assistance on a "regular" basis—leaving flexibility to allow for the encouragement of independence rather than the fear that any such demonstration of independence will result in being removed from the program.

Also concerning in its severity, under the new Supervision, Protection, and Instruction standard, the veteran must need "continuous daily care," rather than having to prove, as in the original program, that the veteran requires supervision for safety. In the Code of Federal Regulations (CFR) comments, the VA itself gave the example that a veteran who was experiencing dementia, but was only sundowning, would not qualify for the program because the veteran only needed episodic care and did not meet the "continuous daily care" requirement. Would you want to leave your loved one with dementia alone in the hopes he or she would only need you in the evening? If your loved one had a moderate to severe traumatic brain injury and was able to independently walk the dog in their very familiar neighborhood, would you trust them to go to the store unsupervised with the family's credit card? Again, the lack of flexibility in this standard demonstrates a complete lack of acknowledgement of the illnesses and injuries Congress was trying to address.

Understanding that new regulations and directives must be promulgated to effectively enact legislation, the above examples clearly underline the great disparity between Congressional intent and the operationalization of the PCAFC. We encourage Members of Congress to continue to work with VA staff and relevant organizations to thoroughly review the implementing regulations, directive memos, and training modules to ensure that those caregivers and veterans Congress intended to serve are included in this program.

Process Challenges

With the drafting of the new regulations and directives, QoLF staff, along with several other Veteran Service Organizations have made repeated inquiries to the VA requesting information on the decision-making process, standard operating procedures, and training documents to both educate and caregivers and inform our appeals efforts. While information was sometimes provided, we and other VSO's were often denied access to critical procedural information needed to assist veterans and caregivers. To overcome this obstacle, our staff took from October 1, 2020 to September 30, 2021, to review cases of veterans and caregivers who applied under the new regulation to better understand the changes that had taken place. Through this documents review, we painstakingly recreated the application and evaluation documents that were available, as they were intended to give a picture of the functionality and care needs of the veteran and the role the caregiver plays in filling those needs for assistance with ADL's or providing supervision, protection, and instruction. We have attached those documents to this testimony for your review.

Primarily, we would like to applaud VA's attempt to standardize this process and create expansive assessment instruments intended to capture the care needs of the veteran as well as their stated goal, mentioned above, to align the PCAFC program with other related VA programs. However, as we have worked with veterans and caregivers to develop their clinical appeals, we have noticed issues with both the application and appeals process, often resulting in the undue exiting of caregivers from the program. The process and issues are as follows:

1. **Veteran Application Intake or Reassessment Interview**: This document reviews basic biographical information that speaks to the qualifying criteria for the program. It goes over dates of service, ratings, address, etc. The basic biographical information for the caregiver is also listed. The major areas of concern that we have noted on this document include:
    A. *The ratings considered are often incorrect, leaving an incomplete picture of the veteran's previously established need for assistance.* Caregiver Support Staff are only able to access the VHA system which may or may not include the most up to date VBA rating. Any ratings increases or new conditions must be added manually, leading to both coding and transcription errors. This section is often copied and pasted onto multiple other forms, and, therefore, if the error occurs here, it is repeated elsewhere. In addition, seriously wounded, ill, and injured

veterans are often assessed for Special Monthly Compensation, Aid and Attendance, and housebound status. While these ratings indicate a higher level of need for assistance, their documentation is not easily identifiable during the PCAFC intake process, leaving an incomplete picture of the veteran's current needs and missing an opportunity to align these programs and evaluations. For example, we recently assisted a caregiver and veteran who, among other errors, was listed as missing an eye when he was actually missing his colon and rectum, obviously requiring different types of care and assistance. To be clear, both of the veteran's eyes are fully intact and functional, but a coding error led to a completely false narrative of the veteran's needs. After pointing out this error and requesting new exams to rectify the problem, we were told that the appeal was a "self-report," and that they had to go with what was in the record.

We are finding that a large percentage of applications have these errors in the ratings, but we have also been informed that CSP staff will be able to access VBA ratings from VBA "in the near future." However, the program has required ratings information since its inception, but it is still not reliably accessible. Because one of the qualifying criteria of the program is a 70% rating, it is vitally important that CSP be able to access this information sooner rather than later.

B. *Existing Fiduciaries, Guardianships, and Conservatorships are often not documented.* During the intake interview, CSP staff are required to ask about fiduciaries, guardianships, and conservatorships because, similar to the programs listed in the previous section, these designations require a proven level of need for supervision, protection, and instruction. Thus, if the CSP staff fail to ask the question, a documented need for assistance is missing from the caregiver's application. So far, we have had multiple cases where guardianships and the need for a fiduciary were not documented, resulting in at least two veterans with an active guardianship being exited from the program. While this is likely a training issue, we cannot be sure because, again, we have requested but not seen the training documents.

2. **PCAFC/PCM Collaboration:** This document lists 5-7 basic questions that are supposed to be filled out by the veteran's Primary Care Manager in collaboration with the CSP. The CFR states that this collaboration is to be done to the maximum extent possible. The major areas of concern include.

A. *The PCM is rarely the person filling out the document, meaning that the input of the clinical staff most familiar with the veteran is not considered.* While the VA is not tracking the number of assessments filled out by the PCM vs. CSP staff, ninety percent of the cases that Qualify of Life Foundation have reviewed have not been filled out by the Primary Care Manager. Instead, there is a note put in by CSP staff, usually the social worker, that says the CSP staff member did a review of the Electronic Health Record and answered the questions for the physicians. In at least one instance, a PCM has responded, in the record, that they do not agree with the conclusion that was drawn by the CSP staff.

B. *The information requested from the PCM is too generic and does not speak to the veteran's care needs.* Questions consist of describing the treatment plan if one exists, listing medication, asking if the veteran is able to understand the treatment plan, if the caregiver is involved with the veteran and treatment plan, if the caregiver is able to understand the treatment plan, if the care needs can be safely carried out in the home, and if there is evidence that the veteran has been recommended for institutional care. None of these questions speak to the veteran's need for supervision and assistance with safety or the physician's opinion as to whether the veteran needs an attendant.

C. *Veterans often have multiple PCMs or no assigned PCM.* Due to high turnover rate and COVID, even when the PCM is consulted, veterans may not have consistently seen his/her PCM or the same PCM in the VA. As such answers and notes often cannot truly reflect the needs of the veteran due to a lack of familiarity. One veteran we are assisting has had approximately 12 PCM's in the last 5 years. The number is approximate because there were temporary PCM's that the veteran didn't know were assigned.

D. *Only twelve months of records are reviewe*d. In the PCM collaboration document, there is a specific statement that says, "Documentation for collaboration should be within twelve months from the valid application received date or reassessment date, as applicable." Due to COVID, many veterans have not been able to go to the VA to see their providers, leaving a lack of information. In addition, many veterans who have significant care needs may also be medically stable and do not see their PCM regularly. This does not indicate that their brains have healed or their paralysis remitted, it simply means that they did not have a level of medical need to see a primary care manager. Lack of evidence of seeing a primary care manager does not equate to a lack of need for assistance. Many injuries from Post 9/11 and earlier conflicts have become medically stable, and there is no progress to be made or new therapies to offer. Conditions are stable and static. The need for assistance remains, but the need to see the PCM beyond periodic evaluation does not exist. For example, neuropsychological testing for those with brain injuries that shows a particular lack of executive functioning is not normally repeated once the maximum level of functioning is achieved (usually about 24 months post-injury). Nerve conduction tests for those with paralysis, pinched nerves, etc. are usually not repeated once loss of sensation is documented. In both cases, the need for assistance likely still exists, but the veteran no longer sees the PCM to address those issues. Therefore, due to the 12 month limitation, evidence may be missed documenting the need for assistance, especially for those who have been injured for multiple years.

E. *Specialists are often not consulted.* Due to the severity and complexity of their illnesses and injuries, many veterans see specialists beyond primary care. Neurologists, spine specialists, oncologists, orthopedists, psychologists, psychiatrists, etc often provide the majority of a veteran's care depending on the need. Those doctors would be better able to answer the questions about the veteran's treatment plans, needs for assistance, and possible need for institutionalization in the absence of a caregiver, but are often not consulted.

F. *Case management is often lacking*: Over the years, VA has struggled to provide comprehensive holistic and proactive case management, especially to the severely injured— the target population of PCAFC. In some cases, VA even documented that they were unable to provide the case management across multiple facilities, even for care for which they are paying. Even so, the VA has stated that "management of medications and appointments are not qualifying activities" for the PCAFC program. However, caregivers of those who are unable to manage their own care have had to spend extraordinary amounts of time navigating systems of care on behalf of the veteran and monitoring medication. Without this type of assistance, many veterans who otherwise require a caregiver would not be able to navigate the complex bureaucracy of the VA and would lose access to the programs and services they desperately need. Therefore, the need for assistance with case management should be considered a qualifying factor under the Supervision, Protection and Instruction standard of the PCAFC program.

3. **Veteran Assessment:** This interview, normally conducted by a social worker, includes an assessment document that repeats much of the information about ratings, medical conditions, and medications that the veteran takes that can be found on other forms. The veteran is also supposed to be asked if they see outside providers. The veteran must go through and answer questions about employment, educational history, substance abuse/mental health history, history of pain, dietary concerns, daily diet, exercise, treatment goals, changes in health, memory, concerns for their safety, and if and how they feel the caregiver is supporting their treatment goals. Then the caregiver is asked to weigh in on all of those aspects while the veteran is present. The caregiver must answer questions about the veteran's participation in childrearing, household chores, how the caregiver assists in ADL's, concerns the caregiver has surrounding the veteran's memory, mental health, sleep habits, safety in the home, safety outside the home, preparations the caregiver makes if they have to be away from the veteran, etc. Our issues surrounding this evaluation include:

A. *CSP staff often fail to ask about information from outside providers*. Many veterans that have multiple serious medical conditions also have multiple insurance options, including TRICARE, Medicare, and/or private health insurance. As a result, many use a hybrid collection of medical providers. As such, all of the treatment records need to be available for VA CSP to make an accurate decision on whether or not a veteran has a clinical need for assistance.

B. *Even if VA is aware of outside community care providers, time is not always allowed to collect and add outside records into the system before files are sent to the decision-making Caregiver Eligibility and Assessment Team (CEAT).* Therefore, those records, most of which are records from specialists or even other VA providers like Vet Centers, are not included in the information used to make a decision about the level of assistance needed. We often have cases that from the receipt of the call to inform the caregiver of the beginning of the reassessment process to a determination being made is less than 14 calendar days. These cases usually conclude with removal from the program. Given the complexity of the medical care required by these individuals, this is not a long enough period of time to gather, assess, and evaluate the necessary records.

C. *Outside records are often not visible to the veteran/caregiver nor are they entered in the electronic medical record.* If a veteran and caregiver submit outside records, several scenarios can ensue, all depending on the policy at individual VA Medical Center. If the Caregiver Support Team at a VA has scanning authority, then the CSP staff can scan the records directly into the veteran's chart. Unfortunately, this scan is not able to be seen by the caregiver and veteran in the MyHealtheVet record as the images are scanned into a different system. If CSP staff do this, they usually place a note in the Electronic Health Record that notes that outside records were scanned into the veteran's record and are usually identified by name and the records system in which they were input so CEAT can potentially see the records. If a CSP does not have scanning capabilities, then the veteran and caregiver may be told to take the records to the Records Office and have them scanned in. In this scenario, the records can take weeks or months to upload and still cannot be viewed by the veteran and caregiver through MyHealtheVet. Most applications are pushed forward without indication that the records have been added to the veteran's record. Another scenario has the CSP tell the veteran and caregiver to take the veteran's outside records to the PCM to have the PCM decide if they should be added to the record for consideration. In one instance, the veteran submitted 760 pages of mental health records from the Vet Center he attends for weekly mental health appointments only to be told by his physician that the records would not be added to his chart because it would take months to get that much material added to his record. In scenarios such as this, the CEAT is making decisions without all of the necessary information. This variation in policies and procedures at VA Medical Centers causes undue confusion and hardship on the part of the veteran and caregiver. To address this, QoLF recommends that the local CSP staff be given scanning privileges to ease this already difficult process.

D. *"Duty to assist" is not practiced in this process.* In the VA, there is a standard of "duty to assist" a veteran to seek care and to collect records. In the process of CSP evaluation, this duty to assist would translate to the CSP staff helping the veteran and caregiver gather outside records and ensuring their appropriate placement in the VA medical record. While there are certainly some very helpful CSP staff, often the veteran and caregiver are left to their own devices to track down records and ensure their proper use.

4. **Veteran Functional Assessment:** This assessment repeats much of the same information from the Veteran Assessment, but instead of it being done as a psychosocial interview and a listing of concerns, it is an exam that is supposed to gauge the functional ability of the veteran to perform both physically and cognitively. It is performed by a clinician (nurse or therapist) who usually has not read the information from the preceding

Veteran Assessment. Each ADL is broken down into separate components and the veteran and caregiver are asked how the caregiver assists the veteran in the performance of those specific functions. The examiner then has a list of dependency choices, which after listening to the veteran and caregiver describe the assistance given, chooses a level of assistance that the veteran needs— this ranges from independence to complete dependence. Then there is a list of questions on criteria for Supervision, Protection, and Instruction. The following are concerns related to this portion of the assessment:

A. *Scoring is unknown for SPI criteria.* Under the program, veterans are evaluated for the ability to perform ADL's and the need for Supervision, Protection, and Instruction. After reviewing multiple assessments, it is clear that a specific set of question and qualitative matrices are used to score and evaluate a veteran's ability to perform ADL's. The veteran is then assigned a defined level of functionality for ADL's. With respect to SPI, however, there are no clearly defined questions, or, as mentioned above, no cognitive evaluation tools administered, that relate back to the areas of evaluation for SPI functionality (self-neglect, self-direction, etc.), nor qualitative measurements for levels of functionality, leaving the evaluation matrix unknown. As a result, it is incredibly difficult to determine how functionality is assigned for each item, and even more difficult to appeal a denial if a caregiver is unclear why he or she was denied in the first place. This leaves many veterans, especially those living with severe mental health disorders, severe brain injuries, and dementia, who are often evaluated under SPI, without a caregiver.

B. *Supervision, Protection, and Instruction questions do not directly correlate to items on the criteria for consideration.* There are multiple categories under consideration for Supervision, Protection, and Instruction such as self-preservation, safety both inside and outside of the home, medication management, self-neglect etc. Each category has questions that the examiner asks to understand the need for assistance within that category. These questions do not necessarily correlate to the specific item on the Supervision, Protection, and Instruction checklist. For example, a standard question for self-preservation would be, "If the house were on fire, what would you do?", asked of the veteran for a response. The question itself has multiple layers of thought processes. First a veteran has to be able to identify a fire. He has to then acknowledge that fire is a danger. Then he has to be able to formulate a plan to deal with the danger— get help, get out, etc. He has to be able to then put whatever plan there that he created into action. If that plan is not executable, then the veteran has to be able to think of an alternative plan and execute the plan. Simply asking a veteran, "What would you do if there was a fire?", and recording an answer does not only speak to self-preservation, it speaks to multiple layers of thought processes and execution. Any failure at any step could result in catastrophe. This question does not address the actual step at which the process may fail for the veteran, nor do we know how the answer is considered.

C. *No actual measures of cognitive function are administered during the functional assessment portion of supervision, protection, and instruction.* In the ADL portion of the Veteran Functional Assessment, the veteran can demonstrate her ability to perform the ADL's. In the Supervision, Protection, and Instruction portion of the exam, one of the key components of demonstrating functional ability is a person's cognitive impairment. There is no assessment of cognitive impairment administered as part of the Veteran Functional Assessment. Despite easily administered, validated and available tools, such as MoCA and SLUMS testing, a key detector of even mild cognitive impairment/dementia is not administered in this assessment.

D. *Evaluator and veteran are mismatched.* While a clinician (nurse, PT, OT, LCSW) is required to perform the functional assessment, he/she is often mismatched with the veteran and likely has no prior involvement with the veteran. For example, a physical therapist could be performing the assessment on a veteran with a severe mental health disorder and be unfamiliar with the manifestations of the disorder. While there are set questions to ask, again, without having a clear set of evaluation criteria, it is unknown if an assessor's clinical background or lack thereof would impact the decision of choosing a functionality level.

E. *Questions should be asked of Specialists, not just veterans and caregiver*s. Again, due to the complexity and severity of the injuries sustained by veterans applying for the program, they often see a myriad of specialists. As indicated above, and especially for Supervision, Protection, and Instruction, having a specialist's feedback on a veteran's functionality—especially when the injuries and illnesses are not readily apparent-- would dramatically impact the level of evidence that is provided for functional deficits in this area. Those specialists would be able to point to specific areas of concern that they have noted in treatment, something which if captured early in an injury or progression of dementia, may not be found in the last twelve months of records because there would have been no reason to revisit that particular deficit in the notes once it was established by testing or evidence. To remedy this lack of information, QoLF has asked some veterans and caregivers to give their mental health provider or neurologists the same list of Supervision, Protection and Instruction criteria by which by the veteran and caregiver are scored. These specialists are then able to offer direct clinical information and recommendations regarding the veteran's true needs and deficits. However, as helpful as this information is, we have also experienced pushback when asking providers to fill out this document for the VA record, as "the questions would elicit a lot of information in regards to the needs of a veteran," and the local CSP offices have also discouraged the use of this form including this vital information because it is not the appropriate place in the process. However, as mentioned above, there is often no place in the process for the specialists to provide their clinical judgement.

F. *Has the Veteran Functional Assessment Instrument been validat*ed? This is a question the VSO community has been asking since the summer of 2020. VA used the Special Medical Advisory Group (SMAG) to develop a functional assessment, and held a public meeting to share their final recommendations for the creation of this instrument. The instrument was developed using items from MNChoices and FASI, two individually validated assessments and the SMAG combined the instruments to make a new instrument. SMAG was very careful to say that the newly developed instrument would need to be validated. As of yet, no one has seen the full instrument, and no one has seen the scoring criteria. Thus, we do not know if the instrument that is being used to assess the functional ability of the veteran is actually a valid instrument when compared to other existing validated instruments.

5. **CEAT Review and Decision:** The Caregiver Eligibility Assessment Team (CEAT) is the decision-making body that reviews the application, assessments, and records to make a decision on whether a veteran qualifies for the PCAFC. To make a decision, the CEAT must determine that the veteran meets specific criteria. The majority of these criteria are straightforward, but we have found issues in some of them:

   A. *The veteran must need six months of continuous personal care services.* The CEAT uses the assessments to determine if the veteran has a need for ADL or Supervision, Protection, and Instruction assistance that will last for six months or more. As previously discussed, not knowing the actual scoring matrix makes it nearly impossible to determine how a veteran qualifies for the program. We do know, however, that to determine the tier under which the veteran qualifies, 3 questions must be answered. The questions follow: Does the veteran need ADL assistance? Does the veteran need supervision, protection, and instruction? And is the veteran unable to self-sustain in the community? The third question is the one that creates issues. Rather than ask, “Is the veteran able to self-sustain in the community?” that requires a simple yes or no answer, the question is reversed and asks if the veteran is UNABLE to self-sustain in the community. The answer to this question determines the tier level of the veteran. Reviewing this question in the context of clinical appeals has demonstrated that the majority of field staff on the CEAT do not know how to interpret this question. Because it is a double negative, they will incorrectly answer “NO,” and then expound on all of the ways the veteran requires assistance. Rewording this question would make it less confusing for the CEAT and correct some tier leveling errors.

   B. *The program is in the best interest of the veteran.* This specific criteria is defined in the CFR as a clinical decision based on, “consideration, by a clinician, of whether participation in the program significantly enhances the veteran’s or service member’s ability to live safely in a home setting, supports the veteran’s or servicemember’s potential progress in rehabilitation, if such potential exists, increases the veteran’s or servicemember’s potential independence, if such potential exists, and creates an environment that supports the health and well-being of the veteran or servicemember.” In our view, this criterion offers needed flexibility to the eligibility determination by allowing clinical judgement to trump all other criteria. It is important to note, we have not seen a case that rejects the personal care criteria found in section (A) above, but accepts that the program is in the best interest of the veteran. This is a problem, for example, because a veteran with relapsing and remitting Multiple Sclerosis may not qualify under the 6 months of continuous care requirement, but it would be in their best interest to be in the program with a caregiver.

