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HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS

JOINT HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING

AND THE

COMMITTEE ON VETERANS' AFFAIRS
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C O N T E N T S

PANEL OF WITNESSES

APPENDIX

OPENING STATEMENTS

PREPARED WITNESS STATEMENTS

QUESTIONS FOR THE RECORD

CONTENTS (cont'd)

Page

STATEMENTS FOR THE RECORD

HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS

Wednesday, June 5, 2024

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

The Committee met, pursuant to notice, at 10:01 a.m., Room 50, Dirksen Senate Office Building, Hon. Robert P. Casey, Jr., Chairman of the Committee, presiding.

Present: Senator Casey, Tester, Murray, Brown, Gillibrand, Blumenthal, King, Hassan, Kelly, Warnock, Moran, Cassidy, Rick Scott, Tuberville, and Ricketts.

OPENING STATEMENT OF SENATOR ROBERT P. CASEY. JR., CHAIRMAN, SPECIAL COMMITTEE ON AGING

The CHAIRMAN. The Senate Special Committee on Aging and Senate Veterans Affairs Committee will come to order.

Welcome to our first joint hearing. This joint committee hearing, this Congress entitled, "Heroes at Home. Improving Services for Veterans and Their Caregivers." It has been more than a decade since the Aging Committee held a joint hearing, and I want to thank Senator Tester and Senator Moran for bringing together our two Committees today to examine the important issues and unique challenges faced by veterans and their caregivers.

I also want to note that Senator Scott, a member of our Aging Committee, will be serving as the Ranking Member for the Aging Committee hearing today that is part of this joint hearing, and I am grateful for his leadership in acting and in that capacity.

Our conversation today is particularly timely given that tomorrow is the 80th anniversary of D-Day, commemorating the Allied invasion of Normandy during World War II. We thank those service members who fought on that day, and obviously, just saying that doesn't convey anywhere near the depth of our gratitude for all that they did to save our country and to literally save the world.

We, of course, extend that thanks to those who are serving today, all members of the Armed Forces, for the work they do every day protecting our Nation. Veterans and their families make great sacrifices to serve our country.

Our duty as members of the Senate is to provide support to those who serve our country. We must provide care for those who return home from service with injuries, both mental and physical, and for those who face disease or illness later in life.

Today's hearing is about the military family and paid caregivers who uphold this duty to provide invaluable long-term care to veterans. Joining us today are some of the most resilient people in the Nation, both our veterans and their caregivers, the caregivers who provide unwavering support to the men and women who served in the Armed Forces.

I have said this before, we cannot claim to be the greatest country in the world if we do not have the greatest caregiving in the world, and that includes supporting the military families and their paid caregivers. Military caregivers come in many different forms, spouses, family, friends, neighbors, and paid workers.

The majority, actually more than 96 percent of those caregivers, are women, and we will hear from our witnesses today that caring for a loved one can place a significant physical, emotional, and financial stress on the veteran, the caregiver, and family members.

Additional challenges for caregivers include navigating the VA system, applying for programs, and finding other resources. We will hear today from Peter Townsend, who comes to us from Susquehanna County, Pennsylvania.

He is joined by his wife and caregiver, Lisa, and we will hear from them about the needs and the experience of being a care recipient, and what that care means to his continued quality of life and health. long-term care is intended to provide supports and services to help people live independently and as safely as possible in the setting of their choice.

Caregiving services may include, of course, help with activities of daily living, managing medications, transportation, and so much more. The VA offers a wide range of long-term care programs, providing a model of how to honor the desires of those who want to continue living independently in their homes and in their communities.

For example, many veterans rely on VA respite care so caregivers can take a much needed time off for themselves or home health aide services to help them in their homes while the VA offers options and supports for veterans and their caregivers, we will hear from our witnesses today that we must do an awful lot more.

We must strengthen the long-term care supports that are currently available and help more caregivers access these services. That is why I am proud to support bipartisan and bicameral legislation to expand veterans' access to long-term care services and supports through the Elizabeth Dole Home Care Act.

I want to thank my colleagues, Senator Tester, Senator Moran, and Senator Hassan for leading on this important effort. The VA's Program of Comprehensive Assistance for Family Caregivers, known as PCAFC, is an important support for family caregivers. It has, however, had challenges over the past decades.

As the program has been reconfigured, too many veterans and their caregivers have been denied benefits. This is not a new problem. In 2017, the Senate Aging Committee held a hearing on military caregivers.

During that hearing, two of my constituents, Wanda and Samuel Ickes, discussed how the VA pushed them out of the Family Caregivers Program. In response to those concerns, I released a report on the program entitled, Discharged and Denied. My report found that the VA failed to anticipate the need of the caregivers' program, then abruptly discharged thousands of veterans, all without oversight or a clear appeals process.

Now that veterans of all eras are eligible for the Family Caregivers Program, the VA must, must not repeat its earlier mistakes. The VA should act swiftly to ensure the program benefits every single family it was meant to serve.

With the recent patch and passage in implementation of the Pact Act, we have seen the largest health care and benefits expansion in the VA's history. The Pact Act expanded access to health care for veterans who experienced toxic exposures in the Vietnam Gulf War and post 9/11 eras, which has now helped grant one million claims to veterans.

We need to make sure the VA has the resources it needs to support these newly enrolled veterans and their caregivers, and finally, we need to make sure the VA's resources are accessible to those who are designed to serve.

As Chairman of this Committee, the Aging Committee, I have pushed to make the VA make its websites and technology accessible for people with disabilities, including injured service members, as required by law.

I am pleased that the VA has made progress, but more work remains to be done. I am working with Senator Scott to pass Senate Bill 2516, the Veterans Accessibility Act, which will require the VA to establish a Veterans Advisory Committee on equal access to evaluate the VA's compliance with all, all Federal disability laws.

I want to thank Senator Scott for your support on the Veterans Accessibility Act and to the Dole Foundation for endorsing the bill but thank you for that. We have our work cut out for us, obviously. We need to uphold our duty, and it is our duty, to support our veterans and their families.

We need to make sure the programs designed to serve them are working as intended, and we need to make sure VA resources are accessible. We need to take our lessons learned from the VA to ensure that all who provide long-term care support and services, whether they are military or civilian, family members or direct care workers, we need to make sure that these individuals are valued and are compensated for their work.

I look forward to hearing from our witnesses today about their essential work and how Congress, and especially the Senate, can better support our Nation's military caregivers and their family.

Before I turn to Chairman Tester, I am going to run out because I have to go to Judiciary Committee to introduce a judge for a brief period of time, and I will be running back. I will miss Chairman Tester's opening, but I will make sure that I tune into C-Span to see it.

Thank you. Chairman Tester.

OPENING STATEMENT OF SENATOR JON TESTER, CHAIRMAN, COMMITTEE ON VETERANS' AFFAIRS

Chairman TESTER. We will miss you for a few minutes. Thank you, Chairman Casey. I want to thank Senator Scott for being here from the Aging Committee, for jointly convening this important hearing with the Veterans Affairs Committee to discuss veterans' caregivers.

Look, over the years, I have worked with leadership of these Committees on several important initiatives related to career givers, including the Elizabeth Dole Home Care Act with Ranking Member Moran and Chairman Casey, and the Care Act with Ranking Member Braun. Today, we hope to get additional feedback and direction from our witnesses to guide these and future efforts.

I want to thank all the witnesses for being here. You are critically important in this process. I especially want to welcome Hannah Nieskens. Sorry about that, Hannah. She is from the metropolis of Cardwell, Montana. Hannah cares for her husband, Kelly, who was injured while serving in the Montana Army National Guard back in 2005.

That means she has been Kelly's primary caregiver for nearly 20 years, while raising three kids and working at the White Hall School District. Hannah, I want to thank you for everything you do.

You are an inspiration to the folks on this side of the dais. Our caregivers do their jobs every single day, providing critical care and support to veterans when they need it most, but for them to get the support assistance they truly need, Congress needs to do its job.

I want to note—I would like to note that the House is currently deliberating the path forward on a package of bills negotiated by the Senate and House Veterans Affairs Committee, named the Elizabeth Dole 21st Century Veterans Health Care and Benefits Improvement Act.

This is comprehensive legislation that would expand access to home and community-based care programs for veterans, and bolster home health care staffing, attempts to strengthen the VA caregiver and long-term care programs.

I look forward to getting this piece of legislation done by working with the Dole Foundation, who has been a long-time champion of these issues and this legislation. I look forward to working with the veterans service organizations to finally get this over the finish line on behalf of our Nation's caregivers.

Why? Because our veterans have earned this. With that I am going to turn it over to Senator Scott for his remarks.

OPENING STATEMENT OF SENATOR RICK SCOTT, SPECIAL COMMITTEE ON AGING

Senator Rick SCOTT. Thank you, Chairman Tester. Good morning. I would like to thank everyone for being here today and want to welcome you all to this historic joint meeting of the Senate Aging and Veteran Affairs Committees.

I want to thank Chairman Casey and Tester, as well as Ranking Members Braun and Moran, for having this hearing today. It is an honor to stand in for Ranking Member Braun today, especially on an issue so personal to me and my family and millions of Americans nationwide. I would like to put in Senator Braun's, Ranking Member Braun's testimony into the record.

Senator TESTER. Without objection.

Senator Rick SCOTT. This hearing is an important opportunity to hear about some key issues affecting veterans receiving care and their caregivers as they age. As a Navy veteran, the son of a World War II veteran, I know firsthand the sacrifices made by our military members and their families. I think about my dad, Orba.

He had a sixth-grade education and joined the Army as a teenager, fought in the Battle of the Bulge and did all combat jumps in World War II with the 82nd Airborne. He flew into Normandy that morning. He didn't talk about service a lot, but he was so proud to be in the U.S. Army—proud to wear the uniform and defend our freedoms.

He told me the Germans were bad, the food was bad, the foxholes were bad, so I joined the Navy. None of the opportunities and freedoms we have as Americans would be possible without the dedicated services of our brave heroes like my father and those who have served.

That is why throughout my time as Governor of Florida, I made it my mission to turn our State into the most active-duty military and veteran friendly State in the Nation by championed important legislation and funding to support priorities that matter most to Floridians, Florida's active duty military and veterans families.

Fighting for our heroes continues to be one of our top priorities as a U.S. Senator. I always do everything I can to support our veterans and their families so they can succeed and pursue their dreams in our State.

I am proud to be a co-sponsor and supporter of dozens of veterans related bills in the Senate, including the Elizabeth Dole Home Care Act, the Major Richard Starr Act, and the Pact Act. Our veterans showed up for our Nation and sacrificed so much.

It is so important that we show up, support them after their service, and make sure they have every resource they need. It is also imperative today to recognize the critical role played by our country's 5.5 million military caregivers, who range from spouses, parents, children, friends, and family members, who dedicate their lives and often give up so much to care for those who serve our country.

I have the greatest honor of serving as United States Senator and representing our veterans, honorable caregivers, hardworking Florida families, and their American people. Thank you, Chairman Tester.

Chairman TESTER. Senator Moran.

OPENING STATEMENT OF SENATOR JERRY MORAN, RANKING MEMBER, COMMITTEE ON VETERANS' AFFAIRS

Senator MORAN. Chairman, thank you. I thank you and the Ranking Member, Senator Scott, for leading this hearing today, and I welcome our witnesses and look forward to their testimony.

Caregivers who are often overlooked and forgotten simply have a profound impact on our Nation's veterans. They are invaluable in making certain that veterans with even the most complex conditions receive the care and dignity that they deserve.

It is disheartening to hear too frequently from dedicated caregivers in Kansas and elsewhere about the numerous obstacles they face in dealing with the Department of Veterans Affairs. I have heard from caregivers who were denied services from the VA Family Caregivers Program for vague reasons, and in some cases, were only given a one sentence explanation.

In far too many cases—and a lot of what I know about this is what veterans and their caregivers tell me, and what casework we do in our office to try to solve those problems. Far too often in these cases, the VA is failing to provide families with a clear, detailed explanation of how to appeal a VA decision, or what other VA programs and services they might be eligible for.

This leaves the caregiver and veteran alike in limbo, uncertain how to get the support they so desperately need. Congress expanded the Family Caregiver program to veterans of all ages in the Mission Act, which was signed into law six years ago tomorrow.

While I expect there to be growing pains, that is to be expected when the VA is implementing new legislation, it is always disappointing to hear that the Expanded Family Caregiver Program is not in a better place than it is today.

As we continue to wait for the VA to issue new regulations, I look forward to hearing from our witnesses about the Family Caregiver Program, how it must evolve to provide caregivers and veterans the support they need. I introduced the Elizabeth Dole Home Care Act, which would address the needs of veterans, caregivers, and their families.

This legislation, if implemented correctly, would make it easier for veterans to stay at home as they age by expanding and improving the VA's home and community-based programs. Almost half of VA patient population is over 65, and we know an increasing number of those veterans want to live at home, surrounded by their families, in their communities, and loved ones, rather than the transition into a nursing home.

VA should honor veterans' preferences when, where, and how to receive care. I also look forward to discussing how Congress and the VA can better support state veteran homes, which play a critical role in caring for veterans across the country. We have two in our State, and we are trying to develop a third, and the process we are going through to accomplish that third one is amazingly slow.

Again, thanks to our witnesses, and to my colleagues on the Aging and Veterans Affairs Committees, for being here today, and with that, Mr. Chairman, I yield.

Senator TESTER. I want to thank both of you and Congressman Scott for your testimony. What?

Senator MURRAY. Senator.

Senator TESTER. Oh, it is Senator—you didn't. You skipped that, as I did. Thank you very much, Senator Scott. Sorry about that. I am going to introduce the first witness today, and then we will introduce the second ones before they come up to speak.

The first witness is from Casey Country. His name is Peter Townsend. He is from Auburn Township in the great State of Pennsylvania. Mr. Townsend served in the United States Army on active duty from 1982 to 1986. He later worked as a physician assistant until early retirement in 2014.

Sorry, Bobby, I am taking your thunder. In 2014, due to complications from primary progressive multiple sclerosis. He is accompanied by his wife Lisa who serves as his full-time caregiver. I want to thank you both for being here today, and unless Bob has something you would like to add, you can progress with your testimony, Mr. Townsend.

STATEMENT OF PETER TOWNSEND PA-C EMERITUS, VETERAN AND SELF ADVOCATE, SUSQUEHANNA, PENNSYLVANIA

Mr. TOWNSEND. Thank you. Chairmans Casey and Tester, Ranking Members Braun and Moran, and distinguished members of the Committees, thank you for the opportunity to speak with you today regarding my experiences with caregiver support services available through the VA.

My name is Peter Townsend, and I am currently 60 years old and live in Susquehanna County, Pennsylvania with my wife Lisa, who is also my caregiver. I served on active duty in the United States Army from 1982 to 1986.

Following my discharge in 1986, I went on to work for over two decades as a physician assistant before retiring prematurely due to complications of multiple sclerosis. As my disease progressed, I began to experience significant difficulties with mobility, fatigue, cognition, and bowel and bladder dysfunction, among others.

Today, I rely upon a power wheelchair when out in the community and a walker to ambulate for short distances at home. Through conversations with fellow veterans, I learned that MS was a medical condition that the VA recognized as a service-connected disease, and with the assistance of Paralyzed Veterans of America, of which I am a member, I was able to successfully file a claim and am now rated 100 percent service disabled due to MS. As my symptoms progressed, I began to rely more on the assistance of my wife, Lisa. My MS can vary dramatically.

Although most days are good days where I can function fairly independently, when I have a flare or exacerbation, I can become temporarily incapacitated. During these times, I rely very heavily upon Lisa for assistance with a variety of activities to include intermittent catheterization, transfers, toileting, personal hygiene, dressing, and meal preparation. I have had no fewer than three of these episodes already this year.

Prior to leaving the workforce, Lisa had been working as a case manager for Keystone Community Resources. Eventually, as my condition deteriorated, Lisa decided to retire early from her position at age 61 to be, or to become my full-time caregiver.

Around this time, primarily through a process of self-education and online resources, we learned of the VA's Program of Comprehensive Assistance for Family Caregivers, the PCAFC. We applied when eligibility open to veterans of all service areas in October 2022. Unfortunately, our application was denied.

As I understand it, we were denied due to the VA's determination that I did not require assistance with the performance of certain activities of daily living each time that activity was performed, or that the level of assistance did not ″rise to the level required to participate in the PCAFC.″

This strict interpretation of the eligibility criteria by the VA is of particular concern to veterans like myself with medical conditions whose symptoms are highly variable and unpredictable. Lisa was eventually enrolled into the Program of General Caregiver Support Services, the PGCS.

However, this transition to the PGCS was not automatic, and we went for some time thinking we were enrolled in the general program, although we were not. One of the most valuable benefits of the Program of Comprehensive Assistance is the availability of medical insurance coverage for caregivers through the Civilian Health and Medical Program of the Department of Veterans Affairs, CHAMPVA.

CHAMPVA was the only way that we could afford for Lisa to retire early. Lisa qualified for coverage due to my permanent and total disability rating, so we did not have to rely upon the PCAFC for this benefit.

The Program of General Caregiver Support Services offers fewer benefits than the PCAFC, but one significant benefit it does offer is respite care. We utilize this benefit when Lisa underwent surgery.

Staff at the Wilkes-Barre VA arranged for me to be admitted to the Community Living Center for three weeks while Lisa recovered from her surgery. Lisa knew that regardless of what was happening with my health, I was being cared for so that she could focus on her recovery.

I can't emphasize enough how important this valuable—I should say the valuable—how valuable the respite care benefit was to our family, and it is comforting to know that it will be there if we need it again in the future.

Throughout this journey, our goal has been to create an environment that allows me to live in our home as long as possible, and to avoid the need for long-term care. Participation in VA's caregiver programs helps us to achieve that goal.

The reality is that my current level of disability is such that I am no longer able to live independently and would require placement in an assisted living facility were it not for Lisa's efforts. I would like to make it clear that Lisa and I remain very grateful for all the benefits that we have received and continue to receive.

To show my gratitude, I currently serve as a Redcoat Ambassador at the Wilkes-Barre VA Medical Center. By volunteering, I can help other veterans connect to and navigate services more seamlessly and give back to the organization that has done so much for me.

The system is not perfect, however, and there will always be room for improvement. I encourage the Committees to work with the VA to one, ensure a more seamless transition to the PGCS following denial of the PCAFC. Two, to better communicate resources and benefits available to veterans, and three, value the work of caregivers by passing legislation which would give Social Security credit to caregivers who have left the workforce prematurely to care for their loved ones.

I thank you for this opportunity to share our experiences and look forward to answering any questions that you may have.

The CHAIRMAN. Mr. Townsend, thanks for your testimony. We are grateful that you are here. I will turn next to Chairman Tester for his introduction, and then we will alternate. Why don't we do the introductions first, and then we will turn to our next witness for testimony. Chairman Tester.

Chairman TESTER. Our next witness is Hannah Nieskens. Hannah is, as I said in my opening statement, joining us from Cardwell, Montana. One of the most beautiful places on Earth, I might add.

