WRITTEN TESTIMONY OF STEVE SCHWAB,
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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.