C. *There is a lack of evidence and standards cited for the CEAT decision.* Despite a clear legislative mandate for an explanation of evidence used and why the veteran-caregiver dyad did not meet the criteria for eligibility created by the *Transparency and Effective Accountability Measures for Veteran Caregivers Act*, CEAT decisions still lack the specificity of documents used for determination and only offer generic criteria for rejection. Without having this information, once eligible veterans and caregivers are left reeling from a decision regarding injuries and needs for assistance that have not changed, while some hidden decision-making criteria has now deemed them ineligible for PCAFC. This inexplicable exiting of caregivers from the program has led to a trail of confusion, fear, anger, and resentment on the part of the caregivers and veterans. Some have gone as far to say, "The VA says I'm cured." While this seems to be hyperbole borne out of frustration, on a recent call with VSOs, representatives from the VA said that the reason for the high denial rate was that many veterans had recovered from their injuries for which they were previously found eligible. While, thankfully, some may have recovered, a person missing 90% of his frontal lobe is not going to grow it back, nor did his need for supervision change. A quadriplegic did not suddenly gain functionality, and a veteran with serious mental illness that constantly dissociates from reality did not suddenly become cured of his mental illness. But, their caregivers were all reduced. A more likely explanation in most cases is that the rules changed, leaving many whom this committee intended to qualify, ineligible or reduced in tier.

D. *VHA should be using the VBA standard of "tie goes to the veteran" as precedent to remove any ambiguity on "close calls."* While understanding that this is a stipend and not a benefit, the VBA standard for determining eligibility is relevant. Under 38USC5107(b), "In accordance with the principals that the VA is focused on veteran centric care, the Secretary shall consider all information and lay and medical evidence of record in a case before the Secretary with respect to benefits under laws administered by the Secretary. When there is an approximate balance of positive and negative evidence regarding any issue material to the determination of a matter, the Secretary shall give the benefit of the doubt to the claimant." In layman's terms, the tie goes to the veteran.

6. **Further steps for approval beyond the first CEAT decision:** If the veteran and caregiver make it through steps to receive an initial positive CEAT decision for tiering, then they face the additional steps of Caregiver Training and an additional, lengthy interview called the Veteran In-Home Assessment which goes into even greater detail about the veteran and caregiver's day to day interactions. At the completion of both of those steps, the CEAT then does a final review and if approved the caregiver is accepted

for participation in the program for a one year increment before the process starts over again.

Mental Health/Emotional Toll

When Congress passed the *MISSION Act*, in addition to expanding eligibility to future generations, they took the additional step of making it mandatory for veterans and caregivers to be allowed to give input on how the caregiver assists the veteran. This step was codified because of the understandable outcry from the community that, under the original program, they were not consulted on the veteran's daily needs and assistance provided in the home.

Unfortunately, in trying to address the need to include input from those impacted, the VA appears to have overcorrected by requiring the veteran and caregiver to participate together in the process at almost every turn. While their input is certainly needed, the ongoing and exhaustive nature of repeated interviews takes an emotional toll on those participating, as they must relive and retell the most intimate, humiliating, and private parts of their lives to complete strangers, most of which is unnecessary because it is documented in their medical record. Imagine sitting next to your seriously injured husband while describing in degrading and explicit detail the assistance you provide when he loses control of his bowels due to his brain injury. Furthermore, veterans with mental health disorders, dementia, and traumatic brain injuries often are not aware of their deficits and must now sit and listen as their parent, spouse or other family member relays the information.

During the assessment/reassessment process, the veteran and caregiver have 3 interactions/interviews with the Caregiver Support Program. In two of those interactions, the veteran and caregiver are required to list everything the veteran can no longer do and everything the caregiver has to either do for the veteran or assist the veteran in doing. According to all of the caregivers and veterans with whom we have spoken, they must do all of the interviews together. The veteran must list his own deficits and then the caregiver must describe all assistance provided. If the veteran and caregiver make it beyond the first CEAT decision, an additional interview is required that repeats the same information. If the veteran and caregiver complete all the steps and are successfully approved for the program, then there is a ninety minute quarterly check-in call that repeats the same information. And at the end of the twelve month cycle, re-assessment for participation in the program occurs. If one fails to participate in any one of these steps, then participation in the program ceases. If one "sugar-coats" the information for the emotional benefit of their loved one, then participation ceases. To our knowledge, no other federal disability support program (i.e. Social Security Disability Insurance, VA's own disability ratings schedule, etc) requires a veteran and/or caregiver to go through this experience with such frequency.

QoLF staff recently conducted a call with a number of caregivers who care for some of our nation's most seriously injured veterans, many of whom have given Congressional testimony themselves. When asked about the impact of the repeated assessments, the consensus was that they took such a psychological toll that they were not sure that they even wanted to stay in the program. One caregiver stated, "We have spent the last fifteen years focusing on every improvement our son has made, and in one week, the PCAFC reassessment process wiped that out. I had to recount everything he could not do in front of him. My son who was a nuclear engineer now struggles to put Legos together. He wept during the assessment. I asked if he could leave and was told no. As a mother, it broke my heart and I wondered if this program was worth continuing if this was the toll it took on him. When he starts to recover mentally, we have to go through it all again for the quarterly assessment."

Other formerly Tier 3 caregivers who have been denied are refusing to appeal because of the mental health toll the evaluation takes on their veterans and themselves. One caregiver whose husband cannot even get out of bed without assistance stated, "When my husband received notice that he was being removed from the program, he was both angry, and relieved. Knowing that he still has to depend on me for daily support, only now he knows I have to do it without any [financial] support from the VA. He was also relieved that he will no longer have to sit through an appointment every three months where he must describe in excruciating detail the things that he, as a grown man, can no longer do without the support of another person. For that reason has chosen not to pursue an appeal at this time, even though he knows that it is unfair to me. The relief that he feels knowing that he will no longer have to be humiliated by an ongoing parade of new providers is a relief to me."

The reassessments for the legacy caregivers who have, in some cases, been providing care for more than fifteen years, have taken an even greater toll. One such caregiver said, "The indignity of being forced to repeat all of [the veteran's] disabilities each time we have quarterly and annual assessments is unacceptable. This year alone, within the span of one week in January, [the veteran] and I spent almost 7 hours… listing IN DETAIL all of the activities of daily living [the veteran] cannot perform for himself, the level of assistance needed. I was also asked if he needed a consult for sexual function ([the veteran] does not date). I don't need to tell you my heartbreak and concern as I watched our typically upbeat, cheerful son spend time in his room quietly staring into the distance in the days that followed. We spent all our time distracting him with games, movies and a busy schedule to break him out of the funk. All created by THE organization mandated to care for him and to support me. What causes the most stress for me coordinators and assessors ask? The caregiver support programs cause the most angst and stress in my life."

While Congress did mandate periodic reviews and veteran and caregiver participation should be welcome, it did <u>not</u> mandate quarterly check-ins and annual reviews. You certainly did not mandate that these interviews needed to be conducted with both veteran and caregiver together for the entirety of the assessments. It is not necessary, and, in fact, it may be detrimental, for a veteran to be present while a caregiver lists all of the assistance that they have to provide due to the veteran's injury. Alone, the caregiver can give an honest accounting of the veteran's deficits in the home, and the VA can use medical records as evidence. Please note, while the caregivers with whom we have spoken and for whom we have done appeals have universally stated that this dual participation is required, we do not know if this is standard operating procedure because we have never received the requested documents detailing this portion of the program.

As we focus on policy, sometimes what seems a trivial practical requirement actually has a much more lasting and unintended devastating impact. These are human beings, who, in many cases, have devoted their lives to assisting their loved ones. We owe them the respect that comes with listening to what matters to <u>them</u>. Unfortunately, however, according to another caregiver, after she submitted information to the VA, she was told "I should feel 'lucky' that I had not been totally removed from the caregiver system because they were trying to get all the Legacy caregivers off the system. My husband gave more than 20 years of his life serving his country and can no longer function as he once did, and I should feel lucky? I find that statement offensive and appalling."

In a time where mental health treatment and lowering suicide rates are touted as being a priority, the assessment for the PCAFC is creating a mental health crisis for already vulnerable veterans and families. While on the surface, it seems a trivial requirement, many caregivers report that it takes weeks for their veteran to recover from the quarterly interviews done by the Caregiver Support Program, only to turn around and do it again in a short timeframe.

Conclusion

VA has shared that there is an over 80% denial rate for the initial wave of newly eligible applicants. Official information regarding Legacy caregivers--those post 9/11 caregivers who were enrolled in the original program--is still pending, but our caseload indicates a high number of denials and drops in tier. Given the information presented above, we respectfully ask the Committee to work with the VA and when appropriate, relevant non-profit organizations, on the following items:

- Given the number of places outlined above that a caregiver's application can go awry, the Quality of Life Foundation asks for an immediate moratorium on reassessments until a thorough review of the issues previously mentioned can be completed. In the meantime, reinstate at least Tier 3 Legacy participants, and review the Tier 1 and Tier 2 drops to make sure that specialists, instead of or in addition to the PCM, have the opportunity to clinically review applications prior to determination.
- Work with the VA to realign the program with Congressional intent. Specifically address the population Congress intended to include in this program and the more stringent standards implemented by the VA.
- Increase transparency related to the decision-making process. VA needs to make full assessments, instruments, and decision-making criteria available, including training materials to ensure that caregivers, veterans and advocates have a clear picture of the criteria being used to determine eligibility.
- As part of the CEAT review, immediately re-draft the problematic question mentioned above. Rather than, "Is the veteran unable to self-sustain in the community?," ask instead, "Is the veteran able to self-sustain in the community?" Following our review of cases, this simple change could address a number of unintended lowering of tier level.
- Immediately change the requirement and re-train staff that the veteran does not have to be present for the caregiver's interview and lengthen the timeframe for check-ins and reassessments to lessen the burden on caregivers and veterans.
- While we fully recognize the need to evaluate all of those who apply for the program, we ask that the process for those being re-assessed, especially those who have already sacrificed for so many years to be a family caregiver, be modified to reflect the years of service, "on-the-job" training, and medical evidence that has previously been considered for eligibility under the original program.

- Require VHA to honor its “duty to assist” standard. Ensure that specialists are consulted and that records are obtained from outside providers before files are sent for review.

Mr. Chairman, the Quality of Life Foundation thanks you for holding this hearing and for the opportunity to be here today. We look forward to answering any questions you may have.

Enclosure: Compilation of Educational Materials Prepared by Quality of Life Foundation

Application Process of the Program of Comprehensive Assistance for Family Caregivers (Legacy and New Participants)

As Compiled by Quality of Life Foundation

Background

The VA MISSION Act of 2018 created a new standard for the VA's Caregiver Support Program's (CSP) Program of Comprehensive Assistance for Family Caregivers (PCAFC). It also expanded eligibility beyond Post 9/11 caregivers. These changes prompted a revision in the evaluation process which VA established in CFR RIN 2900-AQ48 issued October 1, 2020. The new standards are defined in VHA Directive 1152(1) issued October 1, 2020. Two significant changes are: (1) the Activities of Daily Living (ADL) standard requires care to be provided "each and every time" an ADL is performed and (2) the standard for Supervision, Protection, and Instruction (SPI) now requires "continuous daily care".

Application and Evaluation Process

The following outlines the steps of the evaluation process that the Caregiver Support Program uses to determine if a veteran qualifies for the Program of Comprehensive Assistance for Family Caregivers. The process utilizes standardized forms available through VHA and posted in medical records. The forms cannot be altered.

For applicants (including non-Post 9/11 veterans), the evaluation process for PCAFC begins with the submission of your VA Form 10-10 CG, Step 1 below. The local Caregiver Support Program handles the review process for both new and Legacy applicants,

Steps

1. **Veteran Application Intake**-- (This is called the Reassessment Interview for Legacy Participants—a Post 9/11 caregiver that was in the Program before 10/1/2020.) This form gathers basic information such as dates of service of the veteran, rated disabilities, and other biographical and logistical information about the veteran and caregiver. It includes basic information about age, address, etc.

2. **Veteran Assessment**- This is an interview in which both the veteran and caregiver are asked a set of questions. The interviewer may ask what the veteran is rated for, what diagnoses they have, and what medications they are on. Even if they do not ask these questions, you should check with the interviewer to make sure all of this information is complete and correct because it is an important evaluation requirement. The VA CSP interviewer usually just copies and pastes this information out of the record. Again, you should carefully review this information once it is placed into MyHealtheVet because it is not uncommon to have errors that are best corrected at this time. Do not trust that the VA has the ratings, diagnoses, or medications correct.

This is also the time to tell the VA CSP if the veteran sees outside doctors. If the veteran sees outside doctors, then please gather those records from those doctors, including community care doctors. Do NOT assume that VA has them.

There will be a standard set of questions that the interviewer, usually a social worker, will ask both the veteran and the caregiver about what the veteran's employment, educational, substance abuse/mental health history, etc. are. The interview will move on to history of pain, dietary concerns, daily diet, exercise routine, etc. The interview will also include other topics such as treatment goals and changes in health. The interviewer will ask the veteran if (s)he feels that the caregiver is supporting their treatment goals. The last question for the veteran will be about home services the VA provides.

In the caregiver portion of the interview, there are specific questions about how the caregiver provides assistance with each ADL. If you have been at this for a long time, it is helpful to write down what you do each day to make sure that you capture all of the assistance you are providing and how you do so. (Some of it becomes so rote that you forget that it actually is a caregiver duty.)

They will also ask if the caregiver has concerns about the veteran's sleeping habits, memory, treatment goals, concerns for the veteran's safety, preparations the caregiver has in place if they are going to be away from the veteran, and if there are any concerns that the caregiver has about the veteran. This is your chance to list all the extra concerns about the veteran's care that you have or duties which you perform that you have not been able to fit in one of the above answers.

If you have a VA fiduciary, this is your time to say so. When this information is posted to MyHealtheVet, make sure that it is accurate, and if not, email in the changes you would like to see notated.

3. **Veteran Functional Assessment**— This functional assessment/interview is done by a different person than the Veteran Assessment. They will NOT have read your answers to the Veteran assessment, so give complete answers to questions they may ask and provide information you feel is relevant to the assessments they are doing.

   The Veteran Functional Assessment is required to be performed by a health professional, most likely the nurse assigned to the Caregiver Support Program. VA has very specific definitions of each ADL and Supervision, Protection, and Instruction criteria. (See the sheet on ADL and SPI evaluations.) The CSP staff will request the caregiver describe what they do for the veteran for each ADL. Be as specific and as expansive as possible. Describe what makes it necessary for you to do each thing for the veteran—for example in toileting, if you say I must clean the veteran's bottom after defecating each time, say why—such as he is missing both arms. Always say what you do, why you do it, and how often you do it (each time, daily, weekly, monthly, etc.)

For the safety and supervision portion of the assessment, they will ask a set of specific questions. Expound on each and every question that is relevant. Answer with what you do, why you do it, and how often you do it. Never just say, "I help with medication management." Instead say, "I help with medication management of ___# of medications because the veteran cannot manage them due to _____________ and I have to do this (each time, daily, weekly, monthly), however often you have to do it. If meds are given, once a day say that. If you monitor medication the veteran is taking, explain why you have to do that. If you have to monitor the friends and family of the veteran because they are easily exploitable due to judgement issues, say so, and explain what disability causes that to be so, and how often/in what situations it happens.

There will be a series of questions about self-direction, exploitation, self-neglect, memory, etc. Once again, be very specific. State what diagnosis requires you to do each thing and how often. The Caregiver Support Personnel will write down your answers, but then they are required to assign the veteran/caregiver a functional level based on each ADL or SPI (See the Sheet on ADL and SPI evaluations to follow). At the end, it is important that you add whatever concerns you have or duties you perform that have not yet been covered. Make sure you read over of the information recorded during this assessment and correct any misinformation as soon as this information is uploaded to MyHealtheVet.

4. **PCM Collaboration**—The Caregiver Support Program team is required to contact the Primary Care Manager (PCM) in order to ask a few questions. The question that appears to be weighted most heavily is, "Without a caregiver, would the veteran require institutionalization?" Another key question is, "Does the caregiver understand the treatment plan?"

   Normally, this questionnaire is only sent to the PCM. HOWEVER, it is strongly suggested that you urge the CSP to ask questions of the veteran's other specialized doctors. For example, if your caregiving centers on Alzheimer's, urge the CSP to talk to the neurologist who manages the condition. If the caregiving needs revolve around a spinal cord injury, then the person who manages the chronic pain, the doctor who orders PT, the physical therapist, etc. should also be contacted.

For mental health disorders, ask them to reference the last neuropsych examination, talk to the treating psychiatrist and psychologist/LCSW (licensed clinical social worker). Note that the standardized evaluation form only requires the CSP team and PCM to go back 12 months from the date of the start of the Legacy review. Therefore, you need to tell the assessor specific concerns that may not have been addressed in the past 12 months, but lend credence to the need for a caregiver—things such as a neuropsych assessment, loss of part of the brain or the body, or the extent of a spinal cord injury. Do NOT depend on your doctors to do this paperwork. Read it over when it is entered in MyHealthEVet to make sure that it is accurate and get it corrected immediately, if necessary.

Once all these pieces are completed, the assessment is sent off to the Centralized Eligibility Assessment Team (CEAT). The decision is made at that level by a team of medical staff that is separate from your local Caregiver Support Program team. The CEAT notifies your team of their decision, and your local team will notify you of the CEAT decision. The target timeline from application submission to initial approval/denial determination is 90 days.

If the veteran and caregiver are approved for the program, several more steps must be completed before the veteran and caregiver are able to receive pay. These include: (1) caregiver training and (2) an in home assessment of health of both the veteran and caregiver. This in home assessment is to ensure the caregiver is able to provide care safely (both mentally and physically). After these steps, the application returns to the CEAT for final approval. Pay is backdated to the date of the application to the program.

If the veteran and caregiver are denied, the veteran and caregiver will be referred to the Program of General Caregiver Support Services.

Assessment of the Activities of Daily Living as Compiled by Quality of Life Foundation

Background

The VA MISSION Act of 2018 created a new standard for the VA's Caregiver Support Program's (CSP) Program of Comprehensive Assistance for Family Caregivers (PCAFC). It also expanded eligibility beyond Post 9/11 caregivers. These changes prompted a revision in the evaluation process which VA established in CFR RIN 2900-AQ48 issued October 1, 2020. The new standards are defined in VHA Directive 1152(1) issued October 1, 2020. Two significant changes are: (1) the Activities of Daily Living (ADL) standard requires care to be provided "each and every time" an ADL is performed and (2) the standard for Supervision, Protection, and Instruction (SPI) now requires "continuous daily care". This sheet describes only the part of the Veteran's Functional Assessment Instrument that deals with Activities of Daily Living (ADL's).

How To Prepare for the Evaluation:

Under the application process step known as the Veteran's Functional Assessment, a nurse with the Caregiver Support Program will ask you, the caregiver, and the veteran how you assist with each Activity of Daily Living (ADL) listed below. If you have been providing care for a long time, it is helpful to write down what you do each day to make sure that you capture all of the assistance you are providing and how you do so. (Some of it becomes so rote that you forget it is actually a caregiver duty.)

During the assessment, be as specific and as expansive as possible. Describe what makes it necessary for you to do each thing for the veteran—for example in toileting, if you say I must clean the veteran's bottom after defecating each time, say why—such as he is missing both arms. Always say what you do, why you do it, and how often you do it (each time, daily, weekly, monthly, etc.)

Activities of Daily Living (ADL's)

1. Eating: The ability to use suitable utensils to bring food and/or liquid to the mouth and swallow food and/or liquid once the meal is placed before a person. (This does NOT include meal planning or preparation.)
2. Grooming: Broken down into two parts
   a. Oral hygiene: The ability to use suitable items to clean teeth or dentures and/or the ability to insert/remove dentures into/from the mouth, and manage denture soaking and rinsing with use of equipment.)
   b. Wash upper body: The ability to wash, rinse, and dry the face, hands, chest, and arms while sitting in a chair or bed.
3. Bathing: The ability to bathe self, including washing, rinsing, and drying self. Does not include transferring in/out of tub/shower or reminders to bathe.
4. Dressing: This is divided into three parts
   a. Upper body dressing: The ability to dress/undress above the waist, including fasteners, if applicable
   b. Lower body dressing: the ability to dress/undress below the waist, including fasteners
   c. Putting on/taking off footwear: The ability to put on and take off footwear that is appropriate for safe mobility, including fasteners, if applicable.