Her husband sustained traumatic brain injury while serving in Iraq, and she serves as his caregiver full-time. She is an Elizabeth Dole Foundation alumna and is an advocate and spokesperson about mental health issues associated with brain injuries.

I just want to say, Hannah, it is not a short trip from Montana to Washington, DC, and thank you for being here.

The CHAIRMAN. Thank you, Chairman Tester. Our third witness is Andrea Sawyer. Andrea is an advocacy navigator for the Quality of Life Foundation's Wounded Veteran Family Care Program.

After her husband sustained injuries in Iraq, she became his caregiver and an advocate for those other wounded warrior families. We want to thank you for being here today and sharing your experiences with us.

I will turn next to Ranking Member Scott, I guess I can call you that today, for the next introduction.

Senator Rick SCOTT. I have the privilege of introducing Fred Sganga, the Executive Director of the Long Island State Veterans Home at Stony Brook University, a 350-bed skilled nursing facility serving honorably discharged veterans and their families.

Fred also serves as the first Vice President for the National Association of State Veterans Homes, as a Board Member of the National Council of Certified Dementia Practitioners. Thanks for being here.

The CHAIRMAN. Our fourth and final witness is Ms. Meredith Beck. Meredith is the National Policy Director for the Elizabeth Dole Foundation. She has dedicated over 20 years to the veteran caregiver in military communities.

We appreciate you being with us today. We will turn for testimony to Ms. Nieskens.

STATEMENT OF HANNAH NIESKENS, CAREGIVER OF POST–9/11 VETERAN, CARDWELL, MONTANA

Ms. NIESKENS. Chairman Casey and Tester, Ranking Members Moran and Scott, and distinguished members of the Committee, thank you for allowing me to testify today. My name is Hannah Nieskens and I have been married to my husband, Kelly, for 20 years.

For 18 and a half of those years, I have also been his caregiver. In 2005, Kelly was a 23-year-old Montana Guardsman activated to Army infantrymen deployed to forward Operating Base McHenry in Hawija, Iraq.

On May 4th, 2005, during a routine patrol, Kelly's Humvee was struck by a large IED. This explosion, the fifth roadside bomb to hit his vehicle since his arrival in November, left the Humvee disabled in an 11-foot wide crater and knocked the squad members, including Kelly, unconscious.

Upon regaining consciousness and exiting the vehicle, they came under heavy sniper fire. Kelly was struck by a large caliber rifle round that traveled through his ribs, hit his armored plates, and ricocheted multiple times through his torso before lodging near his spine. He survived thanks to the extraordinary efforts of medics, doctors, and the E-VAC team.

Upon returning to civilian life, Kelly faced numerous physical limitations. He had mobility issues caused by traumatically herniated discs, as well as nerve damage, pain, and neurogenic bowels caused by scar tissue around his spine and intestines. He suffered from migraines, seizures, and hearing loss. His cognitive impairments, including problems with executive functioning, memory deficits, and mood dysregulation also posed significant challenges.

In 2016, after a decade of limited success with medications prescribed to treat PTSD, an MRI performed through UCLA's Operation Mend Program revealed 12 lesions on Kelly's brain, some as large as a dime, confirming a significant TBI for which both proper treatment and benefits had been delayed.

Throughout the past 12 years, the VA's Program of Comprehensive Assistance for Family Caregivers, the PCAFC, has been an invaluable resource for me as I navigated the complexities of Kelly's care and providing me training and support. In 2021, we were subjected to a grueling reassessment process for PCAFC eligibility.

During a nearly two-hour virtual appointment with a contracted occupational therapist, Kelly and I had to painfully recount every limitation he faces. I had to quantify everything I do as a caregiver, which after two decades of caregiving is difficult when those caregiving tasks are so integrated into our daily life.

The resulting report was incomplete and inaccurate, missing critical information and VA disability ratings. Despite efforts by the VA staff and me to correct these errors before review, not all were corrected. The reassessment outcome was that Kelly, and I did not meet eligibility criteria, and I was dismissed from the program.

The decision highlighted several issues. Significant discrepancies exist between the Veterans Benefits Administration and Veterans Health Administration records, leading to incomplete or incorrect ratings in disability information submitted in reassessment reports.

For example, Kelly's VBA rated disability of status post through and through gunshot wound injury coded with VBA diagnostic code for muscle injuries due to wounds caused by gunshots or other missiles was recorded in his VHA records as superficial scars and back muscle impairment, as there was no equivalent diagnostic code in the VHA medical record system.

His VBA rating for neurogenic bowl was recorded in the VHA system as irritable colon. Perhaps more importantly, his 70 percent rating for his TBI was completely missing in the VHA record as a rated service-connected disability.

The reassessment process placed undue emotional strain and stress on us, and I believe reassessment should occur only when a veteran's needs change significantly. Additionally, veterans with specific VBA ratings such as incompetency, aid in attendance, those should have presumptive eligibility for caregiving.

It was also apparent that veterans with stable needs, or those receiving private care, were disadvantaged in reassessments due to fewer VHA medical records in the months preceding the evaluation.

Stable needs does not equate to insignificant needs. Furthermore, veterans who reside in areas with limited access to specialists, such as where we reside in rural Montana, were penalized due to access issues as they do not receive routine, comprehensive evaluations involving multiple specialists.

This May marked 19 years since Kelly's injury. Over these years, I have learned that aging significantly amplifies the challenges faced by people with disabilities. Withdrawing support for disabled veterans with high needs and their caregivers is incomprehensible.

As the brain and body age, the need for consistent and comprehensive care for our veterans only intensifies. Removing caregivers from PCAFC could lead them to seek more expensive care options for their veterans, including home health aides through Medicare or the VA Programs.

Utilizing home health aides instead of caregivers exacerbates the significant nationwide shortage of home health aides. In addition, the availability of home health aides, especially in rural areas like our small Montana town which has a population of 68, is none too few.

Thank you for allowing me to share my story and the challenges we face. I appreciate your commitment to improving the lives of veterans and their caregivers. I am happy to answer any questions you may have.

The CHAIRMAN. Ms. Nieskens, thank you for being here with us today, and thanks for traveling to be here. It is a long distance and grateful to have the benefit of your family's story. Next, Ms. Sawyer.

STATEMENT OF ANDREA SAWYER, NATIONAL ADVOCACY DIRECTOR, QUALITY-OF-LIFE FOUNDATION'S WOUNDED VETERAN FAMILY CARE PROGRAM, WINSTON-SALEM, NORTH CAROLINA

Ms. SAWYER. Chairman Tester and Casey, Ranking Members Moran and Scott, and members of the Committee, thank you for holding this hearing.

I am the Advocacy Director for the Quality of Life Foundation which serves caregivers of the seriously injured veterans. We create educational resources surrounding PCAFC and are one of the few organizations that assist with clinical appeals for PCAFC. Over the years, legislation and policy surrounding caregivers has evolved.

The original legislation created the Caregiver Support Program for post 9/11 Veterans. Post 9/11 Veterans accepted into PCAFC under this regulation are called legacy caregivers. The Mission Act of 2018 expanded eligibility to PCAFC to veterans of previous generations. The VA drafted new regulations in 2020.

By March 2022, there was a high denial rate for eligible applicants from previous generations, around 70 percent, and legacy review denials were around 80 percent. VA paused legacy reassessments in March 2022.

Since then, VACO has rewritten the regulation, but no new regulation has been published. After the March 2022 SVAC hearing on PCAFC, VACO held collaborative sessions with VSOs to discuss what we saw as the problems with the regulation.

However, in the fall of 2022, the VA Office of General Counsel stopped these conversations and declared VA within the confines of rulemaking. Since that time, VSOs have been given no guidance on what will be in the new regulation for the program.

We ask the Committees to work with VA and stakeholder organizations on the following items. Congress needs to clarify that the mission of PCAFC is to recognize the sacrifice of caregivers providing services for their seriously injured veterans.

Services so that in the absence of a family caregiver, would be required to be provided by the VA. Remind VA that the Caregiver Support Program was intended for the seriously injured, not the severely injured.

Codify the activities of daily living, and supervision protection and instruction needs should only require regular assistance so that veterans are not denied PCAFC for attempting any level of independence within the areas in which they need assistance.

Require that all veterans medical providers give input on a veteran's application for PCAFC, and remove the language in the statute that states, to the maximum extent possible, when requiring such input.

Require VHA to honor its duty to assist, to collect outside medical records. Create a pathway to advocacy to require VA to develop a program to allow VSOs to navigate the Veterans Health Administration on behalf of veterans and caregivers.

Mandate that those veterans and caregivers needing additional assistance beyond PCAFC are allowed to be presented with all of their potential options for care. All of these items are in the Senator Elizabeth Dole 21st Century Veterans Health Care and Benefits Improvement Act, as well as listed between, the Elizabeth Dole Home Care Act and Senator Tester's Care Act.

Examine caregivers' financial security for post caregiving. Senate Bill 3885, the Veteran Caregiver Reeducation, Reemployment, and Retirement Act would create pathways for caregivers to reenter the workplace and study, allowing them to contribute to retirement accounts and Social Security so that they are not destitute in their later years.

When testifying before Congress, then VA Secretary Shulkin said that VA wanted to change PCAFC to align it with other VA programs. One lawmaker at a time responded, I am concerned that the VA may attempt to justify changes to the program at the expense of our most vulnerable veterans, rather than working to expand the program. This is exactly what has happened.

VA made the cheaper to run PCAFC harder to get into than the more expensive geriatrics and extended care programs. A PCAFC caregiver is paid between $8.60 an hour to $13.86 an hour. VA reimbursement rates for home health aides ranged from $31 an hour to $81 an hour.

We are simply asking you to restore PCAFC to one that supports seriously injured veterans who have a need for assistance on a regular basis. Allowing family caregivers to supply this care in the home has proven to have better health outcomes for veterans, as well as cost savings for the government.

By passing the Senator Elizabeth Dole 21st Century Veterans Health Care and Benefits Improvement Act, and the Veteran Caregiver Reeducation, Reemployment, and Retirement Act, Congress would reinforce support of veterans and their family caregivers, and veterans' desire to age in place at home.

Veterans have given their all to defend America. Shouldn't we honor their right to age in place, at home, with the caregivers of their choice? The Quality of Life Foundation thanks you for holding this hearing, and we look forward to answering any questions you may have.

The CHAIRMAN. Ms. Sawyer, thank you for your testimony. We are grateful you are here. Next, Mr. Sganga.

STATEMENT OF FRED SGANGA MPH, FACHE, LNHA, LEGISLATIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE VETERANS HOMES, LONG ISLAND, NEW YORK

Mr. SGANGA. Chairman Casey and Tester, Ranking Members Scott and Moran, and members of the Committees, thank you for inviting the National Association of State Veterans Homes, better known as NASVH, to testify on ways to improve and expand support for aging veterans and their caregivers.

As you know, NASVH is an all-volunteer organization representing the interests of all 165 state veterans homes, which combined operate 158 skilled nursing care programs, 47 domiciliary programs, three adult day health care, or ADHC programs.

I am currently the Legislative Officer and past President of NASVH. However, my full-time job as Executive Director of the Long Island State Veterans Home at Stony Brook University, a 340 bed skilled nursing facility serving honorably discharged veterans and their families.

Mr. Chairman, state veterans homes provide approximately half of all federally supported institutional long-term care for veterans, yet we receive less than 20 percent of the VA's total nursing home care budget. It is clear that the State Home Partnership provides a tremendous value for VA by leveraging matching State funding for the benefit of all the veterans we serve.

Although the veteran population is projected to decline in future years, there will always be significant numbers of veterans who will need traditional nursing home care. While we agree that VA should continue to expand home and community-based care, it should be an in addition to not a subtraction from facility based care.

One of the most promising areas to expand home based care is through the stay-at-home adult day health care programs, which helps to maximize the veteran's independence and enhance their quality of life, as well as provide much needed respite for the family caregivers.

The Long Island State Veterans Home operates a 40-slot medical model adult day health care program serving 75 veterans, six days a week, Monday through Saturday. We provide them with a full array of clinical services offered at our skilled nursing facility, including physical, occupational, and speech therapies, nutritional counseling, meals, recreational therapy, as well as things like bathing, grooming, and hair care.

We help stabilize chronic medical conditions, reduce emergency room visits and potential hospitalizations, delay or prevent nursing home placement, and provide significant respite for caregivers. In fact, we can save a caregiver multiple trips it would take to provide all the services that we are able to provide in one single visit at the state veterans Home.

Adult day health care programs can be a critical lifeline for both veterans and their caregivers, such as Colonel Mike Grable and his wife, Jeannine. After graduating West Point and having a 27-year military career, Mike had a severe stroke, and for the next two years he required hospital care.

He faced the knowledge that he would need significant physical therapy and extensive support for the rest of his life. Fortunately, we were able to offer Mike the option of enrolling in our adult day health care program at the Long Island State Veterans Home.

Today, he receives the intensive care and support he requires five days a week, while Jeannine, his spouse, was able to return to work as a school nurse, secured in the knowledge that her loved one is in good hands during the day and returns home to her every evening.

Mr. Chairman, the biggest obstacle to States opening new adult day health care programs is the construction or modification of a facility. Unfortunately, current VA regulations only allow existing adult day health care programs to apply for construction grants.

We urge Congress to enact legislation to allow State homes' construction grant program to be used to open new adult day health care programs. In addition, we urge you to work with VA so we can open satellite adult day health care programs that could offer life changing service as an option to thousands of additional veterans and their family caregivers.

NASVH also recommends that Congress create pilot programs to explore new arrangements for providing integrated home and community-based programs through and in partnership with the state Veterans Home Program.

For example, when I was forced to suspend my adult health care program during the COVID–19 pandemic, we were able to quickly pivot to an innovative program that supported veterans at home by providing meals at home, PPE, telehealth, and home care visits.

Finally, I want to thank Senators Tester and Moran for introducing legislation to create a pilot program to provide assisted living care for veterans, which includes state veterans homes. Mr. Chairman, state veterans homes can and must play a greater role in meeting the needs of aging veterans and their caregivers in partnership with the VA and other Federal agencies.

NASVH looks forward to continuing to work with you to ensure that our veterans have greater access to a full spectrum of long-term care options, whether at home or in the State Veterans Home Program.

That concludes my statement, and I would be pleased to answer any and all questions that the members of the Committees may have. Thank you so much.

The CHAIRMAN. Mr. Sganga, thank you for your testimony. We will conclude with Ms. Beck.

STATEMENT OF MEREDITH BECK, NATIONAL POLICY DIRECTOR, ELIZABETH DOLE FOUNDATION, WASHINGTON, D.C.

Ms. BECK. Thank you. Chairman Casey and Tester, Ranking Members Scott and Moran, and members of the Committee, thank you for the opportunity to testify today.

My name is Meredith Beck, and I am the Senior Policy Advisor for the Elizabeth Dole Foundation, a national nonprofit whose mission it is to strengthen, empower, and support America's military and veteran caregivers.

By working with these individuals every day, EDF is keenly aware of the challenges, issues, and remarkable strengths of the community we are honored to serve. While we have outlined additional issues for consideration here in our written testimony, we first want to focus on the urgency of the passage of H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Health Care and Benefits Improvement Act, mentioned previously.

Clearly and without hesitation, the number one priority of the Elizabeth Dole Foundation is the immediate passage of this legislation. It is not an exaggeration to say that we hear from veterans and caregivers every day who are desperate for the support provided by the provisions in this bill.

Every day we wait, their struggle continues. I will speak more about this legislation later in the statement. Regarding VA's Program of Comprehensive Assistance for Family Caregivers, it remains a significant concern among all generations of veteran caregivers.

We wish to strongly align ourselves with the comments and recommendations made by our partner, the Quality of Life Foundation, who has clearly articulated the program's current challenges in their written testimony.

EDF is a proud—is proud to sponsor the vital specialized clinical appeals work done by QoL. With respect to the anticipated PCAFC regulations outlining new eligibility requirements, EDF notes that the legacy caregiver cohort yet again faces an uncertain future.

Many of these caregivers have endured multiple pauses, regulation and leadership changes, and a lack of previous program standardization. The emotional toil and financial uncertainty caused by programmatic instability have weighed heavily on caregivers and veterans alike, as outlined by Hannah.

Therefore, EDF asked Congress to work with relevant veteran service organizations to consider grandfathering this population, except in cases of fraud, waste, or abuse. This would allow the Caregiver Support Program to focus on its mission of supporting all generations, rather than continuing this years? long division within the veteran caregiving community.

We would like to commend CSP for their efforts to increase the use of respite services and the availability of mental health support for veteran caregivers enrolled in PCAFC. This has served as a lifeline for many who have previously struggle without access to care. Therefore, we encourage Congress to broaden access to mental health services to include those enrolled in the Program of General Caregiver Support Services.

In addition to CSP, VA has many programs that, when accessed, benefit veteran caregivers. Where available, the Veteran Directed Program, for example, has high satisfaction rates across the country.

Unfortunately, despite being created more than 16 years ago and its demonstrated success, Veteran Directed is still not available in every VA medical center. For example, Mary Ward, a Dole caregiver fellow, cares for Tom, her 100 percent service disabled husband and 14 year ALS patient who receives care at the Durham VA.

In 2019, almost five years ago, Mary found out another high need veteran in the area was enrolled in Veteran Directed and began the process of trying to get Tom enrolled. During the intervening years, she has been told repeatedly the program is still unavailable in Durham, again, despite knowing another veteran in the program.

After significant effort on Mary's part, an intervention from EDF, the VA reversed course and Mary was told recently that they would try to enroll Tom. If enrolled, Mary will be able to hire her own familiar home health aides and respite care support to ensure they are meeting Tom's significant needs.

This process should not and cannot be this difficult for veterans and caregivers. As a result of situations like Mary's and Tom's. Ranking Member Moran was joined by Chairman Tester and others to introduce S. 141, the Elizabeth Dole Home Care Act.

In addition to mandating that every VA medical center provide the Veteran Directed Program, the legislation takes a holistic approach to ensuring this and other relevant programs are offered nationwide are appropriately staffed and communicate it to caregivers.

Most notably, the legislation increases expenditure cap for non-institutional care. This would allow the most vulnerable veterans and caregivers the support they need to stay in their homes. Fellow Laura Gary, from Austin, Texas, who is present today in this hearing, cared for her 100 percent service-disabled husband Tom until his death in 2022.

Because of the mandated cap, Laura constantly had to fight with the VA to get the appropriate support so Tom could continue to enjoy movie nights with the family, opening gifts on Christmas morning, and even their son's high school graduation, which happened in their living room so that Tom could attend comfortably, all of which he would have missed if you were in the closest facility two hours away.

It was Tom's greatest wish to be home with his family, and Laura fought every day until his death to make that possible. Eventually, this legislation, which enjoys broad bipartisan support in both houses of Congress, was included in the recently introduced and the previously mentioned H.R. 8371.