5. Toileting hygiene: The ability to maintain perineal/menstrual hygiene and adjust clothes before/after voiding or having a bowel movement. If managing an ostomy, include wiping the opening but not managing the equipment.
6. Prosthetics (Use of Assistive devices): (This includes only prosthetic or orthopedic devices that replaces or supports a body part or function of a body part, does not include supports, belts, lacing at back, etc.) Ability to adjust special prosthetic or orthopedic appliances.
7. Mobility: This falls under two parts
    a. Positioning/Transfers: This falls into six parts:
        i. Roll left and right: the ability to roll from lying on back to left and right side, and return to lying on back
        ii. Sit to lying: The ability to move from sitting the side of the bed to lying flat on the bed
        iii. Lying to sitting on side of bed: the ability to move from lying on the back to sitting on the side of the bed with feet flat on the floor and with no back support.
        iv. Sit to stand: the ability to come to a standing position from sitting in a chair, wheelchair or on the side of the bed
        v. Chair/bed-to-chair transfer: the ability to transfer to and from a bed to a chair or wheelchair
        vi. Toilet transfer: The ability to get on and off a toilet or commode
    b. Mobility (Walking, Manual Wheelchair, Motorized Wheelchair /Scooter): This includes a variety of tasks depending on the type of ambulation. Each form of ambulation should be asked about and the tasks performed for each type of ambulation the veteran uses.

How the Assistance Provided is Evaluated

Once you, the caregiver, and the veteran have described the assistance you give to the veteran, the Caregiver Support Program nurse will then assign a level to the veteran's ability to function for each ADL that best describes his/her level of functioning EACH AND EVERY TIME s/he performs the task. This is based on the description you provide. The levels of functioning are as follows:

1. Independent: Person completes the activity by him/herself with no assistance from a helper.
2. Setup/Clean-up Assistance: Helper sets up or cleans up, person completes activity on their own.
3. Supervision or Touching Assistance: Helper provides verbal cues and/or touching/steadying assistance as person completes an activity. Assistance may be provided throughout the activity or intermittently. (This does NOT include reminders to perform the ADL.)
4. Partial/Moderate Assistance: Helper provides less than half the effort. Helper lifts, holds, or supports trunk or limbs, but provides less than half the effort.
5. Substantial/Maximal Assistance: Helper doe more than half the effort. Helper lifts or holds trunk or limbs and provides more than half the effort.
6. Dependent: Helper does all the effort. Person does none of the effort to complete the activity. Or the assistance of two or more helpers is required to complete the activity.
7. Person refused: Person chooses not to respond to a question for any reason.
8. Not attempted: Person did not attempt this activity or task because there is a short-term medication condition that precludes the person from performing per physician orders. OR

due to safety concerns the person did not attempt to do the activity due to the likelihood of a negative health outcome.

9. Not applicable: This specific activity or task is not something that the person typically completes. This is not because the person cannot complete the task.

Finally

Once this assessment is uploaded to MyHealtheVet, look over the assessment to make sure that it accurately reflects the veteran's functional ability and your description of the assistance that you provide the veteran.

Assessment of Supervision, Protection, and Instruction as Compiled by Quality of Life Foundation

Background

The VA MISSION Act of 2018 created a new standard for the VA's Caregiver Support Program's (CSP) Program of Comprehensive Assistance for Family Caregivers (PCAFC). It also expanded eligibility beyond Post 9/11 caregivers. These changes prompted a revision in the evaluation process which VA established in CFR RIN 2900-AQ48 issued October 1, 2020. The new standards are defined in VHA Directive 1152(1) issued October 1, 2020. Two significant changes are: (1) the Activities of Daily Living (ADL) standard requires care to be provided "each and every time" an ADL is performed and (2) the standard for Supervision, Protection, and Instruction (SPI) now requires "continuous daily care". This sheet describes only the part of the Veteran's Functional Assessment Instrument that deals with Supervision, Protection, and Instruction.

How To Prepare for the Evaluation:

Under the application process step known as the Veteran's Functional Assessment, a nurse with the Caregiver Support Program will ask you, the caregiver, and the veteran how you assist with each aspect of Supervision, Protection, and Instruction listed below. If you have been providing care for a long time, it is helpful to write down what you do each day to make sure that you capture all the assistance you are providing and how you do so. (Some of it becomes so rote that you forget it is a caregiver duty.)

During the assessment, be as specific and as expansive as possible. The CSP staff will request the caregiver describe what they do for the veteran for each aspect of Supervision, Protection, and Instruction. Describe what makes it necessary for you to do each thing for the veteran.

For the safety and supervision portion of the assessment, they will ask a set of specific questions. Expound on each and every question that is relevant. Answer with what you do, why you do it, and how often you do it. Never just say, "I help with medication management." Instead say, "I help with medication management of ___# of medications because the veteran cannot manage them due to _____________ and I must do this (each time, daily, weekly, monthly), however often you have to do it. If meds are given, once a day say that. If you monitor medication the veteran is taking, explain why you have to do that. If you must monitor the friends and family of the veteran because they are easily exploitable due to judgement issues, say so, and explain what disability causes that to be so, and how often/in what situations it happens.

Aspects of Supervision, Protection, and Instruction

1. Medication management: The caregiver's role may be defined as no help or supervision, medication setup, visual or verbal reminders, or medication administration.
2. Self-preservation: The judgement and physical ability to cope, make appropriate decisions and take action in a changing or potential harmful situation.
3. Self-neglect: The veteran may ignore the need to care for themselves due to or through:
    a. substance abuse that leads to health and safety concerns,
    b. behaviors that pose a threat of harm to self or others,
    c. dehydration or malnutrition,

   d. hygiene that may compromise health,
   e. impairment of orientation, memory reasoning/judgment,
   f. inability to manage medication or to seek medical treatment that may threaten health or safety and/or,
   g. unsafe/unhealthy living conditions.
4. Risk of neglect, abuse, or exploitation by another person.
5. Support level to maintain safety in the home, such as assistance with activities that require remembering, decision-making, or judgement.
6. Support level to maintain safety outside of the home, such as assistance with activities that require remembering, decision-making, or judgement.
7. Delusions/hallucinations: Person engages in markedly inappropriate behavior that affects a person's daily functioning and social interactions. Behavior is characterized by a radical change personality and a distorted or diminished sense of reality which may be displayed as catatonic behavior, delusions, disorganized speech, hallucinations, or though disorder.
8. Agitation: Person has a tendency, or would without intervention, to become suddenly or quickly upset or violent as displayed through agitation, anger, or frustration.
9. Impulsivity: Person has a propensity, or would without an intervention, for sudden or spontaneous decisions or actions which may be displayed as a disregard for personal safety
10. Self-direction: This is based on legal capacity. Is the veteran able to identify their own needs? Can this person provide/arrange for their health and safety?

How the Assistance Provided is Evaluated

Once you, the caregiver, and the veteran have described the assistance provided to the veteran, the Caregiver Support Program nurse will notate the veteran's level of functioning based on interventions needed and how often they are needed. This is based on the description you provide. The answers will help determine if assistance is needed from a caregiver to maintain a veteran's personal safety on a DAILY basis.

Finally

Once this assessment is uploaded to MyHealtheVet, look over the assessment to make sure that it accurately reflects the veteran's functional ability and your description of the assistance that you provide the veteran.

PCAFC Qualifying Criteria for the Veteran

1. The member is either a veteran or a member of the Armed Forces undergoing a medical discharge?
2. The individual has a serious injury incurred or aggravated in the line of duty or active military, naval, or air service: on or after Sept 11, 2001, or before May 7, 1975?
3. The individual is in need of personal care services for a minimum of six continuous months base on any one of the following: an inability to perform an activity of daily living (ADL) or a need for supervision, protection, and instruction (SPI)?
    a. Is the individual unable to perform an activity of daily living?
    b. Is the individual in need of supervision or protection based on symptoms or residuals of neurological or other impairment or injury?
    c. Is the individual unable to self-sustain in the community?
4. It is in the best interest of the individual to participate in the program?
5. Personal care services that would be provided by the family caregiver will not simultaneously and regularly be provided by or through another program?
6. The individual receives care at home or will do so if VA designates a family caregiver?
7. The individual receives ongoing care for a primary care team or will do so if VA designates a family caregiver?

THE INDEPENDENCE FUND

Testimony before The Senate Committee on Veterans Affairs
March 23, 2022
Sarah Verardo
PCAFC Caregiver
Chief Executive Officer, The Independence Fund

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.

<u>Need for a New Regulation?</u>

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.

<u>Conclusion</u>
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.

November 9, 2021

The Honorable Denis McDonough
Secretary of Veterans Affairs
810 Vermont Ave., NW
Washington, DC 20420

Dear Secretary McDonough:

The signers below – concerned veteran and military serving organizations – plead our urgent request for an immediate review and revision of the Department of Veterans Affairs (VA) *Program of Comprehensive Assistance for Family Caregivers* (PCAFC) Final Rule Changes issued on July 31, 2020.

Despite the guidance provided by Congress on specific eligibility and participation criteria under the law, the Trump Administration's proposed and final Caregiver rule tightened the eligibility criteria substantially beyond that required by law. 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. VA received more than 200 public comments voicing near universal opposition to these changes from veteran and caregiver support organizations. However, VA's Final Rule, issued on July 31, 2020, failed to incorporate any of the revisions recommended in the comments.

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 believes about 6,700 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.

Second, as you know with the recent court ruling in the Beaudette case, the court found the VA:

- Failed to meet the burdens required to deny Veterans access to the Board of Veterans Appeals for cases regarding the Caregiver program applications or status,
- Failed to show the Congressional intent to replace the Veterans' Judicial Review Act with the weak and historically troubled Caregiver eligibility adjudication and appeals process, and
- Therefore, prohibited the VA from denying Board of Veterans Appeals' review of future Caregiver program decisions.

This after numerous objections were raised to the proposed eligibility and appeals processes in the Proposed Rule, and after the VA promised, and failed, to provide greater clarity on that process during the public comment period.

Mr. Secretary, the Biden Administration now can correct a significant wrong visited upon Veterans and Caregivers by the Trump Administration with this regulation. Specifically, we believe the Department should eliminate and correct the following:

- Eliminate the arbitrary minimum 70% disability rating eligibility requirement,
- Reform the unreasonable requirement a Veteran fail at completing an activity of daily living 100% of the time, where if they only fail 99% of the time, they are ineligible for the Caregiver program altogether,
- Drop the strict prohibition on either the Veteran or the Caregiver working outside the home, even where the work has nothing to do with the Veteran's ability to complete or not complete the activities of daily living that led to their eligibility for the program, or the Caregiver's responsibilities to adequately care for them, and
- Revise the language the Caregiver must provide 100% of the caregiving to the veteran, language for which a strict reading would indicate the Caregiver cannot even sleep for fear he or she would miss a period of supervision, protection, or instruction.
- Revise and codify the eligibility standards under the supervision, protection, or instruction provision to also include such as safety-related instrumental activities of daily living as medication management, especially for blinded or vision disabled Veterans who cannot properly do so on their own.

VA officials have indicated a desire to review the efficacy of the new regulation, which VSOs and MSOs like the signatories below and others deeply appreciate and support. The responsible Department officials under your leadership have been responsive and engaging, but it appears their hands are tied. And such review efforts were overwhelmed by the Department's responsibility to provide access to the Board of Veterans Appeals per the court order. Now that the VA has that process established, the opportunity is ripe for the Department to correct this wrong and put Veterans and Caregivers first. Just as many Caregiver stakeholders offered during the Proposed Rulemaking period – but were not meaningfully engaged – we stand ready to assist the Department in making this program work for Veterans and Caregivers.

Sincerely,

The Independence Fund
Healing Household 6
Heroes Athletic Association
National Defense Committee
Chief Warrant Officers Association of the U.S. Coast Guard
Sea Service Family, Foundation
American Retirees Association
Armed Forces Retirees Association
Jewish War Veterans
Blinded Veterans Association
Non Commissioned Officers Association
Vietnam Veterans of America
Enlisted Association of the National Guard of the United States
Fleet Reserve Association
Save Our Allies
Association of the U.S. Navy
American Logistics Association
Military Order of the Purple Heart
Catholic War Veterans of the USA
Reserve Organization of America
Japanese American Veterans Association
Naval Enlisted Reserve Association
Veteran Warriors, Inc.
VetsFirst

TO THE
UNITED STATES DEPARTMENT OF VETERANS AFFAIRS

PETITION FOR RULEMAKING
TO AMEND PROGRAM OF COMPREHENSIVE ASSISTANCE FOR CAREGIVERS (PCAFC) REGULATIONS RESTRICTING ACCESS TO CERTAIN BENEFITS OFFERED TO VETERANS AND THEIR CAREGIVERS

SUBMITTED BY

THE INDEPENDENCE FUND

AMERICAN LOGISTICS ASSOCIATION

JEWISH WAR VETERANS OF THE UNITED STATES OF AMERICA

VIETNAM VETERANS OF AMERICA

RESERVE ORGANIZATION OF AMERICA

VETSFIRST

AMERICAN MILITARY SOCIETY

FLEET RESERVE ASSOCIATION

CATHOLIC WAR VETERANS AND AUXILIARY OF THE USA

UNITED STATES ARMY WARRANT OFFICER ASSOCIATION

AMVETS

AMERICAN RETIREES ASSOCIATION

ARMED FORCES RETIREES ASSOCIATION

CHIEF WARRANT AND WARRANT OFFICER ASSOCIATION OF THE U.S. COAST GUARD

MILITARY-VETERANS ADVOCACY, INC.

SEA SERVICE FAMILY, FOUNDATION

HEALING HOUSEHOLD 6

VETERAN WARRIORS, INC.

NATIONAL DEFENSE COMMITTEE

NATIONAL MILITARY FAMILY ASSOCIATION

THE MILITARY ORDER OF THE PURPLE HEART

NATIONAL ASSOCIATION OF BLACK VETERANS

February 7, 2022
Amended with additional signatories February 11, 2022

PETITION FOR RULEMAKING

Pursuant to 5 U.S.C. § 553(e) and 38 U.S.C. § 501(a), The Independence Fund, American Retirees Association, American Logistics Association, Armed Forces Retirees Association, American Military Society, Chief Warrant Officers Association of the U.S. Coast Guard, Vietnam Veterans of America, VetsFirst, Reserve Organization of America, Sea Service Family, Foundation, Military-Veterans Advocacy, Inc., Healing Household 6, Jewish War Veterans of the United States of America, Veteran Warriors, Inc., Fleet Reserve Association, National Defense Committee, Catholic War Veterans and Auxiliary of the USA, and National Military Family Association (collectively "Petitioners") hereby petition the Secretary of Veterans Affairs ("Secretary") to initiate a rulemaking process to promulgate regulations to remove certain restrictions on access to benefits offered to Veterans and their Caregivers under the Program of Comprehensive Assistance for Caregivers ("PCAFC"). The proposed rules would (1) eliminate prohibition on work and replace it with the legislation's eligibility criteria of activities of daily living and the need for supervision, protection, and instruction, (2) eliminate the requirement for a Caregiver to engage 100% of their time to provide care to a Veteran, (3) relax the strict requirement for a Veteran to fail 100% of their activities of daily living, and (4) allow for the extended period for reassessment of catastrophically disabled Veterans.

BACKGROUND

In 2010, Congress passed the Caregivers and Veterans Omnibus Health Services Act establishing section 1720G(a) of title 38 of the United States Code.[1] This law required VA to establish a program of comprehensive assistance for Caregivers of eligible veterans who have a serious injury incurred or aggravated in the line of duty on or after September 11, 2001. In 2011,

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[1] Public Law 111-163.

VA implemented the PCAFC through its regulations.[2] In 2018, Congress passed the VA MISSION Act of 2018 which expanded eligibility for PCAFC to Caregivers of eligible Veterans who incurred or aggravated a serious injury in the line of duty before September 11, 2001. Following passing of this law, in 2020, PCAFC expanded to eligible Veterans who served on or before May 7, 1975, including Veterans who served during the Vietnam era. Through PCAFC, VA provides Caregivers of eligible Veterans with certain benefits, including a monthly stipend, training, respite care, counseling, technical support, beneficiary travel, and access to health care.[3]

On March 6, 2020, VA published a proposed rule to revise its regulations that govern PCAFC to change the eligibility requirements for PCAFC and update the regulations to comply with section 161 of the VA MISSION Act of 2018.[4] In response to the proposed rule, VA received 271 comments from the public, almost all of which were critical towards the proposed rule. On July 31, 2020—disregarding the comments—VA published the Final Rule ("Final Rule") that drastically restricts access to benefits offered to Veterans and their Caregivers.[5]

On November 9, 2021, The Independence Fund and 23 other veteran and military serving organizations sent a letter to Secretary McDonough asking him to review and revise the Final Rule. On December 13, 2021, VA responded to the letter and informed the signatories to the original letter that VA will treat their letter as a petition for rulemaking under the Administrative Procedure Act.[6] Petitioners want to thank Secretary McDonough for his willingness to engage in a dialog with Veteran and military serving organizations. Given the Secretary's determination, Petitioners herein supplement their November 9, 2021 letter with (1) specific recommendations as to the

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[2] Part 71 of title 38 of the Code of Federal Regulations.
[3] 38 U.S.C. 1720G(a)(3); 38 CFR 71.40.
[4] 85 FR 13356 (March 6, 2020).
[5] 85 FR 46226 (July 31, 2020).
[6] 5 U.S.C. 553(e).

proposed changes in 38 C.F.R. Part 71, and (2) the proposal to continue the rulemaking process in form of negotiated rulemaking permitted by law under 5 U.S.C. Subchapter III.

REASONS FOR GRANTING THE PETITION

In its current form, the Final Rule drastically restricts access to benefits offered to Veterans and their Caregivers, which is inconsistent with congressional intent. The Final Rule tightened the eligibility criteria substantially beyond that required by law. Namely, 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 Caregivers. VA received 271 public comments voicing near-universal opposition to these changes from individuals as well as Veteran and military serving organizations. However, VA's Final Rule, failed to incorporate any of the revisions recommended in the comments.

Now, Veterans and their families are seeing the harsh impact of these changes. First, as announced by the VA concurrent with the Interim Final Rule issued September 22, 2021, the VA believes that on October 1, 2022, about 6,700 Veterans will be discharged from the PCAFC upon the expiration of the so-called Legacy Applicants eligibility extension. Representing more than one-third of so-called Legacy Caregivers, this dismissal of disabled Veterans from the Caregiver program is completely unwarranted, especially since it was VA who originally determined that these Veterans are eligible for PCAFC. Second, the recent court ruling in the *Beaudette* case found VA's process of 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.[7]

Lastly, the Final Rule's prohibition on work, the requirement for Caregivers to engage all their time to provide care, the requirement for Veterans to fail every attempt at activities of their

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[7] Beaudette v. McDonough, 34 Vet. App. 95 (2021).

daily living, and a relatively short period for a reassessment of catastrophically disabled Veterans, make the PCAFC rules severely under-inclusive, meaning that many eligible and deserving Veterans and Caregivers are unfairly and unnecessarily deemed ineligible for the program.

PROPOSED REGULATION

Accordingly, Petitioners request the VA undertake a rulemaking process to promulgate a rule to correct certain VA rules to the PCAFC regulations in 38 C.F.R. Part 71.

I. Eliminate prohibition on work and replace it with criteria of activities of daily living and/or the need for supervision, protection, and instruction.

In its current form, 38 C.F.R. Part 71 is silent as to whether working is an exclusion criterion for the Veteran. However, 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.[8] 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 or not 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.[9]

Similarly, 38 C.F.R. Part 71 is silent as to whether working is an exclusion criterion for the Caregiver. Although VA acknowledges that each Caregiver's situation is unique (in terms of ability to work from home and having a flexible work schedule) and that the Caregiver may have

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[8] 85 F.R. 46230.

[9] *Id.*

the time and ability to provide the required personal care services to the Veteran while maintaining employment, VA declined to include language to state that employment is not an exclusionary factor for the PCAFC eligibility,[10] 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.

Based on the experiences of Veterans and Caregivers, the lack of language in the regulations relating to employment causes much unnecessary confusion in the process of eligibility evaluation. Although VA's position is clear that working is not in itself an exclusion criterion, this position does not seem to be known to many rank and file VA employees who regularly decline otherwise eligible PCAFC applications because a Veteran or a Caregiver are working or volunteering.[11]

To resolve this problem, Petitioners propose the following changes:

- Add paragraph (d) to 38 C.F.R. §71.20 (Eligible veterans and service members) to state "Maintaining employment or engaging in other pursuits, such as volunteer services and recreational activities, does not disqualify a person from being the eligible veteran or servicemember from being the eligible veteran."
- Add paragraph (e) to 38 C.F.R. §71.35 (General Caregivers) to state "Maintaining employment or engaging in other pursuits, such as volunteer services and recreational activities, does not disqualify a person from being the Family Caregiver."

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[10] 85 F.R. 46230–31.

[11] *Id.*

II. <u>That</u>

In its current form, 38 C.F.R. §71.15 (Definitions) states that "Unable to self-sustain in the community means that an eligible veteran … (2) Has a need for supervision, protection, or instruction *on a continuous basis*." VA states that this language is not intended to mean that the eligible Veteran requires or that the Caregiver provides 24/7 or nursing home level care.[12] Also, VA states that this language will not be used to require Caregivers to provide a log of the activities they perform.[13]

Further, while the VA attempts to state that it, "…is not our intent to require a Family Caregiver to be present at all times"[14] the VA on the same page states the PCAFC program requires the Caregiver to live with the Veteran and that the new regulation is, "establishing an expectation that Family Caregivers are providing services equivalent to that of a home health aide, which are generally furnished in person…"[15] And on the next page, the VA states, "…personal care services must be provided by the Family Caregiver, and that personal care services will not be simultaneously and regularly provided by or through another individual or entity."[16] Regardless, the 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.

To resolve this problem, Petitioners propose the following changes:

- Amend paragraph (c)(1)(ii) of 38 C.F.R §71.25 to read, "(ii) Whether the applicant will be capable of ensuring the performance of the required personal care services without

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[12] 85 F.R. 46278.
[13] Id.
[14] 85 F.R. 46228
[15] Id.
[16] 85 F.R. 46229

supervision, in adherence with the eligible veteran's treatment plan in support of the needs of the eligible veteran."

- Remove the phrase "on a continuous basis" from paragraph (2) of the definition of "Unable to self-sustain in the community" in 38 C.F.R. §71.15 to read "Has a need for supervision, protection, or instruction."

III. Relax the strict requirement for a Veteran to fail 100% of their activities of daily living

In its current form, 38 C.F.R. §71.15 (Definitions) states that "Inability to perform an activity of daily living (ADL) means a Veteran or servicemember requires personal care services *each time* he or she completes one or more of the following [activities]." This definition is too limiting, is more restrictive than the previous PCAFC regulations, is too narrow to properly evaluate a Veteran's disability and symptoms, and may result in Veterans being unfairly and unnecessarily deemed ineligible for PCAFC. 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 current language of the regulation assumes the disabled veterans are some binary automatons, either fully capable of completing ADLs or completely incapable, with no allowance for the variation, aggravation, and progression of a service-connected disability that is at the heart of the disability rating system. Disabled Veterans' assistance needs will vary over time, will often fluctuate even throughout the day, based on such variables as medication, other medical care, or repeated motion), and can vary based on other circumstances (e.g., weather, after post-operative care, physical therapy, seasonally).

To resolve this problem, Petitioners propose in 38 C.F.R. §71.15 to remove the phrase "each time" and replace it 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]."

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.[17] 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.[18] 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 criteria.

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. This is no vaguer or more subjective than the current "each time" language.[19] So, the proposed "any time" language will not be difficult to quantify and will not require VA to establish an arbitrary threshold.

IV. Allow for the extended period for the reassessment of catastrophically disabled Veterans

In its current form, 38 C.F.R. § 71.30 states that "Except as provided in paragraphs (b) and (c) of this section, the eligible veteran and Family Caregiver will be reassessed by VA (in collaboration with the primary care team to the maximum extent practicable) on an annual basis to determine their continued eligibility for participation in PCAFC under this part." Paragraphs (b) and (c) provide the following exceptions:

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[17] 85 F.R. 46234.

[18] Id.

[19] 85 F.R. 46233 (stating that "In some cases, the degree of assistance … may vary throughout the day. In some instances, the veteran or servicemember may only need minimal assistance…."—which creates vagueness and subjectiveness as to the meaning of "minimal" and "degree of assistance").

(b) Reassessments may occur more frequently than annually if a determination is made and documented by VA that more frequent reassessment is appropriate.

(c) Reassessments may occur on a less than annual basis if a determination is made and documented by VA that an annual reassessment is unnecessary.

However, the practice in the field by the Caregiver Eligibility Assessment Team members conducting the assessments about which the Petitioners 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.

To resolve this problem, Petitioners propose the following changes in 38 C.F.R. §71.30:

- Change the language of paragraph (a) to read "Except as provided in paragraphs (b), (c), and (f) of this section …."
- Add paragraph (f) to state "(1) Reassessment of catastrophically disabled veterans (as defined in 38 C.F.R. §17.36(b)) may not occur more frequently than every five years, and (2) Reassessment of permanently and totally disabled veteran (as defined by 38 C.F.R. §3.340) is not required, and will only be authorized by direct order for that individual veteran by the Veterans Integrated Service Network Director covering the veteran's home of residence."

V. Eliminate the unnecessary and arbitrary minimum 70% disability rating

The VA's arguments for imposing a minimum 70% disability rating is based upon its interpretation of the 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" ("As indicated in the proposed rule, this definition [of serious injury] will now include any service-connected disability regardless of whether it resulted from an injury or disease."[20]) 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.

Further, by the VA's own rationale, the eligible veteran could suffer a set of service-connected disabilities which place them at or above a 70% disability rating, but which still leave the eligible veteran capable of performing all their ADLs and not needing any other personal care services. But if non-service-connected disabilities do render them in need of personal care services, they will now be eligible for the PCAFC program even though the required 70% disability rating has nothing to do with the need for that care. This is completely arbitrary and disconnected from the eligibility requirements of the law and appear to be more about restricting eligibility to the PCAFC program (reducing the outlays required to fund it) than it is about drawing any type of eligibility linkage between the eligible veteran suffering a serious injury and they being rendered in need of personal care services.

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

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[20] 85 F.R. 46245.

problem, Petitioners propose to change the definition of "serious injury" in 38 C.F.R. §71.15 to read, "Serious injury means any service-connected disability."

NEGOTIATED RULEMAKING

Petitioners also propose to continue the rulemaking process in form of the negotiated rulemaking process permitted by law under 5 U.S.C. Subchapter III. Although VA does not have any regulations regarding this process, other federal agencies, such as the Department of Housing and Urban Development, the Department of Education, and the Department of Agriculture, have an established process or have engaged in negotiated rulemaking in recent years.[21] Thus, Petitioners believe the VA is able to follow their example and engage in negotiated rulemaking. And, the VA can engage in an Economy Act (31 U.S.C. §1535 and FAR 17.502-2) agreement with those federal agencies that are experienced at negotiated rulemaking, many of them on Veteran-specific issues, to obtain the necessary services to conduct a negotiated rulemaking process for this issue.

Under the law governing negotiated rulemaking, there are several factors that an agency should take into consideration when determining whether to use those procedures.[22] These factors include the following:

- whether a limited number of interests that will be significantly affected by the rule can be identified,
- a committee with balanced representation would be able to be convened,
- there is a "reasonable likelihood" that a committee would be able to reach a consensus on the proposed rule within a fixed period of time,

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[21] *See e.g.*, 84 F.R. 49789, 81 F.R. 83674, 77 F.R. 50561, as well as Congressional Research Service, Negotiated Rulemaking: In Brief, R46756 (April 12, 2021).

[22] *See* 5 U.S.C. §563(a).

- using negotiated rulemaking would not unreasonably delay the issuance of a proposed rule, and
- the agency can commit to using the consensus of the committee as the Proposed Rule.

Negotiated rulemaking can be a useful instrument to supplement the traditional process of rulemaking. The Administrative Conference of the United States observed that informal communications between agency personnel and individual members of the public have traditionally been an important and valuable aspect of informal rulemaking proceedings and that negotiated rulemaking conveys a variety of benefits to both agencies and the public.[23] Administrative law and political science scholars also recognize that negotiated rulemaking has many advantages and there are examples where experiences with negotiated rulemaking have been positive.[24]

Because the traditional rulemaking process did not result in VA adapting any of the changes proposed by the Veteran and military serving organizations,[25] and because the interested Veterans and Caregivers recognize the urgent need to review and revise the PCAFC regulations, Petitioners believe that it is judicious for VA to engage in negotiated rulemaking as soon as possible. The Petitioners respectfully request that a rulemaking, preferably by a negotiated rulemaking process, be commenced to implement a regulation with this effect.

Respectfully submitted,

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[23] *See* Administrative Conference Recommendation 2014-4, "Ex Parte" Communications in Informal Rulemaking (June 6, 2014).

[24] *See e.g.*, Laura Langbein and Cornelius Kerwin, "Regulatory Negotiation: Claims, Counter Claims, and Empirical Evidence," *Journal of Public Administration Research and Theory*, Vol. 10 (July 2000); Cornelius M. Kerwin and Scott R. Furlong, *Rulemaking: How Government Agencies Write Law and Make Policy*, 4th edition (Washington, DC: CQ Press, 2011); Steven J. Balla and Susan E. Dudley, *Stakeholder Participation and Regulatory Policymaking in the United* States, Report for the OECD (October 2014).

[25] *See* 85 F.R. 46226 and 86 F.R. 52614.

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Questions for the Record

Department of Veterans Affairs
Questions for the Record
Committee on Veterans' Affairs
United States Senate
Program of Comprehensive Assistance for Family Caregivers Hearing

March 23, 2022

Questions for the Record from Chairman Jon Tester:

Question 1: Please describe what actions VA is taking to reform the Program of Comprehensive Assistance for Family Caregivers (PCAFC).

VA Response: The Department of Veterans Affairs (VA) currently is undertaking a broad programmatic review using a strategic end-to-end analysis of PCAFC to ensure it achieves intended outcomes for all new applicants, legacy participants and legacy applicants. While this review is underway, VA's Caregiver Support Program (CSP) will continue to enhance and expand services to family caregivers of Veterans, as appropriate, and improve the experience of Veterans and their family caregivers as they access these supports and services. VA will not discharge or decrease any support to legacy participants, legacy applicants and their family caregivers based on reassessment, to include monthly stipends paid to primary family caregivers, before the current eligibility criteria are examined.

VA will continue to complete transitional reassessments of legacy participants, legacy applicants, and their family caregivers to ensure any family caregiver eligible for an increase in the monthly stipend will receive it.

While VA conducts a review and examination of the current PCAFC eligibility criteria, legacy participants, legacy applicants and their family caregivers will remain enrolled in PCAFC and continue to receive support and services under PCAFC, unless revoked or discharged for a reason unrelated to reassessment. VA's review and examination is intended to identify eligibility criteria that impede obtaining intended outcomes for PCAFC participants and whether improvements require changes in policy, regulation or statute.

The program is still on track to expand to include veterans of all service eras on October 1, 2022.

Question 1a: What is the timeline for VA to review the current program and propose a new VA regulation governing PCAFC eligibility criteria?

VA Response: VA has not yet established a timeline for the review of current PCAFC eligibility criteria and development and proposal of potential rulemaking, if appropriate. CSP is conducting a series of stakeholder engagement sessions that are currently taking place with Veteran Service Organizations, Military Service Organizations, strategic partners, Congressional Staff, Caregiver Support Program Staff, Veterans and caregivers to gather information to better inform an action plan with targeted timelines and milestones.

Question 1b: If not yet established, when does VA plan to establish and publish that timeline?

VA Response: As noted in the response to Question 1a, an action plan and targeted timelines will follow stakeholder engagement sessions.

Question 1c: Does VA have a timeline for how long discharges from PCAFC will be suspended?

VA Response: VA does not have a timeline; however, CSP is working closely with other stakeholders to identify and pursue available options.

Question 1d: What outreach to stakeholders is VA planning during development and implementation of new regulations and processes for PCAFC?

VA Response: In addition to the Stakeholder Engagement Sessions noted in the previous responses, CSP is engaging VA and VHA communications teams to ensure information and updates are disseminated to Veterans, caregivers, staff and stakeholders as timely as possible. This dissemination includes communication through website updates; making phone calls to legacy Veterans and their caregivers; publication of Fact Sheets and Frequently Asked Questions (FAQs); and letters to Legacy Veterans and Family Caregivers. Updates also will be provided via the Caregiver Support Program listserv; Veteran Service Organizations (VSO); leadership and communicators; press releases; social media messaging; and other media available platforms as appropriate.

Question 2: Please describe what specific information VA currently provides to an applicant to PCAFC who is denied from the program.

VA Response: When a Veteran and caregiver are determined to not be eligible for PCAFC, caregiver support staff notify the Veteran and caregiver in writing as well as verbally, when able to review the following:

- An explanation of the reason or reasons why they are not eligible for PCAFC.
- Information about and enrollment in the Program of General Caregiver Support Services.
- Information, referrals and offer warm handoffs to other VA and community resources that may be of assistance.

- Inform them of VA Form 10-305, Your Rights to Seek Further Review of PCAFC Decisions. This information can also be obtained from https://www.caregiver.va.gov/.

Question 2a: What information does VA provide information about which eligibility criteria the applicant did not meet?

VA Response: Please see the following response to Question 2b.

Question 2b: What information does VA provide information about why the applicant did not meet this eligibility criteria?

VA Response: VA continues to work towards the development of a standardized decision letter for Veterans and family caregivers that will provide detailed information regarding the PCAFC eligibility determinations.

Currently, VA is refining a draft Notice of Decision template that will provide Veterans and family caregivers with full, transparent and individually tailored information on how VA came to its decision. This Notice of Decision will include PCAFC eligibility criteria and provide information to Veterans and their family caregivers on how they either met, or did not meet, each element of PCAFC eligibility criteria. The Notice of Decision will also include the evidence VA relied on to make its decision, how to obtain information from VA that was used to make its decision and what to do if the Veteran or caregiver disagrees with VA's decision. CSP has worked closely with VSOs who have experience in assisting Veterans with appeals and have leveraged their direct feedback on how to improve this decision letter.

Finally, the Notice of Decision also will include information on other VA benefits or services for which the Veteran or caregiver may be eligible and various points of contact for questions or more information.

Question 2c: What information does VA provide regarding the various options for applicants to appeal a denial from PCAFC?

VA Response: As noted in Question 2, Veterans and their caregivers are informed of VA Form 10-305, Your Rights to Seek Further Review of PCAFC Decisions, and also are mailed a copy following application disposition. This information, along with other information on available appeal and review options, are located on the Caregiver Support Program website: PCAFC decisions – options for further review and appeal - VA Caregiver Support Program.

Question 3: Please describe all assessment processes which applicants to PCAFC and participants in PCAFC must accomplish.

VA Response: CSP uses a standard assessment process for all PCAFC applicants. Veterans and caregivers who apply will complete the following: Intake, where basic information is reviewed and collected; a Veteran and caregiver assessment; and a Veteran Functional Assessment. Details of the steps in the process are outlined at https://www.caregiver.va.gov/pdfs/FactSheets/ApplicationProcessFactsheet.pdf.

Question 3a: How often are the various type of assessments accomplished and how long does each type of assessment typically take?

VA Response: Average time to complete assessments that are part of the application process varies based on the individual, but on average, the following times apply: Application Intake takes 0.5 hours; the Veteran and Caregiver Assessments takes 90 minutes combined; and the Veteran Functional Assessment takes 1-2 hours depending on the complexity of the Veteran's needs.

Reassessments: Approved PCAFC Veterans and Family Caregivers are reassessed on a more, or less frequent than annual basis as clinically indicated. A reassessment review (comparable to the Application Intake) is completed by facility staff. Following the Reassessment Review, Facility CSP Staff complete the Veteran Assessment, Caregiver Assessment(s), and Veteran Functional Assessment Instrument (VFAI), unless any of the aforementioned evaluations are determined to be not clinically indicated. The reassessment steps take approximately the same amount of time as during the initial application process.

Wellness Contacts: VA is required to conduct wellness contacts a minimum of every 120 days, with one wellness contact occurring in the Veteran's home on an annual basis. Wellness contacts give facility CSP staff the opportunity to review the eligible Veteran and Family Caregiver(s)' well-being and the adequacy of personal care services being provided. Wellness contacts provide facility CSP staff the opportunity to identify and provide additional instruction, training, or benefits to the eligible Veteran and Family Caregiver(s) and are not intended to assess for continued eligibility for PCAFC. Wellness contacts average around 20 minutes with the Veteran and Family Caregiver, extending longer where clinically appropriate.

Question 3b: How are these assessments tracked to ensure a participant in the program is not excessively burdened with multiple invasive assessments?

VA Response: Assessments are tracked in the CSP IT system, the Caregiver Record Management Application (CARMA). Upon applying to PCAFC, all applicants participate in a standard assessment process. After enrollment, annual reassessments may be conducted less frequently than annually for both the Veteran and/or family caregiver if a determination is made that annual reassessment is not clinically indicated. In some cases, a reassessment of the Veteran may not be clinically indicated due to the limited opportunity for recovery. In addition, it may not be clinically indicated to reassess a caregiver who is actively engaged in the Veteran's care, has the knowledge and skills to carry out the needed personal care services and there are no identified high-risk factors.

Question 3c: Does VA provide reasonable accommodations for veterans who cannot perform to the strict standards of these assessments due to injury or illness and if so, what accommodations is VA willing to provide and what is the process to gain these accommodations?

VA Response: CSP staff work with Veterans and caregivers to accommodate individual needs when possible. CSP offers flexibility through a variety of ways, such as assessments can be completed by telephone, video call and in-person at the medical center. Assessments can be scheduled at various time of the day to limit disruption to Veteran and family caregiver’s daily schedules. Also, depending on the clinical needs of the Veteran, the family caregiver applicant also may wish to be present and participate in the Veteran assessment and the Veteran Functional Assessment (e.g., if the Veteran has such limitations that they cannot participate in the assessments independently).

Questions for the Record from Senator Maggie Hassan

Questions for Colleen Richardson, PhD, Executive Director, Caregiver Support Program, Department of Veterans Affair

Question 1: Please provide my office with what the VA disseminates to veterans and their caregivers. Additionally, can you please speak to what updated guidance the VA will provide VSOs and Congress, so that we are best equipped to serve veterans and their caregivers?

VA Response: CSP appreciates the support of Congressional members, its staff and Veteran Service Organizations (VSO). Over the past year, CSP has made a concerted effort to increase communication and transparency with our stakeholders by hosting monthly briefings with Congressional staff and members and bi-monthly sessions with VSO and community partners to provide program updates and information as well as training and education on topics of interest.

With the recent VA Deputy Secretary press release on March 22, 2022, CSP has leveraged many communication channels to ensure the widest dissemination, which include updates to the caregiver.va.gov website, communication blasts through listservs, blogs, social media, emails to VSOs, and FAQs. In addition, CSP has reached out to legacy participants, legacy applicants and their family caregivers via phone calls and letters with information on the recent announcement.

Question 2: Dr. Richardson, can you please speak to what further transparency the VA will provide to veterans and their caregivers on the information and findings used in making eligibility decisions?