This overall package includes numerous provisions designed to benefit veterans and caregivers. Despite strong support from the Chairman and Ranking Members of the Senate Veterans Affairs Committee, as well as the Chairman of the House Committee, all major veterans service organizations, and other advocacy groups, this legislation has seemingly fallen victim to the politics of the day and has been plagued by mischaracterization of its provisions.

While caregivers and veterans still face significant challenges today, many can be addressed through continued oversight and the legislative initiatives mentioned in our written and oral statements.

Therefore, EDF calls on Congress to come together, treat H.R. 8371 with the respect and urgency it deserves, and pass it without delay. Veterans and caregivers simply cannot wait any longer for this lifesaving—and lifesaving provisions. Thank you, Mr. Chairman, and we look forward to your questions.

The CHAIRMAN. Ms. Beck, thank you for your testimony. Thank you to all of our witnesses. We will turn to questions. I will start.

Mr. Townsend, I am just grateful you are here and representing, in essence, the people of Pennsylvania and veterans. We appreciate your service in the United States Army, and I want to thank you for sharing the experiences that you have had and offering insights into how you and Lisa have navigated VA caregiving, both services and supports.

You shared that after an infection during an overseas tour in South Korea, you contracted a virus that is known to cause a progressive form of multiple sclerosis in some people. Unfortunately, you are now living with the daily challenges associated with MS.

After a long battle with the VA, you were eventually deemed to have a 100 percent service-connected disability. Like so many others, you have good days and bad days. Even on your good days, you still require some level of assistance with your activities of daily living.

You shared that you applied for the Program of Comprehensive Assistance to Family Caregivers and were denied. How did this make you feel? What were you thinking when that determination was made? And do you feel that the VA's assessment adequately considered your needs?

Mr. TOWNSEND. Clearly, we were disappointed when we received the determination. It is certainly our opinion that VA's current interpretation of the eligibility criteria eliminates many veterans like myself from participating in programs like the comprehensive program in particular, simply by not requiring assistance with certain activities of daily living each time that activity is performed

I clearly think there is room for improvement, and I think that was summarized best by Ms. Sawyer when she recommended the change to requiring regular assistance rather than assistance every single time a veteran performs that particular activity of daily living.

The CHAIRMAN. Thanks very much. I will turn next to Ms. Nieskens. You as well shared your own story and that of your husband, and the work you have done as a caregiver.

In your testimony, you told us that professional home care workers are an essential part of your husband's care team and your support team. You also told us it is often hard to find and keep these workers.

We hear about that a lot. This is a story that I hear all too frequently back home, and we hear it in Washington as well, that it really is a care crisis across the board, not just in this context, but in the context of children and seniors and veterans as well.

I have introduced several bills to improve both recruitment and retention of direct care workers. These bills would benefit older adults and people with disabilities, and we also support the family caregivers who are left with little support or without access to the services.

I would ask you to tell us what it means for you and your family when you are not able to find a home care worker. What steps can we take here in the Senate to make sure that a stable and qualified workforce is there for you and your family?

Ms. NIESKENS. Yes. The availability of home health aides is there is, as everyone here knows I believe, there is a nationwide shortage. I do believe the PCAFC helps to alleviate that burden by allowing family members to fill that gap when those HHAs aren't able to be found.

In addition, I think it is worth mentioning that the median wage for a home health aide in the United States is somewhere between $13 and $14 an hour.

When you consider what that requires for someone to come to my home, the nearest metropolitan area to Cardwell is Butte, Montana, which has roughly 35,000 people, so that is probably where the home health aide would come from.

They would have to commute 40 miles over the continental divide, over a very large pass in the middle of winter to come to my home to provide health aide services. The likelihood of finding someone who is willing to do that for $13.50 an hour is just slim to none.

I do believe that the PCAFC helps to alleviate those needs by allowing people that are already in the recipient's home or immediate community to fill those needs.

The CHAIRMAN. Thanks very much. I will turn next to Senator Scott.

Senator Rick SCOTT. Thank you, Chair. Mr. Sganga, how does your facility assist veterans and their caregivers when the veteran wants to remain in the home, but still need some additional support?

Mr. SGANGA. Our adult day health care program is a phenomenal program. It allows for the veteran to keep his or her own physician, whether they be with VA or whether they be in the private community.

We think we do provide a tremendous service to these veterans six days a week. I would like to give you an example, Senator Scott. When the veteran is in our adult day health care program, it is a six-hour visit. They arrive at 9:00 a.m., and they depart around 3:00 p.m.. During the course of that time, we can get a lot done for that veteran.

Think about someone who is caring for their elderly parent or grandparent who is a veteran. While they are at the home, they can receive phlebotomy because the doctor ordered a blood test.

They can receive a simple X-ray or ultrasound. They can get their teeth examined and cleaned. They can get their eyes checked by our optometrist. They can receive podiatric care, and even receive physical therapy, occupational therapy, and speech therapy. Maybe their hearing aid needs a battery change.

They can even get a haircut. What I just said to you, I just saved the caregiver about eleven trips in the community. That is what we tend to do in the State Veterans Home Program and our medical model Adult Day Health Care Program.

We are keeping veterans out of the emergency room, avoiding hospitalization, and we are certainly delaying placement into skilled nursing facilities. Thank you.

Senator Rick SCOTT. Thanks for what you do. Ms. Sawyer, what is the biggest challenge for caregivers in accessing benefits from the VA?

Ms. SAWYER. I am going to assume you mean caregiver benefits, which are our actually—caregiver benefits actually fall on the health care side, and some of the biggest problems with those really have to do with the evaluation itself.

I would tell you that the law itself doesn't have many problems. The regulation itself has many problems, the implementing regulation, and one of those problems is the language that VA created around each and every time with ADL assistance. It prevents a veteran from having—showing any independence at all.

Should they be able to toilet by themselves once in the entire six months, that prevents them from being eligible for each and every—for ADL assistance, for that ADL because it doesn't meet the standard of each and every time. One of their requests has been that the regulation be changed from each and every time.

However, each and every time is actually in the regulation, not the law, but it was upheld by the courts. Because we have seen VA change this regulation multiple times, we have actually asked that Congress codify that it be regular instruction instead of—instead of how it is broadly worded in the law now. For supervision, protection, and instruction, that standard was also continuous daily care.

A lawsuit, the veteran lawyer lawsuit actually overturned that and created that—said that regular instruction, forced it back into regular instruction, which was the standard in the law. We would ask that that once again be codified within statute so that VA cannot make that change again regulatory.

There is also a standard that VA has put in the regulation that in order to be the higher standard, that a veteran must be unable to self-sustain in the community. We ask that Congress make a little bit of change to that wording, even though it is regulatory language, because currently VA employees don't interpret that correctly.

We have asked it to be evaluated multiple times and what we keep finding is that it continues to be the bane of everyone's existence to get that to that higher level of acceptance. One of the other problems is that folks don't know the options that they have available to them.

If your family caregiver isn't able to perform those duties or needs assistance because let's say you are a tracked and vetted veteran who needs 24 hour a day care, your caregiver, it is impossible for them to provide 168 hours of care per week. The best thing to do would be to have VBC care, home health aide, respite care, a combination of such for those hours.

What we have found is that there are matrixes that VA has in place that govern the amount of hours that you have for GEC programs. Then there are matrixes for the hours for PCAFC programs, and then there are matrixes that govern how those programs interact together. They, however, apply differently to different generations of caregivers currently, and so, it is a confusing maze as to what is available, and to top that all off, those hours differ between different VISN or regional medical communities within the VA.

To go back to an earlier question for just a second, when someone was asking about caregiver wages, there is a mechanism within the VA for your local VA to request—or VISN to request an increase in home health care worker's reimbursement rates. Most VAs, however, do not know how to engage that mechanism.

One way that you could eliminate or lower the shortage of home health care workers is to increase that reimbursement rates so that more people would be willing to take those jobs, and if you look at the current reimbursement rates around VA, in the State of Alabama, the current reimbursement rates are $30.50 an hour—I am so sorry.

The CHAIRMAN. Ms. Sawyer—just wrap up on because we are over time. I am sorry.

Ms. SAWYER. Yes, sorry.

The CHAIRMAN. Senator Scott, thank you.

Senator Rick SCOTT. Thank you.

The CHAIRMAN. We will turn next to Senator Murray.

Senator MURRAY. Well, thank you very much to our Chairmen and Ranking Members for holding this really important hearing today, and I appreciate the testimony from everyone. Mr. Townsend, I want to particularly thank you.

Your story was my family story. My dad was a World War II veteran diagnosed with MS when I was a young teenager, seven kids in our family, and our family went through what your family is. I want to thank you for your service and sacrifice for our country.

I want to thank Lisa for what she, I know, does every single day for your family as well and tell you that is why I have worked so hard to get the Family Caregivers Act passed personally because I know what so many people struggle with, and it is a real challenge.

As Chairman of the Senate Veterans Committee at the time, I worked really hard to implement it to make sure it actually was in line with what our congressional intent was.

This hearing is really important as we evaluate it now, and what all of you have said to us is really important. Mr. Townsend, you answered Senator Casey a little bit, but just tell me, while the VA continues its review now of this program, what do you think we need to particularly focus on?

Mr. TOWNSEND. Particularly with regard to eligibility for the comprehensive program. Once again, I would go back to my previous statement that the VA's current interpretation of the eligibility criteria and requiring assistance with the performance of activity—activities of daily living each time that activity is performed is unrealistic, and as a result, excludes a tremendous number of veterans and caregivers from myself, from what otherwise is a very, very valuable resource, a very valuable program.

Senator MURRAY. Yes, I appreciate that. I totally understand that and that is really helpful, so again, thank you. Thank you for being here and sharing your story, and for what your family has done. I want to turn to Ms. Nieskens. Did I say that correctly?

Ms. NIESKENS. Nieskens.

Senator MURRAY. Nieskens, thank you. Thank you for what you do for your husband and your family and your community and everything in being a care giver.

I wanted to really ask you something that doesn't get talked about a lot, and that is the high level of stress and depression from caregivers, who I know it is especially true for post 9/11 caregivers. Forty percent have met criteria for major depressive disorder.

That is actually twice the amount as pre 911 caregivers and four times the rate than that of non-caregivers. That is really a heartbreaking statistic and I really think it is something we need to focus on.

Can you talk a little bit about what services are currently available for caregivers who need mental health treatment, and what we need to do to really address that?

Ms. NIESKENS. Yes. I agree that that is a startling statistic. I think, you know, that is the reported statistic, but in my experience just being in the caregiver community, I think that the rate is actually higher than that.

One of the things that I think is so important about the PCAFC is the support it does provide to caregivers. There are community functions where they host abilities for caregivers to actually interact with each other to meet other caregivers, and that allows caregivers to feel less isolated.

Being, you know, a caregiver at a young age, I think is something that most people don't expect. That greatly is in contrast to people who are caring for someone who is geriatric, and we certainly expect people of a certain age to have mobility needs, or supervision, protection and instruction needs.

However, to have to care for someone who is in their 20's who has those same needs just is difficult when you are in your 20's yourself, so that certainly is kind of something that the PCAFC does—you know, attempts to do is to support caregivers in learning how to become a caregiver and to connect with each other to provide educational resources.

There is also outside foundations like Quality of Life and Elizabeth Dole Foundation, who also provide caregiver communities and resources and educational calls and so on and so forth for these caregivers.

Ultimately, they are really—I guess, something that Mr. Townsend spoke to was the VA benefit that is allowable if you are a caregiver through PCAFC would be your resource for getting mental health therapy as a caregiver.

If you are just in the program of general care and you do not have a 100 percent permanently and total disabled person, you do not have access to that CHAMPVA, or perhaps that insurance, that would allow you to seek those mental health therapists.

Senator MURRAY. Thank you. Mr. Chairman, my time is up, but I just want to also mention that something that I personally know well is that 2.3 million children live in a household with a disabled veteran.

They provide really unique challenges and responsibilities, and Senator Boozman and I have a bill called the Helping Heroes Act to help establish a new program to support kids who live with a disabled veteran and give them the support they need.

I hope we all look at that as well, so thank you. Thank you all very much.

The CHAIRMAN. Thank you, Senator Murray. We will turn next to Senator Moran.

Senator MORAN. Chairman, thank you. For the first time that I know of, while we have had this joint meeting, and I would say that our witnesses and their testimony are among the most compelling of the many hearings that I have had with veteran issues and aging issues. Thank you. Thank you.

I just want to comment, Mr. Sganga, that I share your view. President Biden's most recent—excuse me, recent budget submission is—requests $141 million for State Home Construction Grant programs. The current list of projects that is in waiting totals $1.2 billion.

This request barely scratches the surface, and I now face this in my own State as we are waiting for new construction project in Northeast Kansas. I just would highlight for the Administration and for my colleagues, this not only delays the care for veterans, but puts the State who is putting money into this project in a difficult situation, planning and financing the project.

Mr. Sganga, I am sure many of my colleagues will work to find further resources beyond the President's request for increases in funding of the State Home Construction Grant program. Thank you for highlighting that.

Mr. SGANGA. Thank you.

Senator MORAN. Let me ask a couple of questions. Ms. Sawyer, I appreciate you working closely with me and Senator Sinema on the Veterans Caregiver Reeducation, Reemployment, and Retirement Act.

Tell me why you think and tell my colleagues why you think it is important for us to consider this legislation and what impact it would have on caregivers' community.

Ms. SAWYER. Thank you, Senator. We appreciate your involvement in creating that Act. It is certainly something that has been a long time coming.

Most personal living caregivers are in situations where the income in their home is unearned. If their veteran was injured and medically retired, they may receive a 100 percent permanent total VA pay and Social Security disability, as well as the PCAFC caregiver stipend. All of that income is unearned.

That means caregivers cannot contribute to Social Security, nor can they contribute to any kind of retirement account. That leaves those caregivers in a very precarious financial State for when their caregiving years and they reach retirement.

The Act, the Reeducation, Reemployment, and Retirement Act that you and Senator Sinema introduced would allow—would study whether or not caregivers would be allowed to contribute to Social Security and their retirement accounts—whether there would be a mechanism that could be created for that to take place.

It would also allow caregivers who had to leave caregiving, either because their veteran passed or they became unable to care give, or their veteran recovered, or their veteran had to go into a State home, it would give them $1,000 per caregiver to renew their employment certifications that they lost due to caregiving, and it would also offer them returnships, which already exist for older Americans within the Department of Labor.

If you have watched The Intern, the movie with Robert De Niro and Anne Hathaway, that is a returnship where Robert De Niro returns into the workplace. That would be the returnship program—we are looking at caregivers, and so, it basically, this bill actually creates a way to secure the financial security for caregivers in their later ages, because as of right now, there is no mechanism for them to be financially secure. Once their veteran passes away, they are looking at being financially destitute in their later years.

Senator MORAN. Ms. Sawyer, thank you for highlighting that. You are a more effective advocate than when I say those things, and I appreciate you putting this into the record for all of us to hear.

Ms. Beck, please give my regards to Senator Dole. We have two Senators that Kansans, consider both of them Kansans, and both Senators used their lives post-Senate career to make a difference in lots of people's lives and particularly veterans. I will be at the Eisenhower Presidential Library tomorrow as we take a look at celebrating, recognizing the importance of D-Day and those who served.

Certainly, Senator Bob Dole in his efforts to recognize World War II Veterans on the National Mall, and Senator Elizabeth Dole in her efforts to make sure that our veterans are cared for correctly, and appropriately, and fully is greatly appreciated in Kansas and across the country. One of the things that—there is times that occur in which I just think, how can this happen?

How can—somebody is bringing me a problem from their veteran perspective and your reaction is, this can't be true. What is going on here? One of them is the dismissal of legacy participants in the caregiver program. It is on pause. We are all pleased about that, but would you highlight, Ms. Beck, that this position of being in no man's land, no person's land in which no answers come, and we just keep waiting?

Ms. BECK. Senator, thank you for that question. I decided a long time ago that the first time—the first time I stop saying, why is this happening, was the first time I shouldn't be doing this anymore.

I think Hannah's story probably explains it best of the emotional, financial uncertainty that has gone along with this program for that legacy cohort of caregivers. There are currently 14,000, approximately 14,000 individuals who are considered as part of that legacy cohort, and that number is dwindling every day due to, unfortunately, deaths, sometime improvement, sometimes divorce, and so, that number is not extraordinarily high and going down. The idea of offering grandfathering to that population of people would be to recognize that they have undergone so many different regulation changes, as Ms. Sawyer pointed out.

That the program intents somehow shifted from seriously injured to severely injured, and there is a significant concern that a number of those legacy cohort who have been found eligible time and time again would then be removed from the program when the new regulations are issued, and so, in recognition of that, and that that was something that the Congress has repeatedly said it was not intended, then the idea of grandfathering that population and moving forward and allowing CSP to focus on actually supporting this population, rather than a divided conversation of eligibility that has gone on for years, would be in their best interest.

Senator MORAN. Thank you.

Ms. BECK. Thank you.

The CHAIRMAN. Thank you, Senator Moran. Senator Tester.

Senator TESTER. Thank you, Chairman Casey. I want to talk about some timelines here to flesh out the way it used to be, and the way it is now, and why. I am going to direct my questions to you, Hannah.

I understand that the challenge here or the problem, from my perspective, has been that there were regulations published almost four years ago, July 31st, 2020, that went into effect October 1st of 2020.

You have been taking care of your husband for nearly 20 years. Can you tell me what it was like before those regulations went into effect?

Ms. NIESKENS. Before the regulations went into effect, I felt supported and I certainly felt like there was a mechanism within the VA where if I needed additional case management or support for Kelly's needs, I knew who to call and who to ask, and I had assurances that I would be able to navigate his care successfully.

Once those regulations passed, and we were dismissed from the caregiver program, as Senator Moran expressed, we feel like we are in a purgatory situation here where we just don't know what the next iteration of these regulations will look like.

Senator TESTER. For further explanation, a regulation was put into effect October 1st of 2020. Nothing changed with your husband. His needs remained the same and potentially even got greater because they are getting older.

Ms. NIESKENS. Correct.

Senator TESTER. Yet, you were removed from the program because of a reassessment?

Ms. NIESKENS. That is correct.

Senator TESTER. That reassessment was required by the new regulation?

Ms. NIESKENS. Yes, that is correct.

Senator TESTER. Were you able to appeal that assessment?

Ms. NIESKENS. Yes. We appealed and we received a letter which basically stated that it was unnecessary to appeal because currently everything was on pause. The entire program was being put on pause due to——

Senator TESTER. The pause wasn't pre-regulation. The pause was post-regulation.

Ms. NIESKENS. Correct.

Senator TESTER. Okay. Tell me what that impact had on your family, the impact of losing that certainty that the Caregiver program gave you before October 1st of 2020.

Ms. NIESKENS. Right.

Senator TESTER. What impact did that have on your family? What the impact did that have on you, and your husband, and your children?