VA Response: VA continues to work towards the development of a standardized decision letter for Veterans and caregivers that will provide detailed information regarding the PCAFC eligibility determinations. Currently, VA is refining a draft Notice of Decision template that will provide Veterans and caregivers with full, transparent and individually tailored information on how VA came to its decision. This Notice of Decision will include PCAFC eligibility criteria and provide information to Veterans and their family caregivers on how they either meet, or did not meet, each element of PCAFC eligibility criteria. The Notice of Decision also will include the evidence that VA relied on to make its decision, how to obtain information from VA that was used to make its decision and what to do if the Veteran or caregiver disagrees with VA's decision. The Notice of Decision also will include information on other VA benefits or services for which the Veteran or caregiver may be eligible and various points of contact for questions or more information. CSP has worked closely with VSOs who have experience in assisting Veterans with appeals and have leveraged their direct feedback on how to improve this decision letter.

Question 3: Dr. Richardson, can you please provide my office with CARMA and PATS-R data specific to New Hampshire and, additionally, Veterans Integrated Service Network 1 (New England) in an effort for the VA to provide transparency on PCAFC?

VA Response:

Veterans Integrated Services Network (VISN) 1 FY22 PCAFC Applications Processing (as of April 14, 2022)

Approximate Unique PCAFC Applications Received	690
Approximate Approved Applications*	140
Approximate Total PCAFC Applications Denied: Excluding Denied as Ineligible*	235
Approximate Total PCAFC Applications Denied as Ineligible*	455
Approval Rate (‘approved’/(’denied: excluding ineligible’ + ‘approved’)	37.3%
Application Median Days in Process	30

* Figure includes Applications that may have been received during FY 21

Manchester, NH HCS FY 22 PCAFC Initial Applications Processing (as of April 14, 2022)

Approximate Unique PCAFC Applications Received	75
Approximate Approved Applications*	8
Approximate Total PCAFC Applications Denied: Excluding Denied as Ineligible*	20
Approximate Total PCAFC Applications Denied as Ineligible*	48
Approval Rate (‘approved’/(’denied: excluding ineligible’ + ‘approved’)	28.6%
Application Median Days in Process*	27

* Figure includes Applications that may have been received during FY 21

Data from the Caregiver Record Management Application (CARMA) system provides a snapshot in time, as of the point when the report was run. Data is agile due to appeal outcomes, reinstatements, delayed data entry and data corrections; data are therefore estimates.

To improve interpretation and understanding of approval decision rates for all stakeholders, the Caregiver Support Program (CSP) has taken efforts to improve how program data has been reported since Phase I expansion on October 1, 2020. Previously, the term “denials” was used as a blanket disposition categorization of Veterans and caregivers’ PCAFC applications. To provide internal and external stakeholders a more complete picture—as well as improve its communication with Veterans and caregivers on the disposition of their applications—CSP has begun to categorize and report applications deemed “ineligible” to give more clear accounting to those who do not meet program eligibility requirements versus those who are “denied” based on a clinical determination.

PCAFC Application is deemed denied as “ineligible” if the following are applicable:

- Veteran does not have a serious injury as evidenced by a singular or combined Service-Connected Disability Rating of 70% or greater.
- Veteran’s serious injury was not incurred or aggravated in the line of duty on or after September 11, 2001, or on or before May 7, 1975.
- Family caregiver applicant is not the Veteran’s spouse, son, daughter, parent, step-family member or extended family member and does not live with the Veteran or plan to live with the Veteran if designated.
- Veteran/Service member or family caregiver applicant reside outside a state, as defined in VA’s rulemaking.
- An applicant applying to receive care from a family caregiver is not a Veteran or member of Armed Forces undergoing medical discharge.
- Death of Veteran or caregiver.
- Family caregiver applicant is not 18 or older.
- Family caregiver applicant failed to complete the application process within 90 days.
- Veteran or family caregiver applicant withdrawing the application.

PCAFC Application is deemed “denied” if any of the following are applicable:

- Veteran is not receiving care at home or will not do so if VA designates a family caregiver.
- Veteran is not receiving ongoing care from a primary care team or will not receive ongoing care from a primary care team if VA designates a family caregiver.

- Veteran is determined to not be in need of personal care services for a minimum of 6 months continuous months based upon an inability to perform an activity of daily living or a need for supervision, protection or instruction.
- Determination that participation in PCAFC is not in the Veteran's best interest.
- Personal care services that would be provided by the family caregiver applicant are being simultaneously and regularly provided by another individual or individuals.
- Family caregiver applicant being assessed as not having the ability to carry out the specific personal care services, core competencies and any additional care requirements.

Office of Patient Advocate Appeal Data for October 1, 2020–February 28, 2022

(as of March 30, 2022)

VISN	Upheld	Overturned	Pending	TOTAL
01	407	20	11	438

The appeal data in the previous table was transmitted to CSP on March 30, 2022, from Office of Patient Advocacy, the authoritative source for appeal data. All facts and figures related to appeals data should be confirmed with Office of Patient Advocate to be considered authoritative.

Questions for Beth Taylor, DHA, Assistant Under Secretary for Health, Patient Care Services and Chief Nursing Office, Veterans Health Administration, Department of Veterans Affairs

Question 1: Dr. Taylor, can you please provide information on what veteran caregiver needs VA has identified relevant to post-9/11 veterans, veterans who served before May 7, 1975, and veterans who served between May 7, 1975, and September 11, 2001?

VA Response: While conducting legacy reassessments, it was identified that there was a cohort of Veterans in need of PCAFC services who were being denied or deemed ineligible for the program under the current regulations. What CSP is learning is that different eras of Veterans have different caregiving needs. CSP also is observing that some Veterans, while they need support services, may need them intermittently and not as frequently as required in the regulation. As we continue to conduct reassessments on legacy participants, legacy applicants, and their caregivers, we are obtaining more information and data on the unique needs of the different service era cohorts and seeking input from our partners and stakeholders on how to enhance the PCAFC program to address these caregiving needs.

Question 2: Dr. Taylor, how will VA's March 22 announcement impact this specific legacy participant, including if dismissal from the program will be halted for the veteran and caregiver, and if they will retain their monthly PCAFC stipend while the VA examines regulatory changes?

VA Response: VA will continue to complete transitional reassessments of legacy participants, legacy applicants, and their family caregivers. Any family caregiver eligible for an increase in caregiver benefits will receive them. Legacy participants, legacy applicants and their family caregivers may decline the reassessment; however, no increase in benefits can be provided without the completion of a reassessment**.**

VA will not discharge or decrease any support to legacy participants, legacy applicants, and their family caregivers, based on reassessment, to include monthly stipends paid to primary family caregivers, before the current eligibility criteria are examined.

While VA conducts a review and examination of the current PCAFC eligibility criteria, legacy participants, legacy applicants, and their family caregivers will remain enrolled in PCAFC and continue to receive support and services under PCAFC, unless revoked or discharged for a reason unrelated to reassessment.

In addition, VA will stop annual eligibility reassessments for non-legacy participants (those admitted after October 1, 2020). VA is currently determining next steps on non-legacy participants who have had a level lowered or been discharged after an annual eligibility reassessment and will update stakeholders as changes are made to these processes.

Questions for the Record from Senator Patty Murray

Question 1: How does VA plan to include advocates' voices in shaping the new PCAFC regulations?

VA Response: VA and CSP intend to use feedback from the stakeholder engagement sessions as part of its programmatic review of PCAFC to ensure it achieves intended outcomes for all new applicants; legacy participants and legacy applicants; and their family caregivers.

Question 2: How will VA ensure veterans and caregivers have full information and transparency about VA's eligibility decisions?

VA Response: VA continues to work towards the development of a standardized decision letter for Veterans and caregivers that will provide detailed information regarding the PCAFC eligibility determinations. Currently, VA is refining a draft Notice of Decision template that will provide Veterans and caregivers with full, transparent and individually tailored information on how VA came to its decision.

This Notice of Decision will include PCAFC eligibility criteria and provide information to Veterans and their family caregivers on how they either met, or did not meet, each element of PCAFC eligibility criteria. The Notice of Decision also will include the evidence that VA relied on to make its decision, how to obtain information from VA that was used to make its decision and what to do if the Veteran or caregiver disagrees with VA's decision. CSP has worked closely with VSOs who have experience in assisting Veterans with appeals and have leveraged their direct feedback on how to improve this decision letter. The Notice of Decision also will include information on other VA benefits or services for which the Veteran or caregiver may be eligible and various points of contact for questions or more information.

Question 3: Please provide the decision matrix (and/or other relevant guidelines) used to determine how PCAFC tier level or participation is impacted by other VA services (e.g., participation in the Homemaker and Home Health Aide program).

VA Response: CSP and Geriatrics and Extended Care (GEC) National Program Offices have jointly developed standardized processes for delineation of services for Veterans and their primary family caregivers. This process ensures that services are not simultaneously and regularly provided by both the primary family caregiver and another individual or entity. Per 38 C.F.R. § 71.20, a Veteran will be eligible for PCAFC if "[p]ersonal care services that would be provided by the Family Caregiver will not be simultaneously and regularly provided by or through another individual or entity." The GEC Case Mix Tool is used in part of the clinical decision-making process and aids in determining a level of care for VA personal care services after eligibility for PCAFC has been established.

During the PCAFC application process, and prior to final approval, CSP staff discuss with Veterans and caregivers the impact enrollment in PCAFC will have on VA personal care services. CSP staff support the Veteran and family caregiver as they make an informed decision about how the Veteran would like to receive their personal care services. Veterans can be enrolled in both PCAFC and GEC personal care service program. Home Hospice services are not considered part of this process and would not be considered regularly and simultaneously services. Participation in PCAFC and Home Hospice does not necessarily preclude a Veteran from also receiving VA personal care services.

Questions for the Record from Senator Tommy Tuberville

Question 1: Can you briefly discuss why some caregivers and veterans may have experienced inconsistent guidance from one VA medical center to another on whether or not they are eligible for the program? Was this primarily before the expansion and regulations were put into place?

VA Response: Prior to expansion on October 1, 2020, CSP did not have Centralized Eligibility and Appeals Teams (CEAT) and PCAFC decisions were rendered from each of the VA's 140+ facilities who were responsible for their own processing of eligibility and appeals decisions. This approach led to variations in interpretations of eligibility criteria. Acknowledging this concern, CEATs were established at each of the 18 VISNs to standardize decision making processes using a dedicated team of providers. The interprofessional team that makes up CEATs is required to complete standard orientation, training and receive ongoing support and oversight.

Question 2: When the VA rolled out the regulations and subsequently received broad criticism, the Secretary himself publicly questioned if the backlash the VA received was a result of the VA's poor communication of programmatic changes to program participants. How could this roll out have gone better and what learnings will be applied to future VA communications related to the caregiver program?

VA Response: CSP acknowledges the need for improved communication with Veterans and caregivers. CSP has made several strides towards improvement which include increased messaging, communication and training with stakeholders and partners. CSP will continue to improve its efforts in working actively with all strategic partners to best communicate and educate on program changes and roll outs related to PCAFC and leverage tools such as the CSP website; social media; listservs; partner meetings and engagements; webinars; letters to caregivers; media opportunities; and Facebook Live/YouTube messaging/podcasts. These efforts are in addition to the CSP stakeholder engagement sessions being conducted with CSP partners, stakeholders and staff.

Question 3: On the briefing to staff last week, you mentioned the need to hire additional staff to process the surge of applications that came with the recent program expansion. What is the plan for this additional staff once the application surge has been processed?

VA Response: CSP worked in close collaboration with the VA Manpower Office to develop a workload analysis model. This model continues to be used to identify necessary human capital resources in support of current PCAFC participants and applications workload, as well as anticipated volume of applicants and participants who will soon be eligible as part of PCAFC Phase II expansion. CSP reviews and references the model for staffing requests to ensure adequate staffing ratios are in place. Staffing allotments for PCAFC Phase II expansion were released to VAMC and VISNs in December 2021 to afford time to hire and train staff in anticipation of Phase II expansion. CSP has set a goal to hire 90% of allocated staff by June 2022. In addition, CSP has updated its training curriculum to include recurring orientation calls to ensure all staff are adequately trained in support of Phase II expansion.

Statements for the Record

STATEMENT OF

MICHELLE FLATOFF, CAREGIVER FOR MICHAEL FLATOFF,

UNITED STATES ARMY MEDICAL RETIREE

AND VETERAN

BEFORE THE

UNITED STATES SENATE COMMITTEE ON VETERANS' AFFAIRS

WITH RESPECT TO

"**Program of Comprehensive Assistance for Family Caregivers (PCAFC)**"

Washington, D.C. March 23, 2022

Chairman Tester, Ranking Member Moran, and members of the committee I would like to convey some issues with the Department of Veterans Affairs Program of Comprehensive Assistance for Family Caregivers (PCAFC) that my family is having.

To give the committee some context, the stated intent of the program according to the VA website is "to provides resources, education, support, a financial stipend, and health insurance (if eligible), beneficiary travel (if eligible), to caregivers of eligible Veterans." It further states that to qualify a veteran must "have sustained or aggravated a serious injury serious injury (now includes serious illness) in the line of duty on or before May 7, 1975 or on or after September 11, 2001; and meet both of the following criteria to be eligible for PCAFC. Among other applicable eligibility criteria, the Veteran must:

a. Have a single or combined service-connected disability rating by the Department of Veterans Affairs (VA) of 70% or more. This requirement is included in the definition of "serious injury;" and
b. Be in need of personal care services (requiring in-person personal care services) for a minimum of six continuous months based on any one of the following:
    - an inability to perform an activity of daily living (ADL)
    - <u>a need for supervision, protection, or instruction</u>.

My husband Michael was medically retired from the United States Army on February 26, 2013. He was rated by the Department of Veterans Affairs for the following conditions: 100% Post Traumatic Stress Disorder with Major Depressive Disorder, 50% Traumatic Brain Injury with Migraines, 40% Lumbar Spine Degenerative Disc Disease. He was also rated for Tinnitus, left and right lower extremity radiculopathy, degenerative joint disease right knee, sleep apnea, and bilateral pes planus.

In addition, my husband was rated at 100% permanent and total for his disabilities and the VA awarded him special compensation for meeting their homebound criteria which is awarded at $350.00 per month (a far cry from the financial costs for constant supervision).

While at the VA we were approached by the VA's Caregiver Program Coordinator, she talked with us and enrolled us in the program. We have been in the program since 2013. We are on the highest of tiers (tier 3) and met all the requirements to be on that tier for every evaluation we received until this last one which was done for legacy participants under the program change.

Prior to this my Husband passed every evaluation for the Caregiver program. The program assessed him as needing supervision, protection and instruction daily. My husband's therapist at the Madison Vet Center believes that he is constant need of supervision, protection and instruction which he stated in his letter to the Caregiver Program for the reevaluation. His psychiatrist at the William S. Middleton Memorial Veterans' Hospital also concurred with his need for supervision, protection and instruction. For 9 years everyone on his care team agreed that he had a constant need for supervision, protection and instruction. With this last evaluation the Caregiver program decided that he suddenly was no longer in need of supervision, protection and instruction in contrast to his Therapist and Psychiatrist and the previous 9 years of evaluations.

My husband suffers from suicidal ideation as well as night terrors that cause hallucinations. When you ask him about suicide, he will tell you the only reason he hasn't done it is because of his children. Every night I am up at least two and a half hours (usually around midnight to 2:30am) watching over him, prepping him for bed and making sure he has his CPAP on. He uses a cane or walker due to his physical limitations and has falls 3-5 times a week due to his TBI. He is unable to dress his lower half. He doesn't use the stove as he has started fires in the past as he has immediate memory problems. Due to that he is unable to make appointments because he forgets the date and time the as soon as he gets off the phone. These are only a few of his limitations, the actual list is much longer. He is not able to manage his own care.

In closing, we have qualified for this program since early 2013 under the need for supervision and protection and have successfully completed quarterly as well as yearly assessments and now we are being told after almost 9yrs he no longer has the need for said program. We will lose $2700.00 a month which covered me being home caring for him while losing the ability to continue my career. How is this beneficial to this veteran and his household when his condition has either stayed the same or worsened? How was this conclusion made when all other assessments of the veterans need for supervision and protection has been strongly noted? There have been no changes made for veterans in need of supervision and protection in the new caregiver requirements and qualifications therefore these veterans being cut are unjustified and causing a great deal more stress on veterans and their caregivers as well as their children. The financial and emotional hardship that has been caused by this reassessment will linger and make it harder for Veterans to trust in the VA and Caregiver Program. We respectfully ask that this committee consider overturning denials related to supervision, protection or instruction, especially those related to mental health and traumatic brain injuries and examine why so many legacy participants who qualified under the aspects of supervision, protection or instruction no longer qualify even though those program requirements have not fundamentally changed.

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VETCENTER | Connection. Camaraderie. Community.

February 4, 2022

To: Program of Comprehensive Assistance for Family Caregivers
William S. Middleton Memorial Veterans Hospital

Re: Michael Flatoff 12-Month Vet Center Treatment Summary

To whom it may concern,

Over the past 12 months, Mr. Flatoff, the Veteran hereafter, has attended 44 sessions with this author. The Veteran's spouse and VA Caregiver, Michelle, has been present for and participated in the vast majority of these sessions. At the request of the Veteran, the frequency of these sessions increased to weekly during this timeframe due the increased strain COVID-19 precautions have had on the Veteran and his family. Veteran's documented chronic anxiety and depression symptoms have proportionally intensified.

Veteran's treatment plan focus has involved addressing catastrophic thinking patterns when feeling helpless, increasing insight into his emotional experience, increasing sustainable self-care practices and strengthening of the therapeutic alliance. Sessions also include facilitation of discussions between Veteran and Michelle to address presenting concerns about Veteran's functioning. Veteran continues to present with symptoms associated with complex PTSD and Major Depressive Disorder, including persistent suicidal thoughts. Thus far, Veteran has been more expressive of his internal experience during sessions and receptive to feedback from Michelle and me. No issues of abuse, safety or exploitation have been reported nor has cause for concern arisen during our sessions.

Regarding the Veteran's capacity in Instrumental Activities of Daily Living, I can only speak to my direct observations and the reports of Veteran and Michelle. Per these interactions, the Veteran is dependent on Michelle for transportation, memory and concentration assistance (ex. reminder of daily tasks, medication management, care coordination), migraine support (ex. minimization of exposure to disturbing stimuli), fall recovery (ex. falls 2-3 times/week), management of the household and financial affairs and constant observation and co-regulation when he is emotionally distressed.

Respectfully,

Jason Thilges, LMFT
Madison Vet Center Director

WRITTEN TESTIMONY OF SHAWN MOORE, LMSW, VETERAN CAREGIVER, ADVOCATE, AND DOLE CAREGIVER FELLOW WITH THE ELIZABETH DOLE FOUNDATION BEFORE THE SENATE COMMITTEE ON VETERANS' AFFAIRS UNITED STATES SENATE ON THE VA'S PROGRAM OF COMPREHENSIVE ASSISTANCE FOR FAMILY CAREGIVERS

March 23, 2022

Chairman Tester, Ranking Member Moran, and Members of the Committee, I am pleased to submit my written testimony on the VA's Program of Comprehensive Assistance for Family Caregivers.

I met my husband, Bryan Moore, in 2013 when he was being medically retired from the Army after 23 years of service. My husband was in the 160th Special Operations Aviation Regiment where he completed seven tours to Afghanistan. He came home with invisible wounds and received his disability rating of 100% the same year. He was rated at 70% for PTSD alone. In less than seven months he was in the first of many stays at the VA in a PTSD program.

I first became Bryan's caregiver in 2013 at a tier 2 when I was still his girlfriend. We got married in 2015 and have been a part of the PCAFC since then. My husband had his first suicide attempt by hanging in 2017. I was a police officer at the time in Kansas City, MO and thankfully so. My training gave me the ability to compartmentalize my feelings and find my husband that day. He was at a dead-end road, not breathing. We got there just in time. I then asked the caregiver program to be moved to a tier 3 and it was granted and we have been at this tier since then. In 2019 I left a 15-year career as a police officer because I spent more time at home caring for him than at work. I could not leave while I was on a scene when I would get a call from him. Last year he was bumped up to 100% for PTSD. My husband has since attempted suicide several different times with each time me getting him to the ER. In this past year, he has been in an acute care setting (in-patient) 5 times which is where he is at as I write this.