Ms. NIESKENS. Right. Basically it creates a large sense of uncertainty. What does the future look like? Because if this resource for all of these caregivers, including myself, is going away, what re-places it? I don't know. I don't have those answers, and so, it becomes increasingly difficult to fathom how to meet Kelly's needs in the future.

Senator TESTER. Financially, what would it do to you?

Ms. NIESKENS. That would mean that I would lose the caregiver stipend, which means that a significant portion of her income is simply going away.

Senator TESTER. Thank you for that. It is my understanding that the new regulations are there and just haven't been released. That is correct. I see a head nod. That is good enough. Thank you. I want to go over to you, Meredith. Appreciate your comment that we have got some really good bills that actually get things done and get hung up because of politics of the day. You are spot on, and quite frankly, it ain't right.

Good policy is good policy regardless of political party and regardless of who is carrying it, and we ought to look at it from that standpoint. I want you to take a moment to summarize, because you are intimately familiar with the Elizabeth Dole Home Care Act, and I want you to summarize and particularly highlight why this bill is so important for our Nation's caregivers.

If you could refer it back to some of the challenges that Hannah just explained, that would be helpful.

Ms. BECK. Yes, sir. Just to be clear, do you prefer the Elizabeth Dole Home Care Act and the package, or just the Elizabeth Dole Home Care Act? Yes, sir.

Senator TESTER. My mic works. Keep it simple.

Ms. BECK. The Elizabeth Dole Home Care Act, as I mentioned, has probably most importantly for the most severely injured, and most ill, is the provision on removal of the cap.

That is, we have got—I have caregivers who are watching right now, who are waiting every single day to ensure that they are able to get the services that they need in the home to keep the veterans that they care for in their home.

Those are going to be the individuals who have long-term ALS, MS, severe traumatic brain injuries, and without that removal of that cap to, which everyone seems to agree including the VA, that they will potentially have to move to a nursing home because that cap prevents them from getting the care and services inside their home.

Also included in the legislation is the requirement that Veteran Directed program be within every VA medical facility because that program in addition can actually help to support a lot of those caregivers who may not qualify for PCAFC for one reason or another because you are actually allowed to pay your family caregiver under that program.

That is significantly helpful for those who care for an individual who have cognitive disabilities or mental health disabilities that at the moment may or may not qualify for PCAFC and gives them the flexibility and control of who they are hiring in their home because often veterans with those conditions don't want somebody who is unfamiliar in their home, and so, you are able to hire a friend or family to do that. The other provisions in the legislation include mandating that the other programs within the VA that provide those care services, home health aides, home based primary care

are mandated to stay within the VA because while those are a little bit more widely available than Veteran Directed, as we have seen in PCAFC, there is a concern if it is not legislated, it can be taken away.

Senator TESTER. Thank you very much for that explanation and I appreciate all of your testimonies.

The CHAIRMAN. Thank you, Chairman Tester. I will turn next to Senator Ricketts.

Senator RICKETTS. Great. Thank you very much, Mr. Chairman. There are over 16.2 million veterans living in the U.S., including a 111,000 that are calling Nebraska home. These brave women and men have made great sacrifices for our country when they put on the uniform, and I am committed to making sure they have got quality benefits and care that they have earned.

Now, that is why I introduced the Tax Cuts for Veterans Act. The bill would make military retirement pay tax free at the Federal level, just like we did it in Nebraska where we made tax free. Furthermore, across the country, there are more than 6.5 million veterans and military caregivers who provide $14 billion in unpaid labor for America's wounded warriors every year.

Family and others who provide care for veterans spend on average $11,500 of their personal income in out-of-pocket expenses and related to the caregiving of the veterans every year, which is roughly about one and a half times the—higher than what other family caregivers spend.

The U.S. Department of Veterans Affairs offers support and resources for caregivers of veterans enrolled in VA health care through the VA caregiver support program. This program provides caregivers with the access to VA health benefit—or health care benefits, caregiver education, financial aid, mental health services, and up to 30 days respite care.

Only 34 percent of veterans have used their earned benefits at VA healthcare. Ms. Sawyer, over 33 percent of Nebraskans veterans live in rural areas that can create unique challenges for those veterans and their caregivers.

Do the VA caregivers' programs offer any resources that specifically help veterans and caregivers living in rural communities? If so, how do they provide support that addresses the unique challenges those veterans face?

Ms. SAWYER. Thank you for the question. In rural areas, as with caregivers who are in urban areas and that can't get out of the home, there is—or there are mental health programs that are virtual programs that have been put in place by PCAFC. If you are a member of the Program of Comprehensive Assistance for Family Caregivers, you now have access to therapy virtually through that PCAFC program.

You also have options for respite care, in-home or in facility, if they can find a home health aide caregiver—that being the concern. What I was saying earlier is in rural areas where it is difficult to find a home health care workers, there are mechanisms in place where a VA can raise that reimbursement rate, which would make it more attractive and possibly make health care workers more widely available in rural areas.

Because, as Hannah said, trying to get someone to come across the continental divide for $13 an hour is rather daunting. In South Dakota, they have managed to raise the reimbursement rate to $85.05 an hour.

Where in Alabama, it is $30.50 an hour. If your VAs are able to raise that reimbursement rate, you would have better access to those home health care workers. Also, it is difficult sometimes for caregivers and veterans to travel to VA facilities, so certainly community care makes sense.

The concern then is, for the program of comprehensive assistance, is that those records need to be able to get into VA medical records, which is what we see is keeping people from being accepted into the program. It is not that there is a lack of a need for assistance from the—of the veteran. There is a lack of evidence of a need of assistance, and that is partly because those outside records never get into the VA, or their practitioners aren't asked about the specific needs of the veteran. What is examined in PCAFC, in that evaluation process is not actually ever asked about during your yearly exam.

Your PCM never evaluates you for ADL or supervision and protection needs. Those are usually done by specialists, and most of the time you see your specialists in your community rather than traveling 200 miles or 400 miles, in the case of Hannah and her husband in Montana.

You have to have that mechanism to get those records in. At Quality of Life, we actually issue a questionnaire to specialists that would actually document those needs and then have that submitted to the VA by the veteran and caregiver. One of those things is really getting that documentation into the VA.

Senator RICKETTS. Is that really relying on the veterans then for asking that, or is there another way to make sure that that kind of information can be captured when they go see those specialists?

Ms. SAWYER. There is a duty to assist that that exists within VBA, and we have worked with Dr. Richardson and her team to really train her team on duty to assist within VHA.

It would be helpful if Congress could codify duty to assist in the Veterans Health Administration, which would mean that if a veteran and caregiver identify that there are outside medical records that need to be obtained for the evaluation process, it is VA's responsibility to get those records so that they may be considered in that process.

While Dr. Richardson has trained her staff to do that, it is by sheer force of will and leadership power that she gets her team to do that, but that actually doesn't necessarily exist within VHA itself.

Senator RICKETTS. Great. Thank you very much, Ms. Sawyer. Thank you, Chairman.

The CHAIRMAN. Thank you, Senator Ricketts. We will turn next to Senator King.

Senator KING. Thank you, Mr. Chairman. There is an unspoken theme to this hearing as it has unfolded, and that is implementation is as important as vision. We deal in laws up here, but the majority of what you have been talking about today has been implementation of the laws.

We can pass great laws, but if they are not adequately implemented, it ain't going to work, and one of the best examples—Mr. Sganga, you may know about this. Three and a half years ago, we passed a law about domiciliary care at state veterans homes, and we are still waiting for the regulations three and a half years later.

In the meantime, our veterans homes in Maine are losing something like $3 million a year based upon the lack of having this back payment and the implementation. Tomorrow is the anniversary of D-Day, and I have mentioned this before in this Committee, I like to remind people when they tell me how long things are going to take, that Eisenhower retook Europe in 11 months.

We should not be waiting years for regulations to implement the laws that we pass here, so I hope that can be a theme, Mr. Chairman, of this Committee. Not that the VA is—they are bad people, or they are not—they are trying not to enforce the laws.

Somehow we have to break through the delays and the sort of sometimes the nonsensical, such as what you endured Hannah, implementation. Because one of the other themes here is home care is, a, preferred, and b, cheaper.

We should be encouraging it. Mr. Townsend, I presume you would rather be at home than in a hospital or a nursing home.

Mr. TOWNSEND. That is absolutely correct.

Senator KING. The care that you are receiving, even at an adequate reimbursement rate, is still a lot cheaper than what it would be in one of those institutions. Isn't that correct?

Mr. TOWNSEND. That is also correct, sir.

Senator KING. My mother used to use the term pennywise and pound foolish. I guess it must be an English term. In our case, it would be pennywise and dollar foolish. This is a case where we are nickel and dimeing on what is a much, much lower cost alternative. Is that not correct? This is the big picture as I see it. Ms. Beck.

Ms. BECK. Yes, sir. It is—these are human beings, first of all, and as you said, the care in the home is causing in most cases better outcomes, whether better health outcomes or better quality of life.

From the perspective of cost savings, the idea, as has been pointed out previously, that the PCAFC program has higher standards to get to become a part of, then the more expensive—home health program.

Senator KING. I appreciate that. I am going to cut you off because——

Ms. BECK. Yes, sir.

Senator KING [continuing]. we are out of time. I have got this little digital thing that tells me how many seconds I have left. A good—another example is, Mr. Sganga, the recent CMS rules about staffing ratios. HRSA indicate by next year we will have a 78,000-nurse shortage in this country, and yet CMS is issuing rules for increasing staffing when there is nobody to hire.

I know in our—in Maine, we have lost—we are losing four nursing homes so far this year, one this week. We have lost 26 in the last 10 years because mostly lack of staff. These well-meaning regulations, nobody is against adequate staffing levels, but the well-meaning regulations will end up with less care if we lose nursing home beds. Mr. Sganga, do you agree?

Mr. SGANGA. Well, said, Senator King. I think it is a big problem and something we should be looking at nationwide. We think for just skilled nursing facilities alone, we are going to be lacking about 102,000 registered nurses and certified nursing assistants just to meet that——

Senator KING. Just because CMS passes a regulation doesn't mean those nurses are going to magically spring into existence.

Mr. SGANGA. That is correct. That is correct.

Senator KING. Let the record show that you said, well stated, Mr. King.

I just want to emphasize that. This is a very serious problem. I mean, we are losing a caregiver—and what compounds is the caregivers who are staying are being burnt out because they are having to work so many hours.

We really should be—CMS ought to really be talking about how do we surge people into this industry not requiring staffing levels that are going to end up with not lesser care, but no care for veterans and elderly people throughout the country.

Mr. SGANGA. Just one quick example. During the COVID–19 pandemic, I lost 36 caregivers in a single day on September 21st—I am sorry, September 28th, 2021, and that was due to the vaccine mandate. We had to think quick on our feet that the Long Island State Veterans Home. We came up with a new provider, caregiver title of unit assistant.

These are people who are not certified nursing assistants, but can do many the tasks of the CNAs, with the exception of toileting and bathing. It was great. It worked out well for us. They made a little bit less than a certified nurse assistant, and we found plenty of people to fill this particular role.

The sad part for us as an institution is that we got no credit whatsoever from CMS in terms of the payroll based journal and the fact that we had an alternate type of caregiver to provide the care, to be the hands on, to do things like feeding the residents, helping them get dressed, helping make their beds, helping transfer them around the facility.

We were able, as a state veterans home program, to come up with the bodies to provide the care, but sadly, CMS did not recognize this kind of caregiver. When it came to those, the metrics of providing certain amount of providers per resident, they were not counted.

Senator KING. I think we move CMS out of Washington into Poughkeepsie or Bozeman, Montana or someplace so they know what is actually going on the ground. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator King. We will turn next to Senator Hassan.

Senator HASSAN. Thank you very much, Mr. Chair.

Thanks to you and Chairman Tester, and Ranking Members Moran and Braun for this hearing. To all of our witnesses, not only thank you for being here today, but thank you for the extraordinary work you do in your advocacy, and not only for our country's veterans, but for the people who take care of our country's veterans. It is really important and critical work, obviously.

Mr. Townsend, I just wanted to start with a question to you, and I want to thank you for your service in the Army, for your years of work as a physician's assistant, and for your advocacy. The recent FAA Reauthorization Act that President Biden signed into law included a provision that I authored that will expand access to universal charging stations in airport restrooms.

These changing stations will provide individuals who experience disabilities and their caregivers with a safer and more dignified travel experience. I want to extend a special thank you to the Paralyzed Veterans of America and Disabled American Veterans for their support of this provision.

They really helped get it across the finish line, but Mr. Townsend, can you speak to the importance of making travel more accessible for individuals experiencing disabilities, and how it helps them participate more fully?

Mr. TOWNSEND. With regard to travel, the primary obstacle that I faced since I have become a full-time wheelchair user in the community is the distance.

Senator HASSAN. Yes.

Mr. TOWNSEND. Since becoming a wheelchair user, I am reluctant to consider flying.

Senator HASSAN. Yes.

Mr. TOWNSEND. Therefore, I only travel by ground. I have heard the horror stories from many others about what has happened to their wheelchairs during travel. I can't imagine the frustration of getting to your destination, only to have essentially your legs taken away from you, so.

Senator HASSAN. No, I appreciate that, and that is another issue that we are working on and try to address. I just think a lot of people aren't aware that the lack of access to universal changing rooms can be a real barrier for people with disabilities and their caregivers.

Ms. Beck, I want to thank you for a lot of the work of the Elizabeth Dole Foundation, and thank you for the Elizabeth Dole Home Care Act, which I am a co-sponsor. I have been very proud to work with you on.

In your testimony, you touched on the financial strains experienced by caregivers, especially families of veterans who aren't associated with the VA or who have difficulty accessing VA programs.

The Credit for Caring Act, which has bipartisan support, would help relieve some of these financial strains by providing tax cuts to family caregivers who also hold down another job, which is a pretty frequent situation. Can you discuss some of the financial strains that caregivers might face and how these costs impact them and the people who they care for?

Ms. BECK. Sure. Thank you very much. The—essentially it would be two populations probably involved in that question, and it would be those veterans who are associated with the VA and those who are not.

For veterans who are associated with the VA, there are any number of programs and services that could potentially reimburse or pay for needed supplies. However, one, as we have discussed earlier, accessing information about that, knowing about that, having the time to be able to do that is incredibly difficult, so veterans and caregivers often pay out of pocket, even if they are associated with the VA for sometimes for especially—something as large as specially adapted housing modifications or something as small as Tylenol, Advil, a gauze, anything else along those lines.

Outside—for those not affiliated with the VA, they would obviously be then responsible for those out-of-pocket expenses writ large, and so, we are very much strong supporters of S. 3702, that Credit for Caring Act because of those out-of-pocket expenses that they have to pay for.

Senator HASSAN. Well, I appreciate that. I also just want to note that there are caregivers who work part time jobs as opposed to full-time job, so they are earning less as they are also trying to take on this additional work and these additional expenses.

Last question, and it is for you again, Ms. Beck. It is really important that we obviously support people with disabilities in their homes and for being as independent as they can be, and we have talked a lot today about the workforce shortage here.

We face a shortage of professionals who provide critical services for individuals with disabilities, including direct support professionals who can assist with communication, daily tasks, provide job support, and respite to family caregivers.

My colleagues and I have been working to make sure we have the information we need to support these professionals in the work they do. Most recently getting DOL to adopt a job category for direct support professionals so we can actually track how many of them we have. I just want my colleagues to know how important these people are. I have an adult son with severe disabilities.

We have been blessed with a direct support professional who's been with him 35 of his 36 years, and it has just been extraordinary. These are people who are creative, hardworking, make a huge difference, can provide respite care, and can help people be independent.

Ms. Beck, what else can Congress do to strengthen support services for people with disabilities and the caregiving workforce?

Ms. BECK. One, thank you for that legislation because we have all talked about the shortage issues, and we can't do anything about it until you actually have data that shows where they are and what is necessary. Increasing those reimbursement rates, as has been mentioned.

You know, a lot of these people will do this out of the goodness of their hearts, but there are a lot of people who—most people are going to need to be employed and paid at an adequate rate in order to provide the service that is necessary.

The reimbursement rates, as was mentioned earlier with the—especially within the Department of Veterans Affairs and the varying knowledge of the mechanisms by which you can increase those reimbursement rates.

Because while certainly the Elizabeth Dole Foundation is supporting family caregivers, they also rely on those direct support professionals in order to provide the services that you mentioned, and so, this workforce is incredibly important to us as we are trying to make sure that everyone has the services they need in order to stay in their homes.

Senator HASSAN. Thank you very much. Thank you for your indulgence, Mr. Chair.

The CHAIRMAN. Thank you, Senator Hassan. Next, Senator Kelly.

Senator KELLY. Thank you, Mr. Chairman, and thank you to all our witnesses for being here today. My first questions for Ms. Sawyer.

Ms. Sawyer, one of the most sacred promises that our country makes is to care for our servicemembers when they return home, and I am committed to making sure that our country keeps these promises, and that includes ensuring that our veterans' family caregivers have the support they need to care for their loved ones. I have heard from Arizona veteran families that they were removed from the Program of Comprehensive Assistance for Family Caregivers during the expansion rollout.

They had previously qualified, in some cases for years, for this program. While I am glad that the VA has suspended the reassessments and the discharges for legacy participants, I am troubled that some of the folks who are disqualified still do not have an expedited appeals process.

This is an important issue that is impacting Arizona's veterans and also their families. I have continued to urge the VA to fix this. Ms. Sawyer, could you please share your experience with the changes to this program, the program of Comprehensive Assistance for Family Caregivers.

Ms. SAWYER. Thank you, Senator. In the beginning, when the program was first created, the only appeals that were available were clinical appeals, and they were governed under VA's regular clinical appeal guidance.

When the new regulations were written for the Mission Act in 2020, those appeals, clinical appeals shifted to the centralized eligibility assessment team that was created. With the Beaudette court decision, it opened up multiple avenue—more avenues for appeal.

The VA was—VHA was forced to create supplemental claims, higher level review claims, which all occur under VHA, and then there was an avenue opened up for Board of Veterans appeals claims.

None of those had existed prior to the Beaudette case. Also, because decisions had been governed under regular clinical appeals, clinical appeals in the VA did not—do not require justification. They simply can be listed as approved or denied.

In the—with the Beaudette decision, VA did undertake an effort to do an eight-point letter so now we know——

Senator KELLY. Can you describe what the Beaudette decision was?

Ms. SAWYER. Sure. The Beaudette decision was a court decision that basically said—where basically a veteran and his spouse sued the VA to say, you said we weren't eligible for the program, but we don't really know why because the letter that you sent us doesn't tell us why, and we don't have rights to appeal that we would in other situations.

The Beaudette decision then created those extra avenues for appeals, and it created the need for the eight-point letter. The eight-point letter is a letter that a veteran gets that is—basically mirrors a process that is within the VBA, or the Veterans Benefits Administration, that explains exactly why a veteran is denied.

With the setting up of the supplemental claims and higher level reviews, this was something unique to VHA that they had never done before, and so that's kind of what has taken so long. Originally, VA had to completely set up a process—VHA had to completely set up a process they had never been involved in, and then they had to write regulations, write directives, everything administrative the VA does.

Then they had to train a staff how to do that. In the meantime, they were already accepting those appeals but weren't able to act on them. It took them—they were accepting appeals for between 12 and 18 months before they could actually act on them. They are actually acting on them now for supplemental claims and higher level reviews, and so, we are starting to see some decisions come out of there. One of the things with Quality of Life Foundation we do, though, is to say if you had supplemental information that should have been available at the time of your original denial, while we would urge you to go ahead and submit a supplemental claim, we also want you to, if you have been denied from the beginning, we want you to go ahead and submit a new application using all of that evidence so we can go ahead and get you in the program with that extra information, while at the same time, your supplemental claim runs, which would then if you were accepted under your new application, you would be back paid from your supplemental claim, from the approval of your new application back to your date of your original application.

However, there is a little bit of a narrow window that if that information that we consider supplemental should have been available at your first review, you can actually file it as a clinical appeal and have your appeal acted on—within 30 days that would actually get you back paid to your original application.

Recently we have just, at Quality of Life, had that happen with a veteran. Actually, he was an Arizona veteran, and we got him back paid all the way to his denial in 2021 because they had never contacted his specialist.

Senator KELLY. Sorry, I am way over, but do you feel this is moving in the right direction?

Ms. SAWYER. I feel it is moving in the right direction, but slowly.

Senator KELLY. Okay. Thank you.

The CHAIRMAN. Thank you, Senator Kelly. Senator Warnock.

Senator WARNOCK. Thank you so very much, Chairman Casey. Thanks to you and Senator Tester for holding this important hearing today. First Lady Rosalynn Carter, a great Georgian, used to say that there are only four kinds of people in the world. She said that there are those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.

Yet our caregiving infrastructure is falling short for too many, including our veterans. The VA boasts generous caregiving programs for veterans and their families. I am grateful for the work that happens there, but two of our witnesses today confronted challenges with one Federal program intended to financially support caregivers of injured veterans.

The Program of Comprehensive Assistance for Family Caregivers, or the PCAFC. Ms. Nieskens, I am deeply sorry to hear about your husband's grueling experiences with the PCAFC reassessment process. You are the human face of the public policy issue that we are trying to address.

It is important that we are saying to the families that the goal is the veterans in this work. How tell me, how can the VA improve the reassessment process, so veterans won't have to experience the turmoil you and Kelly faced?

Ms. NIESKENS. The regulatory changes that were implemented, which required ADL assistance each and every time. Supervision, protection, and instruction assistance at a rate of continuous daily care were exclusionary. Therefore, needs such as my husband has for neurogenic bowel and seizure care and things like that, while those are very serious and require constant care, regular care, they are episodic.

Therefore because of that, the nature of the disability itself, they were unable to meet the standard of each and every time and continuous daily care. That language is problematic and should be changed.

Senator WARNOCK. Thank you so much. Again, you are the human face. It is a public policy. Regulations often don't match where people actually live. We have to be very intentional about getting it right.

Mr. Townsend, thank you for your service and for being here today as a witness. Like Ms. Nieskens, you and your wife encountered barriers to receiving caregiving support. Can you talk about your experience getting connected to assistance after the VA denied your application for PCAFC?

Mr. TOWNSEND. After we were denied access to the comprehensive program, fortunately we were still able to access most of the benefits Lisa has since been enrolled in the General Program of Caregiver Assistance.

We are able to participate in benefits such as respite care. We really haven't had—put it this way, the main benefit of the comprehensive program is the benefit—at least for me, is the availability of the medical insurance coverage through CHAMPVA. The other benefit, obviously, is the financial support through the stipend.

We can live without the stipend. What made it possible for my wife to retire early and become my full-time caregiver was that availability of CHAMPVA. In our case, since we were denied access through the comprehensive program, fortunately for us, because of the 100 percent permanent and total nature of my disability rating, we were able to access that benefit through other means, not through the caregiver program itself.

Senator WARNOCK. You were not automatically connected to the caregiver program?

Mr. TOWNSEND. That is true, sir. We—it is interesting that as we went through the process of the application of the comprehensive program, in our meetings with, for example, the social worker at the hospital, she explained to us that if we were denied access to the comprehensive program, we still would be able to access the benefits through the general program.

We assumed that that transition from the comprehensive program to the general program would be almost automatic if we were denied access to the comprehensive program. Come to find out, that is not the case. It was only later, when I contacted the staff at the VA in Wilkes-Barre, that we realized that Lisa was not formally enrolled in the basic or general caregiver program.

She is now, but that was not an automatic transition. Whatever the Committees can do to work with the VA to ensure a more seamless transition between the comprehensive program and the general caregiver program, if you are denied access to the comprehensive program, would be of tremendous benefit.

Senator WARNOCK. You both paint a picture of a fractured system where the constituent parts do not talk seamlessly to one another, and so clearly there is room for improvement in addressing the need for continuity of care, making sure veterans don't fall between the tracks.

Thank you so very much for your witness and your testimony—I think, brings this kind of issue into clear focus and helps us to see the work that we have got to do. Thank you for your service.

The CHAIRMAN. Thank you, Senator Warnock. I will turn to Senator Cassidy.

Senator CASSIDY. Thank you all. You know, I am a physician. You will see that reflected. You can tell that Warnock is a pastor, he went over. You know what I am saying?

Senator WARNOCK. Everybody went over.

Senator CASSIDY. Well maybe that is——

The CHAIRMAN. We had a lot of overs today.

Senator CASSIDY. A lot of overs. That is good. It is an important topic. I thank you for doing that. I am a physician, Mr. Townsend, and I noted that you had said that in your testimony—if people have already asked my questions, I apologize. I have been running around.

This is my sixth thing I have done today. I apologize for not hearing what their answers were, but you spoke about your ineligibility for the Program of Comprehensive Assistance for Family Caregivers because you are 100 percent service related disability didn't require assistance each time the activity is performed.

I am a physician, not a neurologist, but I remember from med school that MS waxes and wanes, and so, there is other conditions which wax and wane. Tell me, how has that played? Is that still an issue? What is the way to approach the VA regarding this?

Mr. TOWNSEND. Thank you very much for that question. You are absolutely correct that medical conditions like mine, like multiple sclerosis is often associated with symptoms that tend to wax and wane, can be severe on certain occasions and less severe. That has certainly been my experience with the condition.

I am confident, that there are many other, veterans out there in similar circumstances. As we talked about earlier, the VA's current requirement that the veteran require assistance with the performance of certain activities of daily living each time or every time that activity is performed is restrictive and has excluded not only myself, but I am sure many other veterans like me, from participation in this very valuable program.

Senator CASSIDY. Is there the solution to propose? Ms. Sawyer, I see you nodding your head.

Ms. SAWYER. Yes, sir. One of the solutions would be that you remove—that VA removes each and every time from the language of the regulation. One of our requests has been that Congress actually codify that it needs to be regular assistance with ADLs, because it was—in the regulation, it was regular assistance with the ADLs until VA reinterpreted the regulation.

Senator CASSIDY. I see.

Ms. SAWYER. We would like—that is why we would like to ask Congress to codify that language.

Senator CASSIDY. Let me ask you, was there an issue with fraud? Why did they reinterpret it?

Ms. SAWYER. VA made a move in 2017 to what they said was to realign the program with other VA geriatrics and extended care programs. Unfortunately, what they did was make this program actually even harder to get into than those other programs. There were actually not—there is this rampant rumor, an anecdote that there is a lot of fraud within this program.

There has not been proven to be a lot of fraud within this program. Has there been some? Sure. Just like you see in every VA program. It is not rampant like it was—like it has been suggested.

The one way that I have been—I would be curious to talk to Mr. Townsend about that you can get around that each and every time standard is that if a veteran then needs supervision with those activities of daily living, they can be—those ADLs can be considered under supervision, protection, and instruction. In the beginning, a lot of VA staffers were not trained to look at it that way under this new regulation.

I would be curious to know if that—if he ever appealed and had it looked at through the lens of supervision protection——

Senator CASSIDY. Okay. I am going to make that a question for the record, just because I want to ask Ms. Beck something.

Ms. SAWYER. Yes. Absolutely.

Senator CASSIDY. Ms. Beck, I had coffee with a woman who is now my age, 66, but I remember when she was 17, and so, and a lot happens in the interim, and one of the things that hasps happened is that she has a son who has been mentally ill, and he is now 40—diagnosed when he was 27. It was—and she said at some points she just felt like giving up. Just like, I can't do it.

We can feel that, right. You mentioned here the issue of support for the supporter. If you had to put your finger on the critical gaps in mental health services for the caregivers, where would your finger land?

Ms. BECK. Sir, thank you for that question. Yes, it is a significant problem that we have seen quite a bit of at the Elizabeth Dole Foundation. I think that one of the major things we recommend in our testimony just to start to impact that problem is that, you know, it has been great. The PCAFC was able to now offer mental health services for those who are eligible for that program, but that is a small minority of the population.

In our testimony, we recommended that it be expanded to those in the general program as well to at least, again, you know, take a larger bite at the apple of addressing that. I do think also that, you know, we haven't—we can also try to remove some of the burden that is felt by those caregivers by addressing some of the care coordination issues that are rampant, speaking of things that are rampant, within the VA.

In almost every case that I have run into in years of doing this and those with the foundation, lack of care coordination has been at the root of the problem for both the veteran and the caregiver.

The amount of time that the caregiver has to spend in navigating those services, and the frustration and the anger of consistently having to repeat and prove your issues, and the needs is weighing very heavily on both caregivers and veterans themselves.

Senator CASSIDY. My friend, she said, every year I have to go and reestablish that it is true that my son has been disabled for mental illness for 20 years. It is like, why? Now, I get you recover from some things, but there is some things you do not recover from. It does seem like we could make some distinctions of that in our law. I got to apologize to Warnock. I went over longer than did he. Thank you all very much.

Ms. BECK. Thank you.

The CHAIRMAN. Senator Cassidy, thank you for your questions. I will just have one question before we wrap up, and I really appreciate the testimony of all of our witnesses. I wanted to go back to you, Mr. Townsend. You are a retired physician assistant and someone who is deeply engaged with other veterans in your community through the Paralyzed Veterans of America and volunteering at the local VA medical center at Wilkes-Barre.

Even with your extensive knowledge of the health care system and your veteran connections, you had to ″self-educate″ on the VA benefits that were available to you. Multiple veterans organizations have said they received no direct outreach from the VA about the caregiver support program.

Often, veterans seem to have heard of the program from a veterans service organization or from a fellow veteran, not from the VA. I am concerned that this haphazard approach—and that might be an understatement.

This haphazard hazard approach to outreach will leave too many families that are eligible in the dark about the Caregiver Support Program. Veterans and their caregivers deserve to know when there is a program that can provide them with the support.

I would ask you, how did you find out about the caregiver support program? That is number one, and number two is, how do you think veterans who are not health care experts are connected to other veterans as you are, can find out about these programs and how to navigate them.

Mr. TOWNSEND. The haphazard approach that you described, Senator Casey, certainly has been my personal experience. Most of what I learned through—it was through a process of self-education, by talking to fellow veterans, by working with veteran service organizations like PBA, by looking at online resources.

Some of those are online resources, in fact, are produced by the VA. It is interesting that one of the things that seemed commonsense to me, because I agree with you, that the VA medical system can be intimidating, even for somebody with health care experience.

One of the first things I thought of, that would occur, would be that when you—particularly when you are new in the system, that you would have an opportunity to sit down with maybe a social worker at the VA and they would explain to you the benefits that you are eligible for, but that certainly was not my experience.

If I could make one recommendation, it would simply be to—for the VA to better educate the beneficiaries of their care, of all the services that are currently available to them, because that communication of information I think often doesn't occur, at least not in the way that it should.

The CHAIRMAN. Well, that is a reasonable proposal. We need a few of those around here. I wanted to close with a statement, and we will wrap up, and all of you have been very patient with your time and your experience and your expertise, and we appreciate you being here with us.

As we heard today from our witnesses, the VA's Caregiver Support Program is a vital and life changing benefit for so many families, but too many veterans are not able to get the benefits that they have earned, and that they and their families deserve. Our service members, and veterans put their lives on the line every day to ensure that America remains the land of the free. We rely on their commitment.

When they are wounded or when they are injured or ill, they need our support, and they need our commitment. With 5.5 million military caregivers in the United States, it is imperative we do everything we can to support the critical workers providing family and other paid caregiving.

As one family in Pittston, Pennsylvania, right near my hometown of Scranton, shared in a statement. For the record, for today's hearing, ″if our son T.J., who lost his eyes and one third of his brain in service to our country, if he is disqualified, then we are left wondering who truly qualifies for these services.″

We must do more to provide support to veterans and caregivers so that they can do their work and are supported fully in the process. We need to provide easier and clearer access to information about the caregiving and long-term care, services and support that the VA offers, as well as easier navigation and support in the application process.

As we heard from Mr. Townsend, veterans shouldn't have to rely upon the word—upon word of mouth to find out about these life changing benefits. We also need to make sure that the VA has the resources that it needs, including a strong, stable workforce to provide veterans with the best and most efficient care, including caregiver support services.

I look forward to working with my colleagues to address the needs of our millions of veterans and their family members who are in need of long-term care. I know we will have a number of statements for the record for this hearing—I should say closing statements for the record for the hearing, and we will enter those into the record at the appropriate time.

I want to once again thank all of our witnesses for contributing their time and their expertise today. I will be entering, and I am just holding up a folder with—containing five written statements for the record.

These are from Pennsylvania veterans who receive long-term care services and support from the VA, or who are enrolled in the Family Caregiver—Family Caregiving Program.

The CHAIRMAN. Last, if any Senators have additional questions for the record for witnesses, or statements to be added to the record, the hearing record will be kept open for seven days until next Wednesday, June the 12th. Thank you all for participating today, and this concludes our hearing.

[Whereupon, at 12:06 p.m., the hearing was adjourned.]

APPENDIX

Opening Statements

OPENING STATEMENT OF SENATOR MIKE BRAUN, RANKING MEMBER, SPECIAL COMMITTEE ON AGING

American veterans represent the absolute best our country has to offer, and they deserve the absolute best when they return home.

Of our country's 16.5 million veterans, nearly half are 65 years or older and 3.2 million have a disability rating over 30%. Given these dynamics, it is essential that we improve how we are caring for our aging and disabled veterans.

Historically, state veterans homes were the only option for aging and disabled veterans in need of skilled nursing care.

Now, we have built a robust infrastructure of 165 facilities across all 50 states by working in partnership with states. However, increasingly both older and younger veterans want to remain in their homes while receiving care, often from their families.

When younger post-9/11 veterans returned home wounded but not fully in need of traditional institutional care, Congress had to reevaluate its care options. Congress established the VA Caregiver Support Programs (CSPs) to better meet the emerging needs of this new era of veterans. These programs provide family caregivers with a menu of services from education to respite care.

Since 2011, the VA CSPs have helped relieve stress for tens of thousands of wounded veterans and their caregivers. In 2020, the Biden Administration published a rule that tightened eligibility requirements for the Program of Comprehensive Assistance for Family Caregivers. This resulted in many participants being kicked off the program and no longer receiving critical caregiver support.

I joined Senator Tester in introducing the CARE Act (S.1792), which pushes back on VA while improving operation and oversight of the Caregivers Program. I was pleased to see that our bill was included in the bipartisan Veteran's package currently making its way through the House. This isn't the only improvement Congress can make to the VA Caregiver Support Programs.

As we are facing critical shortages in the caregiving workforce, Congress and the VA must ensure veterans have access to consistent and reliable respite options. One way we can do this is by leveraging the existing resource available in our State Veterans Homes. Veterans should be able to use their respite hours to access services including in-home paid caregivers and State Veterans Homes Adult Day Health Centers. These health centers provide more robust services for veterans than traditional independent adult day cares and State Veterans Homes are well-positioned to scale them quickly if given the flexibility to do so.

By reinstating the State Veterans Homes construction flexibilities and allowing them to open satellite locations at existing medical and long-term care facilities, Congress can swiftly and efficiently address the respite needs of veterans and their caregivers.

I am committed to working with the Senate Committee on Veterans Affairs to reinstate those flexibilities and ensure all veterans have access to high-quality respite care.

I look forward to the discussion and insights our panelists bring today.

Prepared Witness Statements

U.S. SENATE SPECIAL COMMITTEE ON AGING

″HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS″″

JUNE 5, 2024

PREPARED WITNESS STATEMENT

Peter Townsend

Chairman Casey, Chairman Tester, Ranking Member Braun, Ranking Member Moran, and distinguished members of the Committees. Thank you for the opportunity to speak with you today regarding my experiences with the caregiver support services available through the VA and its Caregiver Support Programs.

My name is Peter Townsend. I'm currently 60 years old and live in Auburn Township, Susquehanna County in northeastern Pennsylvania with my wife Lisa, who is also my caregiver.

I served in the United States Army on active duty from 1982 to 1986. After completing infantry and airborne training, I was assigned to units in Ft. Lewis, Washington, Camp Kitty Hawk in the Republic of Korea and Ft. Bragg, North Carolina.

Following my discharge from active duty in 1986, I used the educational benefits I earned through the Veterans Educational Assistance Program to pursue an education in healthcare and earned degrees in nursing and as a Physician Assistant. I went on to work for over two decades as a Physician Assistant, mostly in primary care, before retiring prematurely in 2014 due to complications of Primary Progressive Multiple Sclerosis.

When I was initially diagnosed with Multiple Sclerosis (MS) around 2007, my symptoms were mild and progressed slowly. Unfortunately, as the disease progressed, I began to experience significant difficulty with mobility, as well as difficulties with fatigue, cognition and bowel and bladder dysfunction, among others. Today, I rely upon a power wheelchair when out in the community and a walker to ambulate short distances in the home.

Through casual conversations with fellow veterans, I learned that MS was a medical condition that the VA recognized as a presumptive, service-connected disease.[1] At the urging of my veteran friends, I filed a claim with the VA for disability in 2019. With the assistance of Paralyzed Veterans of America, of which I am a member, I was successful with my claim and am now rated 100 percent service-disabled due to MS. After receiving my determination, I enrolled for the first time in VA healthcare.

As my symptoms progressed, I began to rely more and more on the assistance of my wife, Lisa. My experience with MS has been that of unpredictability with a wide variation in symptom severity. Most days are ″good days″ where I am able to function fairly independently. However, when confronted by a flair or ″pseudo exacerbation,″ often as the result of a febrile illness or other acute condition, I can become temporarily incapacitated. During these times, I rely very heavily on Lisa for assistance with a variety of activities of daily living to include intermittent catheterization, transfers, toileting, personal hygiene, dressing and meal preparation. Fortunately, these episodes are infrequent and short-lived, lasting from several days to a week or two. Even though infrequent, I have had no less than three of these episodes already this year.