My husband continually takes his medications and goes to therapy at the VA. I manage his care making sure medications are taken on time and reordered and his appointments get scheduled. Since 2017 it has been an absolute fight to be recognized by providers at the VA when he is at in-patient care. Most providers do not know anything about the caregiver program. They do not document in his records how I am the one that gets him to the ER or that I call. Prior to the reassessment of legacy status, I have told his providers of the importance of documenting the need for a caregiver and it has been met with me having to fight to get it done, even though I have literally saved my husband's life on numerous occasions. I manage environmental triggers daily. My husband also has a substance use disorder and was diagnosed with borderline personality disorder last year. I cannot leave my 11-year-old daughter alone with him due to him having very impulsive behaviors.

After leaving the police department, I went back to school for a Masters in Social Work. I speak on a national level on how our communities and providers need to support the entire veteran family unit. I say this because I am appalled at how the PCAFC is being implemented. I advocated on the Hill for the Mission Act to be passed to be inclusive of all eras of veteran caregivers yet I sit here today wondering if we are going to be kept in the program. I do not do any ADL's on a continuous basis. Yet I keep my husband from killing himself DAILY. Our first reassessment with the caregiver program social worker was four hours long. Mind you my husband has been actively suicidal since December, and he had to go through his traumas again. These things that are in his medical chart. Not even a week later we had to do a "wellness" visit with the caregiver staff because it was "due". It is like all common sense has been thrown out the window because the Director of the program said she wants all reassessments to be done prior to the end of March. We have our nurse assessment tomorrow, but I must cancel it due to my husband being in the hospital. I sit here worried about being kept in this program and what response I am going to get for having to reschedule this appointment.

The long reassessments and the fact that they will be done on a yearly basis is too triggering to our veterans who have mental health conditions and traumatic brain injuries. These veterans should not have to sit through a traumatizing two-to-four-hour long appointment when the medical records should reflect why a caregiver is needed. As you can see, this was one more thing that added to my husband's plate and he clearly could not handle it landing him in the hospital again.

One of the VA's primary goals is to reduce veteran suicide, yet they are ignoring the supervision and safety piece of the Mission Act and kicking caregivers out of the program like me. Looking back through 6-12 months is not enough for a veteran who has chronic PTSD and suicidality because you cannot see a pattern. A few weeks ago, I notified my husband's psychologist of the pattern I was once again seeing. A pattern that has been taking place for the past five years that can be seen in the medical chart. The review of the veteran medical records must be extended.

The Safety and Supervision piece of the Mission Act must be more quantifiable so that the CEAT know what to look for in veterans who have mental health conditions. Right now it is so subjective that it is not being followed. The focus is on ADL's which leaves out many veterans of the post 9/11 era. These are the veterans that are coming home with invisible wounds.

I left a career where I had my own health, dental, and life insurance, retirement, and was making close to a six-figure income. The stipend is not a replacement for what I lost so I now work a remote job to make sure I am setting myself up for success when caregiving ends. I am one of the lucky ones to find a job that allows me to work from home. The stipend has allowed us to pay off bills my husband incurred through his time in the service, The program allows me to be designated as his caregiver in his medical chart which I just had to use when I called to speak with my husband's nurse. She did not want to give me any information. I had to ask her if she knew about the VA caregiver program and direct her to his chart where it listed me as his primary caregiver. Medical charts will not reflect the need for a caregiver until ALL providers within the VA are educated about the program.

If a veteran has mental health conditions, those providers need to be consulted with as to the needs of a caregiver during the assessments. Right now only the primary care physician is notified. My husband's primary care doctor knows nothing about his mental health conditions, therefore this step will not help us in the reassessment.

There needs to be an immediate halt of reassessments and new applications to get this right for our veterans. In October a new era will be eligible to apply. Are we going to put these veterans and caregivers through more trauma for a program that is supposed to help? The caregiver community has been wrought with fear right now wondering how they are going to care for their veteran and work at the same time. Caregivers who should have been kept in the program. Veterans and caregivers who have been kicked out of the program should have their cases reopened after a review and revision of the program implementation. They should not have to appeal until this is done. Caregivers are finding out they have been kicked out of the program in the Veterans medical chart before getting a phone call or letter. The reasons given are not enough to even file an appeal on.

As I said previously, I am an advocate and work in this space supporting other caregivers. I feel like I have a lot of support but even I am stressed out over the implementation of this program. After years in the program, there is no reason that a 100% disabled veteran should have to go through these traumatizing reassessments. It is a constant fight with the VA to get his medications correct, his labs done correctly, tests for toxic exposure done, etc. I have NEVER had this type of stress in getting my own care through my civilian provider.

I am thankful for the hearing and implore the committee to take the suggestions of the written and oral testimonies to do what Congress intended to do when voting for the Mission Act – make the program inclusive for all, consistent across all VA's, and support caring for our Veteran at home through their family caregiver. Please, we NEED you to be the voice of our veterans and caregivers. We are NOT being heard at the VA.

AIM
ALZHEIMER'S IMPACT MOVEMENT
alzheimer's association

Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record

United States Senate Committee on Veterans Affairs hearing titled, "Honoring Our Commitment: Improving VA's Program of Comprehensive Assistance for Family Caregivers"

March 23, 2022

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for United States Senate Committee on Veterans Affairs hearing titled *"Honoring Our Commitment: Improving VA's Program of Comprehensive Assistance for Family Caregivers."* The Association and AIM thank the Committee for its continued leadership on issues important to the millions of people living with Alzheimer's and related dementias, including those who have served our nation in uniform, and their caregivers.

Nearly half a million American veterans have Alzheimer's — and as the population ages, that number is expected to grow. In 2015, an estimated 486,000 veterans were living with Alzheimer's. The annual number of veterans newly diagnosed with dementia has increased more than 22% since 2008. For veterans, prevalence may grow even faster in future years because they have a higher risk of developing dementia. Evidence indicates that moderate and severe traumatic brain injury (TBI) increases the risk of developing certain forms of dementia. More than 1 in 5 combat wounds from the wars in Afghanistan and Iraq involve brain injuries, and more than 430,000 veterans have been diagnosed with TBI since 2000 — 12.7% of them with moderate or severe TBI. Post Traumatic Stress Disorder (PTSD) is two to five times more common in veterans compared with the general population and has been linked to an increased risk of dementia.

Given the prevalence and increased risks, we note for the Committee that the *National Plan to Address Alzheimer's Disease* has long featured action items related to supporting veterans and caregivers affected by dementia. Throughout the history of the Plan, the Veterans Administration has disseminated information about all facets of the VA Caregiver Support Program, including the highly successful Resources for Enhancing All Caregivers Health (REACH) VA Program, which it has also helped to pilot in sister agencies. Most recently, the VA Caregiver Center implemented a supportive texting intervention for caregivers of veterans with dementia through which caregivers receive information about managing dementia behaviors and their own stress and coping. Additionally, the U.S. Department of Defense (DoD) has funded REACH Hope, Supporting Caregivers of Veterans with TBI and Alzheimer's Dementia/Mixed Dementia: The REACH Hope Behavioral Intervention, to assist caregivers of veterans who are living with TBI and dementia. The three-year study, August 2020-August 2023, combines the REACH-VA intervention and the DoD's Virtual Hope Box mobile app to support caregivers one-on-one in real-time and as needed.

Caregiving can be unpredictable, the Association and AIM are encouraged by the Committee's commitment to empowering veteran caregivers to support the specific needs of veterans, without imposing undue stress or financial burdens. The Association and AIM appreciate the ongoing discussions focusing on this issue and value the steadfast support of the Committee and its continued commitment to advancing policies important to the millions of families affected by Alzheimer's and related dementias and their caregivers. We look forward to working with the

Committee and other members of Congress in a bipartisan way to support the caregivers of those living with this disease.

STATEMENT FOR THE RECORD
PARALYZED VETERANS OF AMERICA
FOR THE
SENATE COMMITTEE ON VETERANS' AFFAIRS
ON
HONORING OUR COMMITMENT: IMPROVING VA'S PROGRAM OF COMPREHENSIVE ASSISTANCE FOR FAMILY CAREGIVERS

Chairman Tester, Ranking Member Moran, and members of the Committee, Paralyzed Veterans of America (PVA) would like to thank you for this opportunity to provide our views on how to improve VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC). No group of veterans understands the benefits of having access to this program more than our members—veterans who have incurred a spinal cord injury or disorder (SCI/D).

Caregivers are one of the most important components of a catastrophically disabled veteran's support system. As a result, the wellbeing of the caregiver directly effects the quality-of-care the veteran receives. In 2010, Congress created the PCAFC for a small number of caregivers caring for only the most catastrophically wounded veterans. The VA MISSION Act of 2018 (P.L. 115-182) expanded eligibility for the program from veterans injured on or after 9/11 to include veterans injured in any era.

The VA MISSION Act outlined a two-phase approach for implementing the caregiver expansion. The law required the first phase to begin on October 1, 2019, approximately 16 months after the law was enacted. However, due to information technology delays and failures, VA did not begin the first phase – which includes eligible veterans who became severely injured or ill on or before May 7, 1975 – until October 1, 2020, a full year later than the law required. At the same time, the department implemented revised eligibility criteria for the PCAFC. All veterans, regardless of era of service, will be able to apply for the program starting October 1.

Effect of More Stringent Eligibility Requirements

Like many veterans services organizations and even this Committee, PVA submitted our concerns about VA's proposed rule. We called into question VA's plan to redefine "serious injury" to mean any single or combined VA service-connected disability that is rated at 70 percent or more. VA acknowledged a full one-third of the current program's participants would be eliminated by this action

We also disagreed with the department changing the definition of an "inability to perform an activity of daily living" (ADL) to mean that a veteran must require personal care services daily, and every time he or she completes one or more of the seven identified ADLs.

PVA believes that a requirement that personal care services must be provided each time an eligible veteran completes one of more of the ADLs is excessive and fails to support efforts by a catastrophically disabled veteran to exert even a small level of independence, when possible. The ability to infrequently perform ADLs should not result in veterans being barred from participating in the program or in currently eligible veterans being discharged from it.

The evidence is clear that the revised regulations on eligibility that took effect concurrently with the Phase 1 expansion have made it far too difficult for many deserving veterans and their caregivers to enter or remain in the PCAFC. Between October 1, 2020, and January 6 of this year, the PCAFC received 127,500 caregiver applications. Of this number, 116,500 applications were processed and 16,600 were approved, and 101,500 were found not eligible and/or denied (87.9 percent).

The VA has reported that the three main reasons veterans were found not eligible or denied are 1) applying during the wrong phase, 2) not having a service-connected condition rated 70 percent or greater, and 3) not meeting the requirement of needing full-time assistance with an ADL. Two out of the three reasons given for denial are based on VA's stringent regulatory requirements which are inconsistent with Congress's legislative intent. As a result, these requirements make it impossible for many of the most catastrophically disabled veterans to qualify for the PCAFC.

A PVA member with a spinal cord injury at the T-5 level is one of those veterans. He is service connected at 100 percent for loss of use of both feet; 100 percent for loss of anal sphincter control; and 60 percent for neurogenic bladder. His combined service-connected rating of Special Monthly Compensation (SMC), R-1, is the second highest level available. This veteran had been part of the PCAFC for several years but was recently informed that he is being discharged from the program because he no longer meets its requirements. The explanation given to the veteran was that it did not *appear* he needs assistance each time he performs an ADL. The word "appear" is key because it seems the evaluator assumed rather than verified the veteran could perform the tasks.

Another member with a spinal cord injury at the T-12 level with identical impacts on health and mobility was removed for the same reason. Like the member above, his combined rating is SMC, R-1. The R-1 rating includes the provision of needing regular aid and attendance, in accordance with 38 USC 1114(r)(1). This veteran has also been part of the PCAFC for several years but is now being unceremoniously discharged from the program.

VA Secretary McDonough expressed concern with the high rate of denials during a December 1, 2021, hearing where this Committee was examining the state of the department. The Secretary promised he would come back to this Committee with a recommendation for reducing the high denial rate, which he also recognized was not the intent of the MISSION Act. On March 22, the VA announced that they will stop PCAFC dismissals pending a full review of the eligibility criteria in light of the high number of denials. We look forward to learning more about how the VA intends to review the criteria and the effect to date on tens of thousands of veterans and their caregivers.

Lack of Transparency

Veterans and their caregivers must be notified as to why VA deems them no longer eligible or not eligible for the PCAFC. Without this information, it raises questions as to why similarly situated veterans receive different eligibility determinations. For example, PVA service officers recently noted that two veterans who had very similar circumstances received different decisions. The veteran who lives in Texas was granted continued participation in the PCAFC while the veteran who resides in Pennsylvania was denied. Without more detailed information about the reason for the denial, it is very difficult to understand the divergent results.

Another service officer pressed the local caregiver office for information on a veteran's denial and made a disturbing discovery. In this case, the staff read off what the VISN specified in its denial. They used terms like the veteran did not have a moderate or severe need for assistance with his ADLs and they were not sure if he had continued need for assistance with them. Also, there was a reference to a cardio procedure and the VISN assumed after his convalescence from the procedure he would not need or warrant the ADL assistance. What they failed to realize is that the procedure happened back in 2020. Clearly VA personnel failed to do their due diligence on this assessment, and the veteran continues to need assistance with ADLs well after this procedure.

When we file a disability claim and the Veterans Benefits Administration denies it, the rating decision explains why the denial took place. This gives us an understanding of what happened and a potential pathway for the veteran to appeal the decision. The PCAFC removal letter does not provide a detailed explanation for the decision, nor does it cite other programs for which the veteran may be eligible.

Veterans with catastrophic disabilities have made sacrifices in the service of our nation and giving them anything less than optimal care and support is unconscionable. VA should be required to provide a detailed explanation of all actions, positive or negative. Without this information, veterans will not be able to properly appeal PCAFC decisions.

Processing Appeals

Appeals related to the PCAFC can be made to the Board of Veteran's Appeals (Board), or the Veterans Health Administration (VHA). Prior to a decision by the Court of Appeals for Veterans Claims (CAVC) in *Beaudette v. McDonough*[1] the only opportunity to appeal was to make a clinical appeal to VHA. In *Beaudette*, the CAVC ruled that the VA must provide every veteran and caregiver who had ever applied for the PCAFC the right to appeal unfavorable decisions to the Board. It also required the VA to apply the procedures of the Appeals Modernization Act (Public Law 115–55) when processing appeals for caregiver benefits. Although veterans and caregivers may now file formal appeals, VA must still establish an open, transparent, and effective system for processing these appeals.

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[1] BeaudetteJandM_20-4961.pdf (cavc.gov)

Additionally, service officers accredited by the VA to represent veterans during the appeals process are still not being granted full access to the veteran's medical records, hindering their ability to properly support their PCAFC appeals. This is a second-tier effect of the lack of transparency discussed earlier, and we urge this Committee to take the necessary steps to compel the department to fully comply with the requirements of the *Beaudette* decision.

Support in Transitioning to Other VA Programs

Many veterans do not understand how the PCAFC interacts with other VA programs and benefits like bowel and bladder care, Homemaker and Home Health Aide, and Aid and Attendance. S. 3954, the Elizabeth Dole Home and Community Based Services for Veterans and Caregivers Act, seeks to expand community-based services for aging and disabled veterans. Section five of this legislation would require the VA to provide a personalized and coordinated handoff of veterans and caregivers denied or discharged from the PCAFC into any other home care program for which they may be eligible. Section six would establish a "one-stop shop" webpage where veterans and their caretakers can find information on other programs and services to support them.

Veterans may be afraid, confused, and angry about being denied for the caregiver program based on the recent criteria changes. Providing a warm handoff and the means to receive personalized recommendations for resources would temper some of these emotions and ensure other programs are accessible and fully utilized. This critically important legislation would make urgently needed improvements to VA's home and community-based services like the PCAFC. We urge this Committee to quickly pass this desperately needed legislation.

PVA thanks you again for this opportunity to recommend ways to improve the PCAFC and provide better support to those who care for our veterans.

VETERAN WARRIORS

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Statement for the Record

Veteran Warriors

Submitted to
Senate Committee on Veterans' Affairs

Hearing on
"Honoring our Commitment: Improving VA's Program of
Comprehensive Assistance for Family Caregivers"

March 23, 2022

Chairman Tester, Ranking Member Moran, and members of this committee, on behalf of Veteran Warriors and our members, thank you for the opportunity to provide input on the Program of Comprehensive Assistance for Family Caregivers (Caregiver Program).

Veteran Warriors is a grassroots nonprofit veteran service organization dedicated to ensuring our government keeps President Lincoln's promise to our veterans, "to care for him who shall have borne the battle, and for his widow and his orphan," is kept and so that no veteran, caregiver, family, or survivor will ever have to face barriers to obtain services and benefits. Founded in 2009, by Navy veterans, Lauren and Jim Price after Lauren returned home from an Iraq deployment with unexplained medical conditions and was denied care by VA after experiencing difficulty and waiting 14 months for an appointment with a pulmonologist, ultimately Lauren sought outside medical care. March 31, 2021, at the age of 56 and just 44 days after the diagnosis was confirmed, Lauren Price lost her battle with a rare cancer related to toxic exposure from her Navy service. Today, Veteran Warriors continues Lauren's mission of filling the gaps, seeking accountability, educating veterans, caregivers, and their families on self-advocacy and VA navigation to ensure they obtain the necessary health care services and benefits they deserve.

BACKGROUND

The Program of Comprehensive Assistance for Family Caregivers (PCAFC)[1] was created under the 2010 Public Law 111-163,[2] *Caregivers and Veterans Omnibus Health Services Acts*, to provide benefits and support to family caregivers of veterans in need of personal care services, such as assistance performing one or more activities of daily living or supervision or protection due to a neurological impairment or injury, including PTSD or other mental health disorders. The PCAFC is the only integrative program of its kind which offers caregivers of eligible veterans with a monthly stipend payment, health insurance, travel expenses, respite, and mental health services. VA issued the Interim Rules[3] by which the program was to operate in 2011 and established the program across all enterprises and PCAFC quickly proved to meet a critical need. This program was initially administered at the local medical facilities by Caregiver Support Coordinators (CSCs) and led by the National Caregiver Support Program Director at the national level. In its first full year, second year fiscal year (FY) 2012, the program far exceeded VA's original estimates of 4,000 veterans; VHA spent about $110 million on the program operations.

VA published the Final Rules[4] on January 9, 2015, most of the Interim Rules were incorporated and clarity was provided on some issues that had been identified; this rule was followed until the implementation of

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[1] **Title 38 of the United States Code Public Law 111-163 Section 1720G(a)**; *Assistance and support services for family caregivers* (May 5, 2010)
[2] **Caregivers and Veterans Omnibus Health Services Act of 2010** (May 5, 2010)
[3] **38 CFR Parts 17 and 71** Caregivers Program; **Interim Final Rule** (May 4, 2011)
4 38 CFR Parts 17 and 71 Caregivers Program; Final Rule (January 19, 2015)

the newest regulation.[5] The program continued to grow substantially with FY 2016 serving 26,989 participants, the highest participant count prior to the first round of mass culling which warranted investigation in 2017. Not long after the temporary pause of 2017, the program resumed full operations, it was business as usual including a consistent rise in denials and discharges. June 6, 2019, the MISSION Act[6] was signed into law, this allowed VA to draft another set of rules which VA did not publish until 2020.

As expected, the budget for the program continued to increase, though the FY 2019 increase was largely due to program expansion under the MISSION Act of 2018, which expanded the program from eligible Post-9/11 veterans to eligible veterans from all eras. Program eligibility expansion to all pre-9/11 veterans and their caregivers was to happen in two stages:

(1) veterans injured on or before May 7, 1975, and
(2) veterans injured after May 7, 1975, and before September 11, 2001.

October 1, 2020, VA opened eligibility to all veterans who served on or before May 7, 1975. VA will open eligibility to those who served May 8, 1975-September 10, 2001, on October 1, 2022.
VA published these proposed rules for public comment March 2020[7] and received over 200 comments urging VA to reconsider as the rules would impose unnecessary restrictions on the program and identifying potential harm to the community the program is intended to help. VA ignored concerns from commenters and codified the rules as Federal Regulation on July 31, 2020[8], just ahead of the long-awaited Vietnam and earlier eras veterans' eligibility expansion on October 1, 2020. The new rule being the basis of program operations has caused dismay and chaos as veterans feel the adverse effects of the new rules from all directions; for some, mainly Post 9/11 veterans, the program is the scaffolding of survival, for many, primarily those from the Vietnam era, it was hope that quickly faded with declined applications and denied appeals, and for Gulf War-era the question remains: will VA delay eligibility again?