Prior to leaving the workforce, Lisa had been working as a Case Manager for Keystone Community Resources in Montrose, Pennsylvania, a company that provides services to adults in the community with intellectual and developmental disabilities. Eventually, as my condition deteriorated, we decided that Lisa would retire early from her position in June of 2022 at age 61, in order to be my full-time caregiver.

Once again, primarily through a process of self-education and online resources, we learned of the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC). So, when the VA opened eligibility for the program to veterans of all service eras in October 2022, we applied. Unfortunately, we were informed the following month that our application had been denied. As I understand it, we were denied entry into the program due to the VA's determination that I did not require assistance with the performance of certain ″activities of daily living″ each time that activity was performed, or that the level of assistance did not ″rise to the level required to participate in the PCAFC″.

This strict interpretation of the eligibility criteria by the VA is of particular concern to veterans like myself with medical conditions like MS whose symptoms are

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[1] VA Benefits and Services for Veterans with Multiple Sclerosis - Multiple Sclerosis Centers of Excellence

highly variable and unpredictable. My concern is that because of this current interpretation by the VA of the eligibility criterion for the Program of Comprehensive Assistance, many other veterans like me and their caregivers are being denied access to this extremely valuable program. I'm confident that I am not the only one!

After our application for the comprehensive program was denied, Lisa was eventually enrolled into the Program of General Caregiver Support Services (PGCSS). However, this transition to the PGCSS was not automatic and we went for some time thinking that we were enrolled in the general program, although we were not.

One of the most valuable benefits of the Program of Comprehensive Assistance, is the availability of medical insurance coverage for caregivers through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA). The availability of CHAMPVA was the only way we could afford for Lisa to retire early and fortunately for us, she qualified for coverage under the program due to my permanent and total disability rating. This option, however, is not available to those veterans denied Access to the PCAFC, whose disability rating is less than 100 percent, permanent and total.

Although the Program of General Caregiver Support Services offers fewer benefits than the PCAFC, one significant benefit it does offer is respite care. We were able to utilize this benefit earlier this year when Lisa underwent total knee replacement surgery in January. The Spinal Cord Injury and Disorder (SCI/D) Clinic Coordinator was able to arrange for me to be admitted to the Community Living Center at the Wilkes-Barre VA for three weeks while Lisa recovered from her surgery. Lisa knew that regardless of what was happening with my health, I was being cared for so that she could focus on her recovery. I can't emphasize enough how valuable the respite care benefit was to our family at that time, and it's comforting to know that it will be there if we need it in the future.

Throughout this journey, our goal has been, and will continue to be, to create an environment that allows me to live in our home as long as possible and to avoid the need for long-term care. Participation in the VA Caregiver Program helps us to achieve that goal. The reality is that my current level of disability is such that I am no longer able to live independently and would require placement in an assisted-living facility were it not for Lisa's efforts.

I would like to make it clear that Lisa and I remain very grateful for all the benefits that we have received and continue to receive! These include, but are not limited to, the Home Improvements and Structural Alterations (HISA) grant that we used last year to partially fund the complete remodel of our master bathroom to make it fully wheelchair accessible, as well as other grants and services that I am eligible for but have yet to utilize. We thank the Veterans Administration for the services that they have already provided and the excellent care that I continue to receive.

One of the ways that I am able to show my gratitude is by volunteering at the Wilkes-Barre VA Medical Center. For over two years I have served as a Red Coat Ambassador, once a week, as a way of serving my fellow veterans and by giving back to the organization that has done so much for me.

The system is not perfect, however, and there will always be room for improvement. I encourage the Committees to work with the VA to ensure a more seamless transition to the PGCSS following denial of the PCAFC. Also, there needs to be better communication to veterans of the resources and benefits available through the VA, particularly those newly enrolled in VA healthcare. Lastly, taking care of a loved particularly those newly enrolled in VA healthcare. Lastly, taking care of a loved Finally, as a member of PVA, I would be remiss if I did not mention the need for Congress to pass the Elizabeth Dole Home Care Act (H.R. 522/S. 141) which will further improve upon the resources and services available to veterans like myself and their caregivers. This legislation addresses some of the most urgent needs of veterans and the people who care for them, and they should not have to wait any longer. I urge you to pass this bill as quickly as possible.

I thank you for this opportunity to share our experiences and look forward to answering any questions that you may have.

U.S. Senate Special Committee on Aging
″Heroes at Home: Improving Services for Veterans and Their Caregivers″″
June 5, 2024
Prepared Witness Statement
Hannah Nieskens

Chairmen Casey and Tester, Ranking Members Braun and Moran, and Members of the Senate Special Committee on Aging and Senate Veteran Affairs Committee, I am honored to testify today. My name is Hannah Nieskens, and I have been married to my husband, Kelly, for twenty years. I have been his caregiver for eighteen and a half of those years.

In 2005, Kelly was a 23-year-old Army infantryman deployed to Forward Operating Base McHenry in Hawijah, Iraq. Hawijah, located in the Sunni Triangle, was a hotspot for insurgency activity during the Iraq War. On May 4, 2005, during a routine patrol, Kelly's Humvee was struck by a large IED. This was the fifth time a roadside bomb had hit his vehicle since his arrival in November, but this time the damage was catastrophic. The explosion left the Humvee disabled in an 11-foot-wide crater, and the squad members, including Kelly, were knocked unconscious.

Upon regaining consciousness and exiting the vehicle, they came under sniper fire. Kelly was struck by a large-caliber rifle round that traveled through his ribs, hit his armored plates, and ricocheted multiple times through his torso before lodging near his spine. He survived thanks to the extraordinary efforts of medics, doctors, and the evacuation team.

Kelly was honorably discharged and did not receive medical retirement or Servicemembers' Group Life Insurance Traumatic Injury Protection (TSGLI). I believe this was partly because he was under a stop-loss order when he was wounded, as his formal separation date had already passed, and partly because he was a National Guardsman activated to active duty Army service and was unaware of these benefits.

Upon reintegration into civilian life, Kelly's physical limitations were evident: mobility issues, painful scars, nerve damage, neurogenic bowels, migraines, seizures, and hearing loss. However, his cognitive impairments presented the greatest challenges, including executive functioning issues, memory deficits, mood dysregulation, impaired judgment, impulse control problems, chronic sleep deficit, anxiety, difficulty establishing and maintaining relationships, and inability to concentrate. In 2011, after being referred by Kelly's VA psychiatrist, I was accepted into the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC), which has been a lifeline for us. The support and assistance from the PCAFC staff have been invaluable in managing Kelly's care and providing support and educational opportunities for me; I have nothing but good things to say about the VA Montana PCAFC staff.

However, I did have concerns about Kelly's healthcare. The Veterans Health Administration (VHA) doctors had prescribed numerous medications to manage his symptoms with limited success. In 2016, I shared my concerns with another caregiver I had met through the PCAFC, suspecting that many of Kelly's symptoms were due to TBI rather than PTSD. PTSD typically improves with treatment, but TBI symptoms often worsen over time as the brain ages. Kelly's symptoms had steadily worsened. My friend recommended UCLA's Operation Mend program, which provides comprehensive assessments for veterans. Kelly was accepted to the UCLA program, and in June 2016, we traveled to Los Angeles for an 8-day evaluation. Despite the neurologist's initial expectations that a brain MRI was unlikely to show anything of significance 11 years after the injury, an MRI revealed twelve lesions on Kelly's brain, some as large as a dime, confirming a significant TBI from the blast. I recall the doctor asking Kelly if he remembered any symptoms from 2005. He said he remembered having tremendous headaches for 3-4 months and that his helmet would not fit on his head for a few weeks. However, at the time, the care for his gunshot wounds took priority.

The discovery of brain lesions, the results of UCLA clinical neuropsych testing, and a UCLA spine evaluation enabled us to reopen Kelly's Veterans Benefits Administration (VBA) benefits claim to address missing and low disability ratings. Kelly's (VBA) initial TBI disability rating had been 10%. I attribute this low rating to the lack of a comprehensive neurological exam and the absence of a brain MRI. After a thorough review of 29 sets of medical records spanning 2004-2016, Kelly received additional benefits backdated to December 2016. These included a 100% permanent and total rating, a 70% TBI rating, aid and attendance benefits, a 50% rating for migraines, and service connection for neurogenic bowels. I was also appointed his VA fiduciary due to the cognitive deficits of TBI, including impaired judgment and memory, which rendered him incompetent by VA definition.

In 2021, ten years after entering the VA's Program of Comprehensive Assistance for Family Caregivers, we were notified that Kelly needed a reassessment for our eligibility for the PCAFC program. Honestly, given the magnitude of Kelly's needs and the fact we had long been established with the program, I trusted that this process would only reaffirm what was already known. How wrong I was. The reassessment process was grueling and heartbreaking. During a nearly two-hour virtual appointment with a contracted occupational therapist, Kelly and I had to painfully recount every limitation he faces. When Kelly became emotional while discussing toileting needs due to neurogenic bowel, the examiner was unable to see his tears, and she pressed on.

I also had to try and quantify everything I do as a caregiver. This is difficult when you have spent nearly two decades as a caregiver because all of the support I provide is so integrated into our daily lives. I did my best to recount my caregiving tasks, including personal care assistance with activities of daily living (ADLs), medication management, meal preparation, transportation, behavioral and emotional support, mobility assistance, financial management, home adaptation, and advocacy and support with healthcare providers.

The resulting report was incomplete and inaccurate. Perhaps the most egregious error was a statement that read in part, ″He has had a gunshot to the head.″ The report also missed critical diagnoses and VBA disability ratings. For example, Kelly's VBA rated disability of status post through and through gunshot wound injury, coded with VBA diagnostic code 5320 for muscle injuries due to wounds caused by gunshots or other missiles, was recorded in his VHA records as superficial scars and back muscle impairment, as there was no equivalent diagnostic code in the VHA medical record system. His VBA rating for neurogenic bowel was recorded in the VHA system as irritable colon. Perhaps most importantly, his TBI disability, including the rating of 70%, was completely missing in the VHA record as a rated service-connected disability.

I did my best to advocate to get these disability codes fixed before submission of the reassessment document for the Centralized Eligibility and Appeals Team (CEAT) review. Despite the best efforts of the VA staff, the incorrect diagnoses could not be corrected due to inequivalent diagnostic codes between the VBA and VHA systems.

The reassessment outcome was stunning. Ironically, on March 23, 2022, the very day of the Senate Veteran's Affairs Committee hearing entitled ″Honoring Our Commitment: Improving VA's Program of Comprehensive Assistance for Family Caregivers,″ a nurse at the Centralized Eligibility and Appeals Team (CEAT) reviewed Kelly's and my case and determined that ″the Veteran and caregiver do not meet eligibility criteria.″ We were issued a letter dismissing me from the program.

I have wondered, due to the timing, if this person actually did a thorough review of the reassessment report or if, on the morning of March 23, the CEAT staff hastily ejected a number of program participants, anticipating that the Senate hearing may result in a halt to all impending evaluations.

Regardless, this decision highlighted several issues:

1. Data Discrepancies: VBA and VHA records are stored in separate databases, leading to incomplete or incorrect ratings and disability information in the VHA record.
2. Process Discrepancies: A thorough VBA assessment, considering extensive evidence from multiple medical sources over a decade, contrasted sharply with a superficial VHA evaluation based on a one-time exam with an examiner unfamiliar with Kelly's needs and limited records review spanning six months.
3. Outcome Discrepancies: The VBA examination process identified a need for aid and attendance ″to protect the Veteran from the hazards or dangers incident to the Veteran's daily environment.″ The VBA also determined a rating of incompetency due to ″cognitive deficit as of TBI.″ The VHA reassessment determined that a ″daily need for supervision, protection, or instruction for a minimum of six continuous months″ did not exist.
4. Penalizing Stable Needs: Veterans with stable needs or those receiving private care are disadvantaged in reassessments due to fewer medical records. The lack of frequent doctor visits should not be interpreted as an insignificant need. Veterans with stable needs are less likely to doctor frequently and, therefore, do not have an extensive health record.
5. Penalizing Access Issues: VA Montana Healthcare strives to provide service to veterans but faces chronic understaffing and a lack of specialty care providers.

Kelly has not seen a VA clinical psychologist, so there are no notes in the VHA system from such a specialist about his cognitive impairments for supervision, protection, and instruction (SPI). Similarly, he has not been seen by a VA occupational therapist to document his physical assistance needs. The neurologist who recommended aid and attendance for Kelly retired this year, transferring his care to the only other VA neurologist in the state, located over 200 miles away. Kelly used to receive care from a VA psychiatrist via telehealth, but she also retired, and his medication management was transferred to a pharmacist via telehealth. Through community care, Kelly receives regular spinal injections from an orthopedic surgeon for mobility and visits a community care chiropractor for pain and mobility needs. Due to VA staffing challenges and shortages, veterans may not develop comprehensive VA medical records with internal notes regarding ADA or SPI needs. In our case, I believe the lack of a detailed VA medical record in the six months preceding the evaluation worked against us.

6. VBA Ratings Do Contribute to Program Access: The only positive outcome from the PCAFC reassessment was that adding Kelly's 70% TBI VBA rating to the VHA data system made him eligible for additional support. In September 2022, a VA Polytrauma/TBI program caseworker contacted us regarding his TBI and offered additional services for which he was eligible. When I explained that his TBI had occurred in 2005, the caseworker was initially surprised that he was only now being identified for needed care. ″Better late than never,″ she said.

Considerations and Recommendations:

1. Presumptive Need: By its very nature, aid and attendance and serving as a fiduciary are forms of supervision, protection, and instruction. I believe certain VBA ratings should, by their nature, be presumptive of caregiving needs, such as incompetency, aid and attendance, or housebound status. I believe it would save the VHA a whole lot of time, energy, and expense if it utilized the VBA records as part of its assessment process to eliminate reassessments for veterans with presumptive ratings and conditions.

2. Threshold of Need: Define in law that ADL assistance does not need to be ″each and every time,″ as currently stated in the regulation and upheld by a court as an allowable interpretation. The current definition is exceptionally problematic for certain conditions. For example, a diagnosis of neurogenic bowel and treatment for encopresis with constipation and overflow incontinence requires substantial and timely hygiene assistance. However, by their nature, these conditions are episodic and irregular. Similarly, the threshold for supervision, protection, and instruction assistance should be ″regular,″ not ″continuous daily care.″ Requiring ″regular″ assistance with certain SPI needs to maintain personal safety can also be episodic. For example, acting as a fiduciary involves continuous, regular responsibilities, but not necessarily daily tasks. Likewise, providing care during a seizure episode or dissociative fugue state is continuous but not daily, yet these situations demonstrate a ″regular″ need for safety and protection assistance.

3. Costlier or Unavailable Alternatives: Removing caregivers from PCAFC could lead them to seek more expensive care options for their veterans, including home health aides through Medicare or the VA programs. Utilizing home health aides instead of caregivers exacerbates the significant nationwide shortage of home health aides. In addition, the availability of home health care aides, especially in rural areas, like our town in Montana, which has a population of 68, is none to few.

4. Reassessment Volume: Approximately 16,000 people need a new PCAFC reassessment before September 2025. I fear another rushed process will be neither comprehensive nor valid, placing undue emotional strain and stress on veterans and caregivers. I believe reassessments for PCAFC should not be annual. Instead, reassessments could occur when a veteran's needs change significantly, as determined by a doctor or the PCAFC team.

5. Comprehensive Evaluations: Specialists should be involved in reassessments. Medical records from providers outside the VA, whether through community care or private care, should be obtained and considered. Given the high staff turnover within the VA, records may need to be reviewed for a period longer than six months to find the most accurate information.

This May marked 19 years since Kelly's injury. Over these years, I have learned that aging significantly amplifies the challenges faced by people with disabilities. As the brain ages, it naturally undergoes changes that can affect cognitive function, memory, and overall neurological health. In individuals with a traumatic brain injury (TBI), these aging processes can be accelerated, leading to a more rapid decline in cognitive abilities and exacerbating existing neurological issues. Similarly, the body's physical aging process impacts mobility and other bodily functions. Muscles weaken, joints become stiffer, and the risk of developing chronic conditions grows.

These increasing needs make daily activities for people with disabilities more challenging and require continuous, specialized care.

Withdrawing support for disabled veterans with high needs and their caregivers is incomprehensible. As the brain and body age, the need for consistent and comprehensive care for our veterans only intensifies. Removing the critical support systems provided by programs like PCAFC not only jeopardizes the health and well-being of veterans but also places an undue burden on caregivers, making it increasingly difficult to manage these complex and evolving needs.

Thank you for allowing me to share my story. I am happy to answer any questions you may have.

U.S. SENATE SPECIAL COMMITTEE ON AGING

″HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS″″

JUNE 5, 2024

PREPARED WITNESS STATEMENT

Andrea Sawyer

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

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

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

Congressional Intent vs. Implementation

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

As a result of this new legislation, the Department of Veterans Affairs drafted new implementing regulations, including revising the criteria for admission and developing new application, assessment/evaluation, and approval/denial processes. As a result, and due to the complexity of the new evaluation and appeals processes, QoLF refocused its efforts and created educational resources for those applying for the program and assisted in the preparation of clinical appeals for those who have been denied. Through our work, our staff has developed a unique understanding of the operational and policy questions and challenges surrounding the roll-out and implementation of the post-MISSION Act PCAFC program. However, let me be clear QoLF is NOT offering any clinical judgement, we are simply assisting the caregiver and veteran to identify factual errors and omissions in the record, gather documents supporting their case, and articulate their arguments in clear, concise language.

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

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

Where We Were:

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

1. Language in the regulation requiring assistance ″each and every time″ an Activity of Daily Living (ADL) was completed;
2. Language in the regulation requiring ″continuous daily care″ for supervision, protection, and instruction;
3. Language of serious injury v. catastrophically injured;
4. Language surrounding the ″ability to self-sustain in the community″ with respect to tier determination;
5. The length of time of the history of the veteran's condition being evaluated in the record (past twelve months);
6. Gathering of the outside records and specialists' input; and
7. Lack of evidence provided by the CEAT (Clinical Eligibility Assessment Team) decision to understand the discharge or level decision rendered.

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

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

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

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

Where We Are:

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

1. *″Each and Every Time″:*The legality of the requirement that a caregiver must assist a veteran with an Activity of Daily Living (ADL) ″each and every time″ it is completed for eligibility in the program has been reviewed. The Sheets decision ruled that this strict interpretation of assistance with ADL's under VA's regulation was allowed under the legislation creating the PCAFC. However, VACO CSP has acknowledged that this strict interpretation is keeping veterans, especially older veterans, out of the program and penalizing veterans for being able to do anything for themselves, impeding progress in rehabilitation and potentially causing harm. Changing the ADL language to ″regular assistance″ would align the language with the frequency of assistance under other VA programs, as well as allow veterans to

function at their highest potential when able to without fear of losing their caregiver. Changing this language will require a regulation change.

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

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

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

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

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

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

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

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

4. *″Unable to self-sustain in the community″:*For purposes of determining the tier level of the veteran, the Caregiver Eligibility Team (CEAT) has to answer the question, ″Is the veteran UNABLE to self-sustain in the community?″ Due to the

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

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

5. *Review of past twelve months of records' review:*In our March 2022 SVAC testimony, we addressed that a review of twelve months' worth of records may not accurately capture the veteran's needs, especially during and immediately after the COVID restrictions often kept patients from being seen in clinic. Additionally, if veterans and their practitioners have long-standing relationships, doctors may not take the time to restate a veteran's needs in every record. Conversely, due to the high turnover of VA physicians, a veteran and his primary care physician may have only met together once before an evaluation for PCAFC was completed by the physician.

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

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

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

The second issue with a veteran's outside records is the placement of the records in a veteran's medical records. This is true for services provided through Community Care or through other insurance, TRICARE, or MEDICARE. The records must be received and uploaded into the VA medical records system in order to be considered as part of the PCAFC application. However, EACH veterans Affairs Medical Center (VAMC) Information Technology (IT) Office determines who has the ability to upload these records-leading to variations in procedures and the time needed to complete the process. Some facilities allow the CSP office to directly upload the records into the system, while others require the Primary Care Manager (PCM) to first go through the records to determine what needs to be scanned in and then send it to VA Records at the facility for scanning. Other facilities require that outside records be taken directly to a VA Records office. Further, none of these circumstances allow the veteran or caregiver to see the Records office. Further, none of these circumstances allow the veteran or caregiver to see the Records office. Further, none of these circumstances allow the veteran or caregiver to see the Records office. Further, none of these circumstances allow the veteran or caregiver to see the

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

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

QoLF has recommendations for this issue later in our testimony.

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

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

This was a LARGE ask of the PCAFC program as it was different than any other VHA program and these processes did not exist previously within VHA. Since the Beaudette decision, the PCAFC program had to create a more robust VHA clinical appeals process, get feedback on that process from VSOs and other stakeholder groups, and get training on the existing eight-point letters used by VBA. PCAFC then had to develop a model, have it approved by Office of General Counsel, develop the IT template, develop training on how to implement and complete the letter, field test it, adjust it, and then train and implement this enterprise wide at each VISN.

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

QoLF believes development of a CEAT decision-making form and eight-point letter has solved the issue of being able to determine how a decision was made by CEAT, what information was considered, and if that decision complied with PCAFC guidelines.

Where we need to be:

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

1. Lack of Congressional intent behind the expansion of PCAFC to older generations;
2. PCAFC participant re-employment and retirement needs;
3. Aging caregivers and Caregiver-GEC interaction or non-interaction;
4. The recommendation by some to move the program to the VBA;
5. Interaction of IT policy and CSP at local facilities regarding outside medical records' entry; and
6. PCM and Specialty Care Provider input in the assessment and evaluation process.

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

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

While the program was never created to be a dollar-for-dollar replacement for wages a caregiver had earned or could earn in the workplace, it was considered a recognition of the caregiver being unable to work due to the needs of the veteran. With the expansion of PCAFC, older Veterans with service-connected ratings who had non-service connected serious conditions creating a need for assistance, were rightfully included in the program, and in all fairness, this was a necessity as proving whether or not a WWII veteran's dementia or diminishing ability to complete ADL's was related to a seventy year old injury would be virtually impossible and not the type of clinical decision VHA makes. However, if the caregiver was older, retired, and Medicare eligible, then the original intent of PCAFC did not apply. If the MISSION Act changed the intent of the program to compensate a caregiver for a service that would otherwise be provided by the VA, then the intent is changed, but there is no clear record of this change of intent for expansion. This means that the VA has had to guess at the intention of the MISSION Act expansion, making it difficult to figure out how to merge an existing program intended for a younger generation with generations of older Veterans for whom the original intent does not apply.

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

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

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

While PCAFC was never meant to be a dollar-for-dollar replacement for wages lost, designating the stipend as unearned income has created a growing concern as these caregivers age and have no way to contribute to either Social Security or a retirement fund. Some caregivers will exit PCAFC when their Veterans pass away, years before they are eligible to draw from retirement plans, but they will have expired employment certifications or will need to prove their worth in a new workplace after having been out of their professional fields while they were caregiving.

In addition, due to the nature of the veteran injuries, these survivors will not receive any significant life insurance making the survivor financial outlook bleak.

Department of Defense programs exist for military spouses as they move duty station to duty station so that they can re-certify their employment certificates or receive new training. The Department of Labor has a model for returnship programs for older workers who return to the workplace after an absence. VA should develop models to help caregivers return to the workplace and save for retirement so that caregivers do not pass from PCAFC into poverty with the passage of their Veterans. Also, in light of this, employment that does not interfere with the duties of caregiving should not be held against a caregiver's suitability.

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

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

1. Until recently, PCAFC did not track referrals to GEC from PCAFC, allowing for loss of PCAFC to create a vacuum in the assistance for the veteran because GEC did not initiate an evaluation of the veteran for services.

QoLF does believe PCAFC has implemented a request that a veteran and caregiver will be connected to GEC for evaluation for GEC programs in the absence of a qualifying caregiver, but QoLF remains concerned that the GEC programs may not be able to fill the need in a timely manner. This is addressed in H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act.

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

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

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

shortages. She was having to call EMS repeatedly to help her get the veteran up to bathe and change him, which is what the HHA contracted care was supposed to help her do.

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

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

QoLF believes that the VDC program can be a good option for some caregivers, but the CSP program provides a much more comprehensive host of services and is administratively less burdensome to the caregiver.

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

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

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

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

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

QoLF would offer some suggestions to see that PCMs' and specialty care providers' input is provided:

1) Congress should remove the language ″to the maximum extent possible″ when describing the input of the physician in the MISSION Act;

2) VA creates a form that is filled out once a year where the PCM documents a discussion of a veteran's ADL's and makes a decision to refer to Occupational Therapy (OT)/Physical Medicine and Rehab for a Functional Independence Measurement and Functional Assessment Measurement score (FIM-FAMs) or full OT exam. Mental Health Providers and/or neurologists would be required to complete a SLUMS (or similar mental status) score yearly and decide if further evaluations or service referrals were needed; and

3) VHA should develop a training for all medical providers within VA to address why documenting current needs, even if takes time and is repetitive, is needed for the PCAFC evaluation, as well as other clinical support services that VHA provides.

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

Conclusion

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

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

U.S. SENATE SPECIAL COMMITTEE ON AGING

″HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS″″

JUNE 5, 2024

PREPARED WITNESS STATEMENT

Fred Sganga

Chairmen Casey and Tester, Ranking Members Braun and Moran, and Members of the Committees:

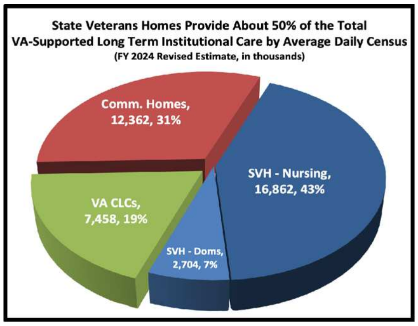
Thank you for inviting the National Association of State Veterans Homes (NASVH) to testify on ways to improve and expand support for aging Veterans and their caregivers. As you may know, NASVH is an all-volunteer organization dedicated to promoting and enhancing the quality of care and life for the Veterans and families in our Homes through education, networking, and advocacy. Today, there are 165 VA-recognized State Veterans Homes (SVHs) across the nation operating 158 skilled nursing care programs, 47 domiciliary care programs, and three adult day health care (ADHC) programs. All 165 SVHs are members of NASVH, the only organization that represents their collective interests, and our membership is expected to continue growing with 13 new Homes expected to seek VA recognition by the end of next year.

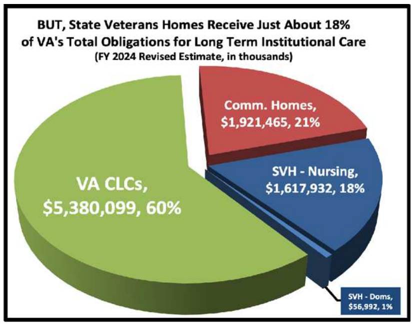
I am currently the Legislative Officer and a past President of NASVH, however my full-time job is Executive Director of the Long Island State Veterans Home at Stony Brook University, a 340-bed skilled nursing facility serving honorably discharged Veterans and their families. I also serve as an adjunct professor in the Graduate Healthcare Administration Programs at Stony Brook University and Hofstra University, where I lecture on the topics of healthcare leadership and long-term care management.

Background of the State Veterans Home System

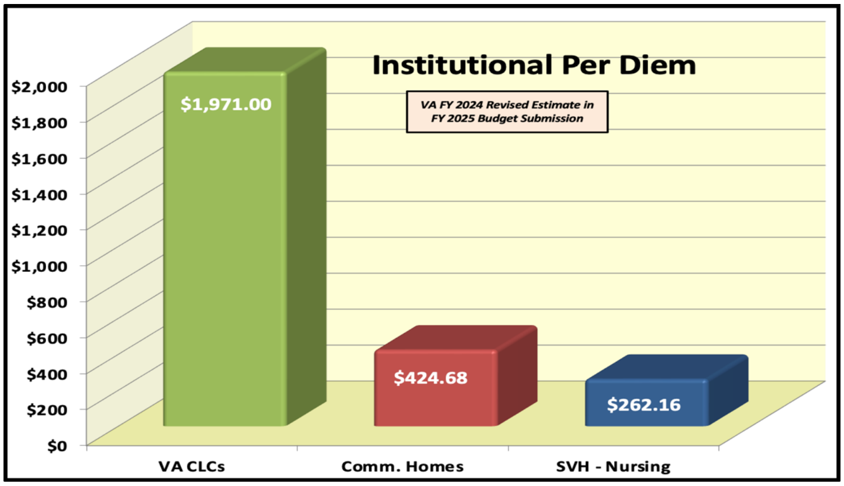
Messers Chairmen, the State Veterans Homes program is a partnership between the federal government and State governments that dates back to the post-Civil War period. To help cover the cost of care for Veterans who choose to reside in SVHs, VA provides per diem payments at different rates for skilled nursing care, domiciliary care, and ADHC. VA also provides State Home Construction Grants to cover up to 65 percent of the cost to build, renovate, and repair SVHs, with States required to provide at least 35 percent in matching funds.

Today, there are over 30,000 authorized State Home beds providing a mix of skilled nursing and domiciliary care. SVHs provide approximately half of all federally-supported institutional long-term care for our nation's Veterans according to VA's most recent budget submission. However, State Veterans Homes will consume less than 20% of VA's total FY 2024 obligations for Veterans' long-term nursing home care.





According to VA, the institutional per diem for SVH skilled nursing care is approximately $262; by comparison, the rate for private sector community nursing homes is about 60% higher ($424), while the rate for VA's Community Living Centers (CLCs) is about 750% higher ($1,971). Although there are important differences among these programs that account for some of the cost differences, it's clear that the SVH partnership provides tremendous value for VA by leveraging matching State funding for the benefit of the we serve.



Oversight of State Homes

VA certifies and closely monitors the care and treatment of in SVHs, which includes a comprehensive recognition survey before any new Home can be certified to receive federal financial support, and an annual inspection surveys to assure resident safety, high-quality clinical care, and sound financial operations. SVHs must meet extensive VA regulations covering more than 200 clinical standards, in addition to dozens of fire and life safety standards.

About 75 percent of State Homes are also certified to receive Medicare support for their residents and must undergo annual inspections by the Centers for Medicare and Medicaid Services (CMS) to assure safety and quality care. In addition, State Homes usually function within or are overseen by a state's department or division of' affairs, public health, or other accountable agency, and typically operate under the governance and oversight of a board of trustees, a board of visitors, or other similar accountable public body.

Aging Need a Full Spectrum of long-term Care Options

Today, there are an estimated 8.3 million living aged 65 or older, approximately 4.9 million who are 75 or older, and 1.3 million who are 85 or older. VA data shows that SVHs care for a significantly older veteran population than either VA CLCs or community (contracted) nursing homes. State Homes also provide more long-stay care and more end-of-life care, as would be expected for their older veteran population. In total, the average daily census (ADC) for all VA-supported nursing home, both long and short stay, is only about 32,000; which is less than one-half of 1% of the approximately 8.3 million living 65 or older, and just over 2% of those 85 plus; and these percentages are projected by VA to drop in future years.

Over the past decade, VA has been placing greater focus and resources on home- and community-based services (HCBS) and NASVH strongly supports expanding these services to provide aging a full spectrum of long-term care options. However, the amount of nursing home care offered by VA today is woefully inadequate compared to the overall number of eligible. Although the need for nursing home care may diminish as the veteran population declines in future years, it will never go away: there will always be significant numbers of who lack adequate family support to allow them to age at home. There are also many of who will be able to utilize HCBS to remain in their homes for as long as possible but will eventually reach an age and stage where traditional nursing home care is necessary. For these reasons, Congress and VA must continue to make smart investments to sustain and expand traditional bed-based care. VA should expand home- and community-based care, but it should be an addition to, not a subtraction from facility-based care.

NASVH and our member State Veterans Homes will continue to seek new and innovative ways of delivering long-term services to aging and ill Veterans, including through a range of graduated care options for Veterans who need support to age in place. SVHs understand aging Veterans' needs and have expertise in connecting them with their VA benefits and services. With our clinical knowledge and extensive infrastructure, State Veterans Homes could serve as hubs in communities across the country, particularly in rural areas, to offer aging Veterans a full spectrum of long-term support services, including home-based care.

Opportunities to Expand SVH Adult Day Health Care Programs

In addition to skilled nursing and domiciliary care programs, SVHs are authorized to offer Adult Day Health Care (ADHC), which is a non-institutional alternative to a skilled nursing facility for aging Veterans who have sufficient family support to remain in their own homes, but who need or will benefit from a day program that promotes wellness, health maintenance, and socialization. ADHC can help to maximize the participant's independence and enhance their quality of life, as well as provide much-needed respite for family caregivers.

Medical Supervision Model ADHC provides a higher-level of care, including comprehensive medical, nursing, and personal care services combined with social activities for physically or cognitively impaired adults. This program is staffed by teams of multi-disciplinary healthcare professionals who evaluate each participant and customize an individualized plan of care specific to their health and social needs. There are currently only three State Veterans Homes operating ADHC programs - New York, Minnesota, and Hawaii - although several other states are working on plans that could lead to additional programs in the future.

At the Long Island State Veteran Home, we have a 40 slot Medical Model ADHC program, with about 75 Veterans currently enrolled. We operate a six day-a-week program, Monday through Saturday, for six hours each day, from 9:00 AM to 3:00 PM. We also provide door-through-door transportation that is fully wheelchair accessible, with ambulettes picking up the Veterans and returning them home at the end of the day. We provide these Veterans with the full array of clinical services offered at our skilled nursing facility, while allowing them to live in their own home. Those services include physical, occupational, and speech therapies; clinical nutritional counseling, along with three meals (includes dinner to go); recreational activities provided by a Certified Therapeutic Recreation Specialist (CTRS); along with personal care, including bathing, grooming, and hair care. Our ADHC program helps to improve the quality of life and maintain the independence of the veteran. We also help stabilize chronic medical conditions, reduce emergency room visits and potential hospitalizations, delay or prevent nursing home placement, and provide significant respite support for caregivers. In fact, we can save a caregiver multiple trips it would take to provide all the services we are able to provide in one day.

ADHC programs can be a critical lifeline for both Veterans and their caregivers, as shown in the story of one of our residents, West Point graduate and Army Colonel Mike Grabel. After a heavily decorated 27 year military career, that included three tours in Iraq and Afghanistan, Mike had a stroke. For the next two years, he required hospital care and faced the knowledge that he would need significant physical therapy and extensive support for the rest of his life. His wife Jeannine was with him every step of the way during his recovery. Due to the level of support Mike required, and the need for Jeannine to return to work, they had to consider whether the best option was placement in a skilled nursing facility. Fortunately, we were able to offer Mike the option of enrolling in our Adult Day Health Care program. Today, Mike receives the care and support he requires six days a week, including door-through-door transportation, nutritious meals, and comprehensive medical and personal care services. Jeannine was able to return to work as a school nurse, secure in the knowledge that her loved one is in good hands.

To increase Veterans' access to SVH ADHC programs, NASVH offers two recommendations. First, VA and Congress should modify and/or clarify current regulations so that the State Veterans Home Construction Grant program can be used to construct, modify, or expand SVH facilities to operate new or expand existing ADHC programs. VA's current interpretation of federal regulations does not allow a SVH to apply for a construction grant in order to begin a new ADHC program; it may only seek a grant to expand or replace a facility being used currently for ADHC. Although dozens of states have expressed interest and taken steps towards offering adult day health care services, the single greatest barrier to entry is the construction of new or modification of existing space to properly operate an ADHC program. We call on Congress to work with VA to make this commonsense adjustment to encourage expansion of SVH ADHC programs.

Second, VA should authorize and take actions to encourage SVHs to establish satellite ADHC programs outside their facilities and campuses in more conveniently located areas where there are high concentrations of Veterans who could use these services. The Long Island State Veteran Home's ADHC program can only serve Veterans in Suffolk County because of the distance they would have to travel. However, we have been working for several years to open a satellite ADHC program in Nassau County, which would open up this life-changing service as an option to thousands of additional Veterans and family caregivers.

Additional Home-Based Care Services in State Veterans Homes

In addition to expanding ADHC programs, NASVH also recommends that Congress and VA explore other ways for SVHs to develop new home-based programs, including ones similar to VA's Home Based Primary Care, Homemaker Home Health Aide Care, Respite Care, Palliative Care and Skilled Home Health Care. For example, during the COVID pandemic, I was forced to temporarily shut down our ADHC program under State orders intended to protect Veterans. However, I was able to pivot to an innovative program that supported the Veterans enrolled in our ADHC program by providing meals, PPE, telehealth, and home care visits. VA was able to support this temporary program using emergency powers granted to the Secretary during the pandemic.

Given the flexibility and financial benefits to VA from partnering with State Veterans Homes, there are myriad possibilities for better addressing the changing demographics, needs and preferences of Veterans today and in the future. Many State Veterans Homes already offer a number of medical and therapeutic services that could be provided on an outpatient basis for Veterans participating in home-based programs.

With our expertise on the needs of aging Veterans, SVHs could develop an array of home-based services to support Veterans who want to age in their own homes. When they are no longer able to remain at home, SVHs could ease their transitions to facility-based skilled nursing care. Such an integrated non-institutional program could begin as a pilot program, with different states customizing it to meet local circumstances. NASVH recommends that Congress consider establishing pilot programs to explore new arrangements for providing integrated home- and community-based programs through and in partnership with State Veterans Homes, offering a full spectrum of support from home care to skilled nursing care.