MISSION Act contained three small sections for the PCAFC in Subtitle C – Family Caregivers Sec. 161, 162, and 163, giving clear and unmistakable instruction as to Congress' intent and expectations for the program:

- *161* – expansion of the program to include veterans of all eras,
- *162* – implementation of the IT system to assess and improve the program, and
- *163* – modification of the annual evaluation report with a description of any barriers to accessing and receiving care and services.

Since the MISSION Act expansion of the Caregiver Program, VA has received over 127,500 applications with only a 13% approval rate. The majority of denied applications were denied due to the program's restrictive eligibility criteria and assessor or CEAT documentation that is in direct contradiction of the medical needs documented within the veteran's medical record by treating providers. VA's newest regulation has an arbitrary requirement that the veteran have a minimum service-connected rating of 70% and require assistance with an ADL 100% of the time or "daily" supervision to maintain their personal safety, however, "daily" is not defined. While Congress defined certain eligibility criteria, key definitions were left up to the Secretary's discretion, such as "in the best interest of the veteran" to which VA has taken to be a catch-all for disqualification based on personal opinion.

VA has taken what was a great program that met a critical need to alleviate some of the daily stress within the veteran community and turned it into something that is unnecessarily stressful, daunting, degrading,

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5 Final Rule took effect October 1, 2020 (July 31, 2020)
6 Public Law No: 115-182 (June 6, 2018)
7 38 CFR Part 71 PCAFC Improvements and Amendments Under the VA MISSION Act of 2018; Proposed Rule (March 6, 2020)
8 38 CFR Part 71 Improvements and Amendments Under the VA MISSION Act of 2018; Final Rule (July 31, 2020)

and treated as a welfare program. There is an unexplained focus on the veteran and caregiver's education, if they are well educated, it is noted in the record along with various comments regarding the veteran's ability to have obtained higher education degrees or certificates while failing to acknowledge the fact that someone's education has no bearing on their need for assistance. They also do not factor in that a veteran or caregiver may have received that degree before the injury. In addition, veterans and caregivers who are employed, or volunteer are heavily scrutinized and falsely assert the staff's personal opinion as fact while failing to acknowledge the human factor of inability versus disability. It is no longer a program that is intended to serve veterans who suffer from injury and other impairments from their military service, instead it behaves as an investigative program that is geared towards discharging and denying veterans access to vital services provided by their caregivers to meet their basic daily needs based on their own personal bias and opinion. For instance, comments on a families' finances and home, to quote PCAFC staff, "this house is nice, you don't have a financial burden." The statement is inappropriate and shows a personal bias as financial status has no bearing on a veteran's disability. Rather than honoring our veterans and their caregivers who now serve in the shadows, the program has a reputation of searching social media and the internet to find any bit of information to "prove" the veteran is not in need of caregiver assistance; the program fails to acknowledge photos can be deceiving and just because a veteran requires assistance does not mean that veteran is an invalid, someone who is disabled is not necessarily incapable. The new culture of the program must change to end the bias behavior to focus on being supportive, not manipulative.

It has been said many times before any program expansion will have bumps along the way, the issue is VA has intentionally created these bumps and this unnecessary stress for the veterans and caregivers by ignoring over 200 public comments urging VA to reconsider and noting the concerns for the community which were submitted by veterans, caregivers, community members, VSOs, and Congress. VA cannot deny knowing the "unintended consequences" after concerns have been repeatedly voiced across various enterprises for the past two years. None of this is an "unintended consequence."

Application Process

PCAFC has a multistep application process that veterans and their caregivers must navigate which allows VA 45 days to complete the review process after receiving an application. This review timeline can be extended an additional 45 days, totaling 90 days, by Caregiver Support Coordinators under two circumstances:

(1) if the caregiver has not completed the required training, or
(2) the veteran is hospitalized during the application process.

<u>Previously</u> the CSC would review the application to determine a veteran's is eligibility, and if found eligible, approve the application. After approving the application, the CSC would determine the level of care the veteran requires—Tier 1 (10), Tier 2 (25), or Tier 3 (40) hours of care per week based on the Scoring Methodology. The number of hours is assigned a Tier, and caregiver's stipend amount was calculated based on the veteran's Tier and zip code. In FY 20, caregiver stipends ranged from about $460 to $4,600 a month.

<u>Now</u>, CSCs review the application to determine a veteran's is eligibility and schedule an Intake Assessment for the veteran and caregiver. If the veteran is found to meet 'administrative' eligibility, the Veteran and Caregiver Psychosocial Assessments[9] are schedule which will go over the veteran's ADL and safety needs, family history and demographics, veteran disabilities, education, employment/volunteer, hobbies,

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[9] Veteran and Caregiver Psychosocial are two separate assessments, each assessment takes approximately 1 hour to complete.

children names/ages/special needs, etc. Following the Psychosocial Assessments, another assessor[10] will schedule the Veteran Functional Assessment (VFAI), this is a repeat of veteran needs from the psychosocial assessment. Once the VFAI is complete, the CSC will submit the assessment to the Clinical Eligibility and Appeals Team (CEAT), CEATs typically review 50-100 assessments daily, they make a decision that typically doesn't match the veteran's need and update the record with their decision. The CSC will contact the veteran and caregiver to discuss the CEAT decision, if the decision is discharge, the CSC provides a letter with little to no information regarding the decision. If the decision is to continue with the process, a tentative Level (replaced Tier) is noted, the CSC schedules the caregiver training. Following the caregiver training, another assessor will contact the veteran and caregiver to complete the Home Assessment, the home assessment is a repeat of the prior assessments and discusses safety factors, asks about running water, pests in the home, locks on doors, etc. After the Home Assessment is complete, the CSC submits it to the CEAT again, the CEAT will review and will either approve or deny. Following the decision, the CSC contacts the veteran and caregiver to give them the decision. If the discharged the veteran and caregiver will receive a letter, if approved to remain in the program at a lower Level, they may appeal, if approved to remain in the program at Level 2, nothing more is required. CSC will input the stipend Level into the system and payments automatically start. Of note, this long process is required yearly, there are also quarterly wellness assessments per year.

Monitoring Requirements

Participation in the program requires ongoing evaluation to monitor the veteran's well-being, adequacy of care provided by the caregiver, and the level of supervision provided. PCAFC conducts Wellness Assessments every 120 days, and an annual reassessment which involves the full multi-step assessment to determine continued eligibility. If any changes in a veteran's condition are identified during the Wellness Assessment by the assessor, it can lead to a full reassessment of eligibility, including possible discharge from the program, an increase or decrease in the level of care. Initially, quarterly monitoring sessions were an opportunity for CSCs to provide caregivers with information and services, such as upcoming peer support group meetings, respite care, and to ensure the caregiver had access to mental health services, if needed. However, the Wellness Assessments have now turned adversarial and are viewed as another means for assessors to document false information in the veteran's record, interrogate the veteran and caregiver with requiring the veterans to "rehash" their limitations related to their conditions and needs for assistance, and to potentially discharge the veteran.

Initial/Annual Eligibility Assessment

Eligibility assessments are daunting and a significant source of stress for veterans and caregivers as they feel interrogated and threatened by the program staff during assessments. Veterans have voiced their concerns that the program's new practices are not good for their mental health, stating they feel they must constantly prove their needs and are left feeling worthless or ashamed of their limitations following assessments. Program staff claim veterans and caregivers are hostile or noncompliant when the dyad asks basic questions for clarity, such as why they are having to schedule a quarterly assessment just a couple weeks after completing an assessment. There is a consistent pattern of PCAFC staff refusal to answer very reasonable questions, instead of answering, the staffer will label the dyad as "hostile," provide the dyad with a harassment pamphlet via email or regular mail, and state the staffer will document the dyad does not wish to schedule at this time, resulting in noncompliance and immediate removal from the program. Veterans and caregivers were recently required to meet with their Caregiver Support Coordinator (CSC) to go over the Roles and Responsibilities, many caregivers were alarmed were the CSC informed them if they question any part of the assessment, they are noncompliant with program requirements and can be discharged – effectively removing the dyad's rights.

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[10] Functional assessors vary: RN, OT, PT, MD, Social Worker

The new assessment process is complicated, stressful, and redundant in its questioning. To complete the process the veteran and caregiver are required to do an Intake assessment, Veteran Psychosocial Assessment, Caregiver Psychosocial Assessment, Veteran Functional Assessment, Caregiver Training, and finally a Home Assessment. Each assessment averages 2-3 hours of questioning, again, answering redundant questions within the single assessment as well as any prior assessments in the process, this is unacceptable and unjustified. Most denials follow the Functional Assessment as the CSC submits the Functional Assessment to the CEAT for review. If the CEAT approves the dyad to continue with the process, the CSC notifies the caregiver of training and schedules a Home Assessment. Veterans can be discharged following the Home Assessment. There is no consideration of the veteran's medical record or any real effort to consult with the veteran's providers, the staff nor the CEAT review the documentation. We have assessment decisions which will reference a medical note that supports their decision, but that note doesn't match. There are clear discrepancies within the assessor and CEAT notes for most of our veterans, showing a systemic issue of false documentation. If a veteran's medical note states total assistance with ADLs and the CEAT states the veteran requires partial assistance; or a veteran's neuropsych exam shows the veteran is severely impaired and the assessor or CEAT document the veteran does not require supervision to maintain their safety.

Appeals

VA has made the appeals process complicated for veterans and caregivers by requiring them to go through Patient Advocate to file for an appeal for a Clinical Review, the dyad is required to call the Patient Advocate to get information on how to file the appeal, there is no other information provided, not even a mailing address. For those wanting to file a Supplemental Claim, Higher-Level Review, or appeal to the Board of Veterans Appeals, most dyads face great difficulty in locating anyone within VA to tell them how to proceed, and they are left to their own devices to locate an accredited agent or attorney who understands the process to appeal. Many organizations do not understand the appeals process; however, Veteran Warriors is experienced in handling clinical appeals. In our experience, VA becomes less and less cooperative with providing the necessary information for a veteran or caregiver to successfully appeal. An issue we are facing is the substantial amount of misinformation documented by the program staff, the information is factually incorrect and easily contested. A veteran should not have to appeal blatant lies, in most cases, the falsehoods must be correct via an amendment request before they can proceed with an appeal, otherwise the result will be the same as it is based on clear inaccuracies. Unfortunately, the amendment process is not without challenges of its own as the request goes to the write of the note who improperly documented, typically they are reluctant to change their records and the request is denied. After going to the writer's supervisor and then the Chief of Staff or Director, both of which typically deny, the dyad is required to appeal to the Office of General Counsel (OGC). Appealing to the OGC is not a quick process by any means, it can easily take two years or more for OGC to render a decision. This is where we run into an issue with the time frames of having to appeal a record with false documentation that a writer refuses to correct, even with clear evidence they are wrong, because the dyad only has 60 days from the date the PFACF decision letter was mailed out to file an appeal for a Clinical Review and one year from that date the letter was mailed to file a Supplemental Claim, Higher-Level Review, or appeal to the Board of Veterans Appeals. Documentation inaccuracies hinder a successful appeal and if an amendment is required, the veteran will likely be outside the window to appeal once the corrections are made, therefore, removing the veteran's due process rights.

Contrary to VA's assertion that all PCAFC decisions are deemed medical determinations, there are legal determinations that are in play and must be addressed. Veteran Warriors firmly supports the right of veterans and caregivers to appeal non-medical determinations made by PCAFC. We would urge Congress to oppose any legislation that would overturn the right to appeal to the Board of Veterans Appeals or restrict access to any avenues that could benefit a veteran challenging a PCAFC decision.

Lack of Effective Governance and Accountability

Over the years, program has strayed away from providing eligible veterans and their caregivers with consistent and appropriate access to the program. Approval and continued participation have become increasingly difficult as the program culture has drastically shifted causing veterans and caregivers to view the program staff as a barrier to consistent and appropriate access to care. The concerns of these veterans and caregivers are substantiated by the program staff who have demonstrated a systemic problem of documenting false information within the veteran medical records. There are concerns within the community that such false documentation could result in decreased ratings upon VBA audit, or the lack of necessary care from a new provider who could review the note and believe the veteran has improved. Unfortunately, these concerns continue to grow with the lack of accountability.

There are numerous conflicts of interest concerns, including veterans who have had extensive issues with provider who may not be assigned to the program as assessors or in other capacities. The internal bias is substantial and VA lacks governance that ensured accountability for program on all levels. Veterans with high profile cases for a variety of reasons, include their own advocacy or that of that caregiver, have been subjected to access by various staff throughout the facility and within the program. When inquiries are made about the reason for a staffer's unauthorized access of the medical record, program staff and managers tend to band together to fabricate a story that will prevent the staffer from repercussions. Systemic issues of improper access to a veteran's record have been a topic of discussion for years, to date, there has been no attempts for accountability or the protection of a veteran's private medical record.

Veterans who are caregivers for other veterans are subjected to a high level of internal bias, conflicts of interest, and improper access of medical records. Program staff are now documenting in the caregiver veteran's personal medical record notes about their caregiving and also about the veteran they are caring for, this is unacceptable. Another veterans information should never be placed in the record of a veteran, particularly that of a caregiver. Further, program staff should be prohibited from accessing caregiver medical records, this is a direct violation of the caregiver's privacy and could easily result in a caregiver being afraid to seek medical treatment for their own injuries or conditions. We have a few members who are Military Sexual Trauma (MST) veterans, they are also caregivers for another veteran (spouse, sibling, parent) and have been appalled and concerned that Caregiver Program staff have not only accessed their medical record but also that they have documented about the veterans they are caring for in their record. Protective measures, such as the participating veteran's provider managing these unique cases, must be put into place to protect the veterans from internal conflicts and bias.

As for civilian caregivers, they are concerned when they receive notification of PCAFC staff pulling their personal credit records and private health care records. One civilian member is aghast over PCAFC staff talking about their personal mental health notes during the reassessment process while the veteran was present. This member, like many other caregivers, seeks mental health counseling as a means of self-care, imagine references being made about the notes from your counseling sessions during your assessment. Without accountability, these practices will continue, and caregivers will begin refusing to seek care to maintain their health. Protective measures to ensure the security of caregiver records must be put into place to protect the caregivers so that they will continue to care for themselves without fear.

For those caregivers who are advocates, there are a lot of them, there is a high level of concern regarding bias and conflict of interest related to the program staff for veterans who are eligible for or participating in the PCAFC. While the veteran may not be involved in advocacy, the caregiver is involved and inherently experiences retaliation from program staff for assisting other veterans and caregivers; behavior includes unauthorized access to the veteran's record, sharing of photos of the veteran record with others, discussion of the veteran's record and the caregiver with other staff and patients. Caregiver advocates experience a great deal of difficulty when it comes to VA when it comes to care for their own veteran due to their advocacy and assisting others in need. Due to the conflicts of interest and internal bias, it has been requested by several caregiver advocates that the veteran's VA provider manage all aspects of the veteran's eligibility, monitoring, and reassessment for the program, but the request has been repeatedly ignored. Protective measures, such as the veteran's provider managing these unique cases, must be put into place to protect the veterans from internal conflicts and bias.

Guidelines:

Veterans, caregivers, and advocates require transparent eligibility guidelines that do not leave room for self-interpretation and personal opinion. Currently, there is no consistency to the assessment process or determination of eligibility. There are VFAI assessments which clearly indicate a need for assistance and the CEAT denies or discharges them without any justification. For example, a veteran is documented as physically unable to arrange for their own needs, or a veteran requires partial/moderate assistance to complete an ADL, one would expect either of these veterans would qualify for the program, but instead we are seeing denials. The term unable to self-sustain is grossly misinterpreted by PCAFC but is required for Level 2. Self-sustain means to provide care for yourself independently, therefore if any veteran who requires any level of assistance technically meets the definition for unable to self-sustain. No matter the definition, there is a desperate need for transparency so that veterans and caregivers know exactly what they are being scored on, how the scores break down and are determined, and what information is used to reach that decision.

Veteran Warriors Efforts:

Veteran Warriors recently launched a petition to garner support for rescinding the restrictive criteria, there are currently 2,380 signatures.

Veteran Warriors recently conducted two separate surveys, one for retaliation concerns and one for Caregiver Program participation and status.

- <u>Retaliation Survey</u> - Of those who participated in the retaliation concerns, 99% report concerns of challenging VA staff, including the CEAT, assessors, and CSCs on improper documentation noted in the caregiver assessments.
- <u>Caregiver Survey</u> - Of those who participated in the Caregiver Program participation/status survey, 86.41% were Post 9/11, 8.93% served on or before May 7, 1975, and 31.36% served during the Gulf War era that is not yet eligible. Of the currently eligible eras, 78.53% were rated 100% permanent and total, and 16.5% of these veterans are awarded aid and attendance but have been discharged. Of the legacy participants, only 4% of respondents were approved to remain in the program following reassessment, 93% discharged, and 3% are currently pending reassessment. Of those discharged, numbers across all three tiers are consistent, no tier is substantially different. 65.53% of respondents reported the veteran required assistance with ADLs and supervision, protection, or instruction, while 7.21% only required assistance with ADLs and 27.26% only required assistance with supervision, protection, or instruction. Of those needing supervision, 43.5% report a continuous need; 34.2% report a daily need.

Recommendations:

- Immediately rescind the restrictive criteria by reverting eligibility criteria to the prior eligibility which does not require unnecessary criteria such as inability to preform an ADL "each" time it is completed or an undefined "daily" need for supervision.

- Establish legislation to clearly define all eligibility criteria, including definitions, needs, and scoring tool.
- Establish a streamlined process and designation for veterans awarded special monthly compensation for aid and attendance as they are already deemed by VBA to require assistance. This recommendation saves Congress money by removing a duplication funds as the need for assistance is already established.
- Establish a streamlined process and designation for veterans awarded housebound. This recommendation saves Congress money by removing a duplication funds as the need for assistance is already established.
- Allow for veteran choice assessments to prevent conflict of interest and internal bias. This recommendation saves Congress money by a provider who is already compensated as the veteran's provider to complete assessment by removing a duplication of resources to complete the review, freeing up CSP assessors to assess those who wish to have the CSP staff assess.
- Require record restriction to prevent unauthorized access to all veteran and caregiver medical records.
- Establish a process for veterans and caregivers to report misconduct, including false documentation, and a process for solid staff accountability for violations.
- Require mandatory retraining of all staff to include ethics training.
- Require transparency and communication with **all** VSOs and stakeholders, diversity is imperative.
- Establish criteria which allows for appeal timelines to avoid veteran's losing their right to appeal due to the need for record corrections; ensure accountability for false documentation.
- Require removal of all reassessment decisions and reprocess all applications that received a denial, including those removed prior to the 2018 moratorium.

CONCLUSION

The VA Caregiver Support Program met a critical need within the community as one-of-a-kind program intended to help support family members dedicated to improving the quality of life and care to disabled veterans. It is essential that VA have appropriate processes and procedures in place to ensure the program operates effectively and delivers the correct and appropriate benefits to veterans and their caregivers. Removal of specific parts of the new regulation is necessary to allow the program to operate as intended without unethically denying veterans in need of assistance access to care and services that are vital to their daily living.

Veteran Warriors members ask that you take a few minutes to read the attachment of personal statements, it's important that their voices are heard. Veteran and caregiver full statements that the short snippets were from can be found on our website along with others who aren't included in the attachment.

Again, Veteran Warriors would like to thank the Committee for the opportunity to submit our views on the Caregiver Program and to share how it is affecting the veterans and caregivers we serve. We look forward to working with you to ensure all disabled veterans and their families receive the medical services and support they need and deserve.

VETERAN WARRIORS

"One Family, One Fight!"

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Attachment: Statements for Caregivers

***The full statements and impact stories for these and others can be found on our website**

- Denied Korean veteran caregiver, 70%. My dad has Parkinsons Disease, bedbound for 15 years, needs total assistance with all ADLs. Dementia causes confusion and need for reminders or calming.
- Denied Vietnam veteran, chair bound with ALS, nonverbal, medical notes consistently state need total assistance with all ADLs and needs will continue to increase as ALS progresses.
- Caregiver of a 100% P&T veteran, SMC aid and attendance, requires assistance with all ADLs, physically unable to self-sustain, assessment inaccurate scoring for ADL and SPI. Assessment notes are easily proven to be inaccurate. Drs not included and supportive medical notes were ignored.
- Vietnam caregiver accepted in 2021 for Level 2, discharged after reassessment. Veteran is bedbound with Parkinson's and MS, total assistance is required for all ADLs. Assessor lied in assessment. First appeal denied, opening second appeal.
- Discharged Post 9/11 legacy caregiver, veteran has current functional score proving severe impairment. Assessor falsely documented abuse, when questioned it was changed because there is no abuse. Drs countered assessment notes, PCAFC said dr had no input and the note is their opinion. First appeal denied.
- Legacy Caregiver three-time combat veteran of OIF. Through my work with the Elizabeth Dole Foundation and my husband's two-decade Army career, I know hundreds of caregivers across the nation. None that I know defined as legacy caregivers have remained in the program. If the caregiver is not in place, this support will undoubtedly cause the injuries to have a much more profound effect. Please conduct a careful and thorough review of the The Department of Veteran Affairs Caregiver Support Program. Those of us who care for those who have borne the battle deserve it.
- Have been a part of the Caregiver Program for five years, 100 % disabled. Just been discharged and will be losing a significant amount of income. I am at risk of being in danger alone. Due to my TBI, I forget things very easily… unsafe for me to climb stairs on my own. for us, being discharged is not only going to put us in a financial burden but more importantly it will be putting myself in a dangerous situation.
- A Veteran cannot receive proper and or complete care, and now we will lose out on the new PCFAC program due to "clinical notes" from the last six months during a pandemic.
- caregiver is worth more than her stipend for sure. They're our unsung heroes as hard as that is for us as hardened vets to admit. Don't strip them of the things they need to do their job. she is still here loving me and fighting for me to receive the best care. I need her. Just do right by them, by us. We give humanitarian aid all the time to other nations. How about we look at the humanity on display within our veteran's homes and give them a break.
- The monthly stipend husband is necessary for us to make ends meet financially. Losing it due to the lack of our doctor's clinicians' notes for what I do for my husband, is a hardship our Veterans and families and most cannot survive without it. Caregiving is ever-changing, it is not linear…If the way our Post 9/11 Veterans are being treated, or I should say NEGLECTED, "22 A Day" will be a small number compared to after the thousands being discharged from the program…. because they are a burden on their family…
- I have been the caregiver of an Iraq war veteran for most of my adult life. I just don't understand how anyone can take money away from someone who has given their all. My husband gave his all for this country, and I've given my all to my husband. Without this program and the financial security that it brings, I fear my family will be torn apart…
- It's an absolute disgrace to our Veterans what is happening. It's absolutely disgraceful and disgusting what is happening! Please wake up!!!! Before it's way too late. Stop this insanity now and fix the problem. We shouldn't have to fear in 8 months that our loved one may hurt themselves (or worse) while we try to make ends meet outside the home…

- Discharged after 9 years due to "not needing 6 months of continuous care." He lacks judgement and rationale thought, needs constant supervision to ensure he is safe and isn't taken advantage of.
- Veteran Caregiver on highest tier for 9 years, based on lack of need for continuous care 6 months or more.... Stop letting veterans down, changing the rules/program is unfathomable!
- Veteran was med retired after 18.5 years of active duty, 100% with housebound, nurse did NOT assess frequency of personal care services provided by the caregiver, twisted everything we said, documented inaccurate information and was very condescending telling my veteran suicide thoughts and feelings were selfish.
- First, we could not access this program because we lived abroad. This forced our family to move back stateside in 2014. We have been in the program at the highest tier since 2014 due to mental health problems. The VA itself has rated him 100% P&T and added "INCOMPETENCY". now he is not competent enough to handle his own finances or to own weapons, but he can be left alone?
- The nurses and OT conducting the assessment have mishandled the interviews and completely counterfeited reality...Many veteran families are reporting the same thing, this seems to be a very common modus operandi. the CEAT teams and people conducting the assessments are COMPLETELY IGNORING the need for Supervision, Instruction, and Protection. We don't understand how something that was sold to the public and VSOs as an EXPANSION, has in fact become a MASSIVE PURGE!
- The assessments are abusive, intrusive, traumatizing. Many veterans were already down spiraling due to the stress caused by these assessments, the thousands of notices of discharge...
- we will have to choose if we want to struggle financially and still stay at home without pay to save our veterans' lives or try to get jobs with more than 10 years of career gap. leaving him alone would pretty much mean coming home from work finding him DEAD sooner or later... and we are not willing to do that to our children who have already endured so much. So we will have to struggle financially, or sell our home, or worse....
- Legacy caregiver of a medically retired OIF USMC post 9/11 veteran, discharged from the VA Caregiver Program (PCAFC). I've given up a rewarding career in higher education to dedicate to my husband's safety and wellbeing.
- Caregivers are on the frontline of home health care every day. I ask Congress to help by utilizing congressional oversight powers as Congress previously rejected any attempts to restrict eligibility into the VA Caregiver Program. I ask that amendments be made to right the wrongs for those who have been unjustifiably discharged, denied or downgraded during the application and reassessment process...
- This program has failed us...turned into something it was never meant to be. It is causing more harm than good. The reassessment process was an interrogation...This is not suicide prevention.
- We were promised when the program opened to other eras that we would not have to reapply and jump through hoops. The redundant 5 annual reassessments is nothing but psychological warfare. These reassessments are creating a mental health crisis.
- The extremely restrictive criteria needs to be rescinded. all or none approach to ADLS is unrealistic. It is essentially easier to qualify for nursing home care. Veteran's care team should be involved in the decision-making process. Stop completely disregarding the veteran's medical records. Stop using records out of context and twisting the veteran and caregiver's words during the assessment...
- assessor kept calling my husband "weird" because he was in a full body paralysis episode during the appointment. She made me pull him out of bed and literally drag him across the room... chewed him out because he couldn't state his full name and date of birth... he was paralyzed and unable to speak. She then wrote that he's fully independent, can identify his own needs and doesn't need a caregiver at all. How can he identify his own needs when he can't talk or move?! only asked about 25% of the questions and didn't document our case accurately at all.

Statement for the Record

Of

Presented

By

Charles Byers, Chair, VVA Health Care Committee0

Before The

Senate Committee on Veterans Affairs

Regarding

Honoring Our Commitment: Improving VA's Program of Comprehensive Assistance for Family Caregivers

March 23, 2022

Good afternoon, Chairman Tester, Ranking Member Moran, and members of the Senate Veterans Affairs Committee. I thank you for holding this hearing today and would like to submit our Statement for the Record on the *Honoring Our Commitment: Improving VA's Program of Comprehensive Assistance for Family Caregivers*.

CAREGIVERS EXPANSION – INTRODUCTION

The Program of Comprehensive Assistance for Family Caregivers (PCAFC) provides a wide range of benefits, including monthly stipends, reimbursement for travel costs, medical coverage, training, counseling, and respite-care caregivers for veterans severely injured during service to their country. Since implementation, the program has assisted thousands.

With the passage of the *VA MISSION Act* in 2018 (P.L. 115-182), many changes were made to the already established PCAFC. Vietnam Veterans of America applauded the long-overdue expansion of access to caregiver benefits, as they provided an opportunity for enhanced quality of life for Vietnam veterans and their families. However, the Veterans Health Administration has reported that most of these older, sicker veterans have been denied access to the PCAFC program because they do not meet the VHA's new eligibility requirements.

On October 1, 2020, the VA's final rule took effect, expanding PCAFC access for veterans who served prior to May 7, 1975. In addition to expanding access, the VA's final rule changed PCAFC program qualification requirements, which resulted in an inordinate number of program application rejections.

As of February16, 2021, approximately 33,000 individuals were enrolled in the program,[1] while roughly 80,000 were denied. Stipends paid to participants are fixed at GS-4 ($2,200 to $3,000 per month). Below are the budget reports from FY 2017 to FY 2021.

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[1] Leo Shane III, *Changes to VA Caregiver Programs Being Reconsidered Amid Complaints*, MILITARY TIMES (Feb. 16, 2022).

VA Budget Reports for Medical Care Obligations for Caregivers Program (Excluding CHAMPVA)

	Actual Budget (2015)	Budget Est. (2016)	Current Estimate (2016)	Advanced Appropriations (2017)	Revised Request (2017)	Advanced Appropriations (2018)	Increase / Decrease (2016-2017)	Increase / Decrease (2017-2018)
FY 2017[2]	$453,623	$555,096	$622,466	$641,509	$724,628	$839,828	$102,162	$115,200
	Actual Budget (2016)	**Budget Est. (2017)**	**Current Estimate (2017)**	**Advanced Appropriations (2018)**	**Revised Request (2018)**	**Advanced Appropriations (2019)**	**Increase / Decrease (2017-2018)**	**Increase / Decrease (2018-2019)**
FY 2018[3]	$493,192	$724,628	$520,932	$839,828	$603,939	$675,777	$83,007	$71,838
	Actual Budget (2017)	**Budget Est. (2018)**	**Current Estimate (2018)**	**Advanced Appropriations (2019)**	**Revised Request (2019)**	**Advanced Appropriations (2020)**	**Increase / Decrease (2018-2019)**	**Increase / Decrease (2019-2020)**
FY 2019[4]	$453,631	$603,939	$488,775	$675,777	$496,032	$510,592	$7,257	$14,560
	Actual Budget (2018)	**Budget Est. (2019)**	**Current Estimate (2019)**	**Advanced Appropriations (2020)**	**Revised Request (2020)**	**Advanced Appropriations (2021)**	**Increase / Decrease (2019-2020)**	**Increase / Decrease (2020-2021)**
FY 2020[5]	$471,421	$496,032	$493,541	$705,219	$705,219	$1,061,867	$211,678	$356,648
	Actual Budget (2019)	**Budget Est. (2020)**	**Current Estimate (2020)**	**Advanced Appropriations (2021)**	**Revised Request (2021)**	**Advanced Appropriations (2022)**	**Increase / Decrease (2020-2021)**	**Increase / Decrease (2021-2022)**
FY 2021[6]	$431,403	$716,664	$706,630	$1,191,686	$1,191,686	$1,536,289	$485,056	$344,603

- FY 2015 to 2016 – the actual budget increased 8.72% ($39.57 million).
- FY 2016 to 2017 – the actual budget decreased 8.02% ($39.56 million).
- FY 2017 to 2018 – the actual budget increased 3.92% ($17.79 million).
- FY 2018 to 2019 – the actual budget decreased 8.49% ($40.02 million).

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[2] FY 2017 VA Budget Report, Vol. II - Medical Programs and Information Technology, VHA-6. (NOTE: All values in thousands.)

[3] FY 2018 VA Budget Report, Vol. II - Medical Programs and Information Technology, VHA-12.

[4] FY 2019 VA Budget Report, Vol. II - Medical Programs and Information Technology, VHA-22.

[5] FY 2020 VA Budget Report, Vol. II - Medical Programs and Information Technology, VHA-11.

[6] FY 2021 VA Budget Report, Vol. II - Medical Programs and Information Technology, VHA-7.

PCAFC BUDGET ANALYSIS

The PCAFC actual budget decreased from FY 2016 to FY 2017. This may be due to an accounting shift, i.e., over the fiscal year where the report was made, VHA may have decided to sever CHAMPVA from the Caregiver reporting, resulting in an apparent decrease in funding on the spreadsheet. The VA budget does not indicate whether CHAMPVA is excluded. However, a substantial decrease in the actual budget from Fiscal 2018 to Fiscal 2019 remains unexplained. Nonetheless, this decrease in budget does not appear related to the final rule change that was contemplated Fiscal 2020.

As stated, the Caregiver final rule took effect on the first day of Fiscal 2021. Assuming (for convenience and consistency) those stipends disbursed at an average of $3,000 per participant per month (stipend payments are fixed to GS-4) and that the approximately current number of participants (33,000) was the same at that point in time, the value of stipends should have totaled $1.188 billion per fiscal year. This amount of cost is consistent with the advanced appropriations granted for Fiscal 2021 ($1.192 billion).

In Fiscal 2020 (the year that VHA issued its intent to make the formal rule change) and 2021 (when the rule change became effective), VHA increased its appropriations requests by roughly 108% and 45% respectively. Given that roughly, 84,000 applicants denied, and assuming they all would have received the same stipend amount, VHA would have needed to request an additional $2.88 billion to accommodate them. Instead, VHA lists advanced appropriations for Fiscal 2022 of $1.54 billion, which would only cover an additional 9.572 participants.

VHA does not appear to be substantially increasing its appropriations requests for future fiscal years. This could mean that VHA intends to use the new final rule's qualification standards to prevent new participants in the Caregiver program that future or current participants expected to receive smaller stipends, or that VHA does not believe it will be able to obtain requested appropriations due to sticker shock.

VA VSN PCAFC REJECTION RATES

The VA's rejection rate of Caregiver applicants is too high, averaging north of 70%. (See chart below.). This is a clear indication that Caregiver program admission standards are unreasonable. Inconsistency in denial rates amongst the VISNs varies significantly. This shows that there is no consistent application of the VA's current program participation standards.

However, if the VA does not know its own standard for program participation, how can veterans and their caregivers? To fix the problem, the VA must first cease and desist its Caregiver Legacy Assessments until Secretary McDonough has honored his commitment to Congress to change the regulatory requirements.

Status of Caregiver Applications for FY 21 on 01 OCT 2021[7]

VISN	Received	Processing	Approved	Denied	% Denied
01	3,155	147	420	2,644	84%
02	3,976	193	584	3,265	82%
04	4,194	503	432	3,323	79%
05	3,634	319	352	3,000	83%
06	9,402	1,606	1,268	6,702	71%
07	11,627	867	1,716	9,204	79%
08	11,673	1,003	1,664	9,228	79%
09	5,107	306	568	4,338	85%
10	5,500	590	1,101	3,929	71%
12	2,996	354	563	2,142	71%
15	3,067	279	428	2,429	79%
16	7,330	1,027	534	5,873	80%
17	8,942	2,347	933	5,906	66%
19	4,887	1,416	404	3,163	65%
20	3,914	360	321	3,257	83%
21	7,193	1,321	723	5,252	73%
22	10,308	1,545	740	8,142	79%
23	3,082	208	723	2,216	72%
TOTALS	**109,987**	**14,391**	**13,474**	**84,013**	**76%**

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[7] VA Prosthetics & Special Disabilities Programs Federal Advisory Meeting, Oct. 2021.

VVA has heard from frustrated members across the United States, and when we ask them to please contact their member of Congress to assist them, their response is that nobody in Congress is listening. This ring true – if Congress had been listening to veterans, it could have stopped the bleeding months ago when the VA issued its press release on September 30, 2021, where it indicated that it would be reassessing 19,500 VA PCAFC legacy participants, 6,700 of whom would be removed from the program.

If the VA fails to make adequate regulatory changes, this will result in grave financial harm for participants who are removed from the program, in addition to wasted time, money, and resources spent processing denials as the program expands to cover veterans of all eras this October.

Perhaps Congress or the VA believed the regulatory change would only affect aging veterans, which is, of course, unacceptable, but post-9/11 veterans are being denied access, as well. When a veteran turns to the VA for assistance after being denied, they are told to file an appeal. As Ron Nessler, a three-tour, severely disabled Vietnam veteran stated, “You can’t file an appeal without complete paperwork.” Mr. Nessler made a concerted effort to submit all his documentation and comply with the VA’s requirements but was eventually denied access. His story is a common refrain amongst VVA’s membership, and when VVA asked Secretary McDonough why veterans were not receiving adequate explanations for why their claims are being denied, he said he would work to change the ADL regulatory requirement imposed by the VA’s new rule, but that he could not change the statutory 70% eligibility requirement.

VVA was hopeful that the VA would not repeat the mistakes it made in 2018 and 2019 with the newly revised PCAFC – mistakes foreseen by Senator Patty Murray (D-WA) – but unfortunately, reports indicate that access to the program is being denied to double- and triple-bilateral pre- and post-9/11 amputees. The only explanation given to these warriors is, “you don’t qualify.”

This situation is shameful and shocking. Veterans gravely injured in service to this country, who require care and treatment for the remainder of their lives, are being denied benefits they have earned. Why? Is funding the only reason for the harsh treatment of our nation’s veterans?

The situation must be rectified, and swiftly, not only because of the pending program expansion in October, but because of what will happen to these veterans if Congress rests on its laurels and does nothing.

Senators Tester/Moran, our veterans need you to honor your promise of care; you must use your legislative power to halt the legacy reassessment, which was never the intent of the PCAFC program. We also challenge you with holding VA accountable for unjustly denying program access to the PCAFC applicants and to compel Secretary McDonough to make the eligibility requirement changes that he has promised veterans in the past.

We thank the Senate Veterans Affairs Committee for the opportunity to submit our statement for the record and look forward to changes that will positively affect our nation’s veterans.

VIETNAM VETERANS OF AMERICA

FUNDING STATEMENT

March 23, 2022

The national organization Vietnam Veterans of America (VVA) is a non-profit veterans' membership organization registered as a 501(c)(19) with the Internal Revenue Service. VVA is also appropriately registered with the Secretary of the Senate and the Clerk of the House of Representatives in compliance with the Lobbying Disclosure Act of 1995.

VVA is not currently in receipt of any federal grant or contract, other than the routine allocation of office space and associated resources in VA Regional Offices for outreach and direct services through its Veterans Benefits Program (Service Representatives). This is also true of the previous two fiscal years.

For Further Information, Contact:
Director for Policy and Government Affairs
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(301) 585-4000 extension 111

CHARLES G. BYERS JR

Born in Houston, Texas, Charles "Chuck" Byers, Jr., currently serves on VVA's National Veterans Benefits Committee, as Chair for VVA's Veterans Healthcare, and as Second Vice President of VVA Chapter 1011 in East Valley, Arizona. Formerly Congressional Liaison for Military and Veterans Affairs for U.S. Congresswoman Debbie Lesko (R-AZ-8th), he is also the past State Commander of the Military Order of the Purple Heart (Arizona Department), and currently serves as their National Legislative Director. Byers has been a strong, lifelong advocate for his fellow veterans.

U.S. Army Specialist (SP5) Byers did his military service in the United States Army from 1966 to 1972. He served as a combat medic in Vietnam from July 1967 to June 1968, with the 9th Infantry division 2/60th, stationed in the Mekong Delta. Byers was wounded on June 1, 1968, when he ran into battle to tend to another wounded soldier. His actions earned him the Silver Star, the Bronze Star with Valor, and the Purple Heart for his service in Vietnam. He subsequently spent six months as a patient in Brooke Army Hospital in San Antonio, Texas. After recovering, Byers stayed in the Army and entered the Walter Reed Army Nursing program, graduating in 1970. He worked in Walter Reed Army Hospital in Washington, D.C., spending six months on the storied Presidential ward, until his discharge from the service in 1972.

Not long after leaving the Army, Byers became a lifetime member of VVA and a Charter Member of VVA Chapter 20 in Rochester, NY. He quickly began working on what would prove to be a lifelong commitment to helping veterans and their families, as he lived and raised his own family in New York and New Jersey. He served in several offices: as the past President of South Jersey Vietnam Veterans Association; as Senior Vice President for the Military Order of the Purple Heart for the State of New Jersey; as County Veterans Service Officer for New Jersey; and on the Governor's Veterans Task Force for New Jersey.

Byers moved from New Jersey to Arizona in August 2012. In addition to his on-going work with VVA, he has volunteered for the past six years as the Chief Veterans Service officer for Arizona, and he continues to do so. He has been credited with helping to build a strong Volunteer VSO Program for Arizona. In 2018, Chuck Byers was inducted into the Arizona Veterans Hall of Fame. Byers and his wife, Cheryl, have three children, five grandchildren, and two great-grandchildren.