Expanding the Spectrum of Care in State Veterans Homes via Assisted Living

State Homes currently offer two levels of residential care: skilled nursing care for those who need significant support completing activities of daily living (ADLs) and domiciliary care, for those who are able to complete their ADLs, but require shelter, food, and other basic necessities. With millions of aging Veterans no longer able to live independently, but whose needs fall in between these two levels of VA-supported care, NASVH believes it is time to begin offering assisted living programs in State Veterans Homes, which could offer greater support than offered by domiciliary care and would cost less than skilled nursing care.

NASVH was pleased to offer our strongest support for S. 495, the Expanding Veterans' Options for Long-Term Care Act, legislation that would authorize VA to create a three-year pilot program to provide assisted living care for Veterans. In particular, we appreciated the inclusion of State Veterans Homes. We understand that a scaled-down version of the pilot program is part of the omnibus Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act and we hope that all Senators will support this legislation. On behalf of our member State Homes and the Veterans we serve, I want to thank Senators Tester and Moran for introducing this legislation.

Continuing Challenges Facing State Veterans Homes

Messers Chairmen, State Veterans Homes are still recovering from the severe impacts of the COVID pandemic, particularly with regard to their financial operations, as every State Home had to significantly increase expenditures for PPE, cleaning and sanitizing supplies, and laundry services. Homes also had enormous increases in personnel costs to cover wages, overtime, hazard pay, sick leave and temporary agency staffing. In addition, many Homes made modifications to buildings and rooms for isolation and further enhanced sanitization measures to include new technologies and new equipment.

During this same time, occupancy levels in most SVHs declined because new admissions were suspended, leaving an increasing number of beds empty. Today, SVHs still face significant challenges in bringing their occupancy rates back up to normal levels, primarily due to national staffing shortages that are impacting all health care facilities. As a result, the level of VA per diem support provided each year to State Veterans Homes has declined significantly in recent years, creating serious financial challenges for Homes to remain solvent at a time when their State budgets are also in crisis. Although VA is authorized to pay a basic per diem that covers up to 50% of the cost of a veteran's care, the basic per diem rate in recent years has been less than 30% of the actual cost. NASVH is seeking new legislation that would set the basic per diem rate permanently at 50% of the daily cost of care.

NASVH is also seeking support from Congress to fully fund the State Home Construction Grant program. Over the past decade, annual appropriations for this program have been extremely volatile: typically providing funding for only a small portion of the qualified state matching grants, with occasional bursts of funding to catch up to the full demand. The backlog of Priority Group one State Home Construction Grants, which includes critical life-safety projects, continues to rise far beyond available federal funding. When the overdue FY 2024 Priority list is released later this year, it is expected to show a need for at least $1.2 billion in federal funds to match what the States have already made available.

Unfortunately, Congress appropriated just $164 million for FY 2024, less than 15% of the amount required to fully fund the program. For FY 2025, VA requested just $141 million, though the House Appropriations Committee proposed slightly increasing that funding level to $154 million in a vote last week. NASVH is seeking support from Congress to substantially increase funding for the State Home Construction Grant program - to at least $600 million in FY 2025.

The funding gap is even worse than it looks due to VA's unwillingness to provide ″Build America, Buy America Act″ (BABAA) waivers for State Home Construction Grants. As you may know BABAA - which was approved in 2022 and became effective in 2023 - requires the federal government and recipients of federal grants to buy most materials and products from US manufacturers. However, the law included a waiver provision for projects that would have a very hard, if not impossible, time complying with the new domestic content requirements due to the unavailability U.S. made components and materials, or the extremely high cost of U.S. made products. There is particularly a sourcing problem for HVAC systems, refrigeration, generators, transformers, electrical controls, and LED lighting fixtures, that are virtually impossible to procure from U.S. manufacturers.

A number of States that previously received conditional grant approvals from VA prior to BABAA's effective date, and who have already expended significant funds for planning, design, and/or long-lead procurement, are now threatened with the loss of federal matching funds, which will almost certainly force them to delay or cancel these much-need construction projects. Without this legislation and these BABAA waivers, many States will have to cancel vital construction projects, and as a result thousands of aging and disabled Veterans would lose the opportunity to receive high-quality long-term care in a State Veteran Home.

Legislation was introduced in the Senate and House (″WAIVER Act″, S. 3886 & H.R. 7514) to require that VA use its statutory authority to provide State Veterans Homes one-time transitional waivers from certain ″Build America, Buy America Act″ (BABAA) requirements that would otherwise prevent many State Veterans Homes from receiving VA funding for critical construction projects. We would urge all Senators to consider supporting this legislation.

Clinical Staffing Challenges

Messers Chairmen, the biggest challenge facing State Veterans Homes is the shortage of clinical professionals. As these Committees are certainly aware, there is a national staffing crisis affecting virtually every health care system, especially for nurses and other critical clinical positions, and particularly in rural and remote areas. State Homes are already challenged in hiring and retaining staff because of workforce shortages and the significant competition from local hospitals, higher-paying transitionary agency positions (e.g., traveling nurses), and other private employers. Current staffing shortages are impacting veteran access to care since many SVHs are turning away new admissions due to their inability to recruit, hire, and retain sufficient staffing.

Furthermore, the recent promulgation by CMS of new minimum staffing standards will further exacerbate our challenges. It is estimated that nearly 94 percent of nursing homes nationwide do not currently meet at least one or more of the three proposed CMS requirements. Although many SVHs are already in compliance, these new standards will increase competition for a limited labor pool - particularly for nurses. These new staffing minimums could result in SVHs being forced to restrict the number of Veterans they can serve, and it is possible we could see some SVHs close altogether, with both scenarios leaving aging and disabled Veterans at risk.

We have been grateful for VA's Nurse Recruitment and Retention Scholarship program which has had a positive impact on a number of SVHs. We are asking Congress to expand that program so that more Homes can benefit from it. At the same time, we believe that a similar program for other critical staffing vacancies - such as physical therapists, dieticians, social workers, etc. - could help boost the ability of SVHs to compete with private sector employers who are able to offer higher salaries and benefit packages. We hope to work with Congress to develop new and innovative programs that will help SVHs recruit and retain sufficient staffing to allow more Veterans to be served by our Homes.

Strengthening NASVH-VA Partnership

Finally, to maximize the effective use of State Veterans Homes' resources and capabilities. VA must finally commit itself to a full and meaningful partnership with States. Too often, SVHs are an afterthought in VA's planning and budgeting processes. This is exemplified by the continuing lack of representation by State Veterans Homes on VA's Geriatrics and Gerontology Advisory Committee (GGAC), despite NASVH having nominated multiple highly-qualified State Home administrators and leaders in recent years.

Messers Chairmen, State Veterans Homes can and must play a greater role in meeting the needs of aging Veterans and their caregivers in partnership with VA and other federal agencies. NASVH looks forward to continuing to work with these Committees and your colleagues in the Senate to ensure that Veterans have greater access to a full spectrum of long-term care options, whether at home or in nursing homes. That concludes my statement, and I would be pleased to answer any questions that you or Members of the Committees may have.

U.S. SENATE SPECIAL COMMITTEE ON AGING

″HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS″″

JUNE 5, 2024

PREPARED WITNESS STATEMENT

Meredith Beck

Chairmen Casey and Tester, Ranking Members Braun and Moran, and Members of the Committees, thank you for the opportunity to testify today. My name is Meredith Beck, and I am the Senior Policy Advisor for the Elizabeth Dole Foundation (EDF), a national non-profit whose mission is to strengthen, empower, and support America's military and veteran caregivers and their families by raising public awareness, driving research, championing policy, and leading collaborations that make a significant positive impact on their lives. By working with military and veteran caregivers every day through our numerous programs including Hidden Heroes Communities, our Hidden Helpers initiative for caregiver children, the Hope Fund which provides financial relief directly for caregivers, our mental wellness workshops, and through our network of Dole Caregiver Fellows in every state, EDF is keenly aware of and has a unique perspective on the challenges, issues, and remarkable strength of the military and veteran caregiving community we are honored to serve.

U.S. Department of Veterans Affairs Caregiver Support Program/Program of Comprehensive Assistance for Family Caregivers

The U.S. Department of Veterans Affairs (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC) remains a significant concern among all generations of veteran caregivers. We wish to strongly align ourselves with the comments and recommendations made by our partner, the Quality of Life Foundation (QoL), who has clearly articulated the program's current challenges in their written testimony. EDF is proud to sponsor the vital, specialized clinical appeals work done by the QoL. As we await the public release of new regulations governing PCAFC, we look forward to continuing to work with QoL to ensure that veteran caregivers are given the support they need and deserve.

With respect to the new PCAFC regulations, EDF notes that the legacy cohort of eligible caregivers, those post-9/11 veteran caregivers who were admitted to the program prior to September 30, 2020, yet again face an uncertain future. Many of these caregivers have repeatedly been found eligible for the program over the years and endured multiple pauses, regulation and leadership changes, lack of previous program standardization, and questionable assessments. While eligible post-9/11 veteran caregivers have benefitted from the monthly stipend included in the PCAFC, the emotional toil and financial uncertainty caused by programmatic instability in the PCAFC have weighed heavily on caregivers and Veterans alike. Therefore, EDF asks Congress to work with relevant veteran service organizations to consider ″grandfathering″ this population of caregivers into the PCAFC, except in cases of fraud, waste, or abuse. This would allow the Caregiver Support Program (CSP) to focus on its mission of supporting all generations of caregivers rather than continuing this years-long division within the veteran caregiving community.

As the VA works to improve support for veteran caregivers of all generations, we would like to commend the Caregiver Support Program for their efforts to dramatically increase the use of respite care for eligible individuals by over 200% percent through the enactment of ″respite champions,″ VA employees whose job it is to support access and coordinate services for those seeking to use respite services. Additionally, the recent availability of mental health support for veteran caregivers enrolled in PCAFC has served as a lifeline for many who previously struggled without access to care. While caregiving for a loved one can be incredibly rewarding for the caregiver and often is vital for the well-being of the veteran, the mental health toll on caregivers can be daunting, as has been noted in numerous RAND studies. Therefore, we encourage Congress to broaden access to mental health care for those beyond PCAFC to include those enrolled in the Program of General Caregiver Support Services (PGCSS) under CSP.

Further, we were delighted to learn of the Administration's FY2025 budget request that included an approximately 20% increase in spending for support and services within CSP. However, we were disappointed to learn recently that, despite the budget request increase and expected program expansion, CSP will not be offered a waiver like other VA programs from the current specific purpose funding restrictions. This means that, in most cases, CSP will not be allowed to hire the front-line social workers, program managers, and nurses that make the program most effective at the local level. This hiring freeze will almost certainly have a detrimental effect on caregivers, Veterans, and VA staff who work very hard to support those in the program.

Elizabeth Dole Home Care Act

In addition to CSP, the VA has many programs that, when accessed, benefit veteran caregivers both directly and indirectly, most of which are housed under Geriatric and Extended Care (GEC). At EDF, we see the positive things that can happen when Veterans and caregivers are connected by caring, passionate providers and social workers to vital programs and services. Additional respite services, the Veteran Directed, Home-Based Primary Care and the Homemaker Home Health Aide are just some of the programs that support the care and quality of life of Veterans and caregivers, especially at home and can serve as a lifeline for Veterans and caregivers in need.

Where available, the Veteran Directed Program, for example, has high satisfaction rates among Veterans and caregivers across the country. This program, a joint offering from the VA and U.S. Department of Health and Human Services (HHS), offers Veterans and caregivers greater choice and control over their care and services by allowing participants to hire familiar friends and family members to provide unskilled care, transportation, skilled care, and other goods and services. Veterans and caregivers can supervise their own employees and hire additional support during the hours that are needed rather than being subject to agency hours and restrictions. In addition, this program has been especially helpful to those who struggle to find appropriate care in their homes either due to contracted agency employee absences or the general dearth of HHA providers around the country as noted in the President's Executive Order from April 2023.

Unfortunately, despite being created more than sixteen years ago and its demonstrated success, Veteran Directed is still not available in every VA medical center. In many cases, VA staff are unfamiliar with the program even if it is technically available at the facility, or the program exists in name only without the appropriate staff available to ensure its availability and success.

For example, Mary Ward, a Dole Caregiver Fellow, cares for her 100% service-disabled veteran husband and 14-year Amyotrophic lateral sclerosis (ALS) patient, Tom, who receives care from the Durham VA Medical Center. Mary is an astute and effective advocate for Tom. In 2019, once Mary found out another high-need veteran in the area was enrolled in the Veteran Directed Program, she began the process of trying to get Tom enrolled. During the intervening years, she has been told repeatedly that the program was still unavailable in Durham, again, despite knowing another veteran was enrolled. Finally, after significant effort on Mary's part and intervention from EDF, the VA reversed course and Mary was told within the last two weeks that the agency would try to enroll Tom in the Veteran Directed Program. If enrolled, Mary will be able to hire her own, familiar home health and respite care support to ensure they are meeting Tom's significant needs.

This process should not and cannot be this difficult for Veterans and caregivers. As a result of situations like Mary and Tom's, Ranking Member Moran was joined by Chairman Tester and others to introduce S. 141, The Elizabeth Dole Home Care Act. In addition to mandating that every VA medical center provide the Veteran Directed Program, the legislation takes a holistic approach to ensuring this and other GEC programs are offered nationwide and appropriately staffed. The bill also attempts to ensures that caregivers have access to information on available programs and services in a centralized digital location and requires the coordination of other available services if a caregiver is denied or discharged from PCAFC for reasons other than waste, fraud or abuse.

Most notably, the legislation increases the expenditure cap for non-institutional care from 65% to 100% of the cost of the closest VA Community Living Center (CLC). This would allow the most vulnerable Veterans and caregivers the support they need to stay in their homes, often leading to better outcomes for veteran families, like the Gareys from Austin, TX. The removal of the cap would help people like Dole Caregiver Fellow Lara Garey, who is present at today's hearing, cared for her 100% service-disabled veteran, Tom, until his death due to complications from ALS in July 2022. Because of the mandated cap, Lara constantly had to fight with the VA to get the appropriate support in their home so Tom could continue to enjoy movie nights with the family, opening gifts on Christmas morning, and even their son's high school graduation, which happened in their living room so Tom could comfortably attend-all of which he would have missed if he were in a facility two hours away. It was Tom's greatest wish to remain at home to be surrounded by the peace and love of his family during the hardest of times. Tom deserved to be home with his family, and Lara fought every day to make that possible. As you can see, she continues to advocate on behalf of caregivers and Veterans in similar situations.

Eventually, this legislation, which enjoys bipartisan support in both Houses of Congress, was included in its entirety in the recently introduced H.R. 8371, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act. While the passage of the original Elizabeth Dole Home Care Act is the top priority for EDF, the overall package includes numerous provisions designed to benefit Veterans and caregivers including:

- Enhanced access to care in the community for those for whom it has been determined by their clinician to be in their medical best interest.
- Enhanced access to residential rehabilitation for vulnerable Veterans.
- Authorizes grants to community-based organizations to provide mental health care to caregivers.
- A long-awaited pilot program to assess the effectiveness of and satisfaction with provided assisted living services.
- Mandates a ″Pathway to Advocacy″ requiring the Secretary of the VA to develop a process to identify, train, and certify outside organizations to assist Veterans and caregivers as they navigate the resources and programs of the Veterans Health Administration.
- Enhanced burial and education benefits for survivors.

Despite strong support from the Chairman and Ranking Members of the Senate Veterans Affairs Committee as well as the Chairman of the House Veterans Affairs Committee, all major veteran service organizations, and disease-related advocacy groups, the legislation has seemingly fallen victim to the politics of the day and been plagued by misinformation and mischaracterization of its provisions. We urge Members of the Senate to reach out to trusted veteran community advocacy organizations to get factual information regarding this legislation to ensure its swift passage, and remove Veterans, caregivers, and survivors in need from the political fray.

Additional Issues:

In addition to issues addressed in the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act, EDF would like to highlight other remaining challenges as well as proposals meant to address them.

As noted above, the lack of care coordination especially for those with the most complex needs continues to be an ongoing challenge for Veterans and caregivers alike. We regularly hear from caregivers who spend hours every day trying to access the care and benefits their Veterans need, to varying degrees of success depending on their knowledge of the available programs and services as well as that of the VA staff with whom they are working. Therefore, EDF supports the following:

- Passage of S. 1792, The Care Act of 2023 introduced by Chairman Tester and Senator Braun establishing the ″Pathway to Advocacy″ discussed previously. This legislation would allow knowledgeable organizations to assist Veterans and caregivers in the navigation of VA services as well as supplement overwhelmed social workers.
- Discussion and passage of legislation recently introduced by Ranking Member Moran and Senator King, the Coordinating Care for Senior Veterans and Wounded Warriors Act. The VA is in the process of implementing its new Care Coordination and Integrated Case Management program which could be helpful for some Veterans. For those with the most complex needs, this legislation creates a pilot program to offer a higher-level of assistance and is a firm step forward in the establishment of more effective care coordination. We look forward to continuing to work with the Committee on this important issue. Consideration of the amount of demonstrated time a caregiver spends coordinating care for the veteran as part of the PCAFC assessment process. Veterans requiring degrees of supervision and protection are eligible for PCAFC, and ensuring access to health care and services should be a major consideration under this criterion.
- Passage of S. 622, the Helping Heroes Act, introduced by Senators Murray and Boozman requiring a full-time Family Support Coordinator at each VA medical Center and requiring the VA to collect data on veteran families to better understand their needs. In the recent past, the VA prioritized the establishment of Family Support Resource Coordinators at each VA medical center, but the position but the position was put on hold as a result of a funding shortfall. These resource coordinators would help connect families and caregivers to the right resources both inside and outside of the VA, potentially providing a longer-term cost savings by proactively connecting families with needed services earlier in their journey.
- The establishment of a case management and social work lead at the VISN level who could help to coordinate training, standardization of services, and serve as a point of contact when challenges arise.

We support all of these initiatives intended to relieve some of the administrative burden for both Veterans and caregivers.

With respect to financial wellness, EDF strongly supports two other pieces of legislation intended to alleviate the financial strain often caused by caregiving as well as how to adjust when the caregiving role has concluded due to improvement, death, divorce or other causes:

- S. 3702, the Credit for Caring Act, introduced by Senators Bennett and Capito and also endorsed by our partner, AARP, would offer a $5,000 tax credit to eligible working family caregivers, both veteran and civilian, to offset the over $7,200 in out-of-pocket caregiving expenses incurred every year. This legislation would clearly remove some of the financial strain experienced by these families, especially those Veterans who are either not associated with the VA or have experienced the difficulty discussed above accessing the programs and services available to them and, instead, pay out of pocket for their needed goods and services.
- S.3885, The Veteran Caregiver Reeducation, Reemployment, and Retirement Act introduced by Ranking Member Moran and Senator Sinema. For many PCAFC caregivers, their caregiving role will come to an end, hopefully due to improvement in the veteran for whom they care, but any number of reasons can be cited for this outcome. This legislation would do many things to alleviate that anxiety including extend enrollment in the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) for up to 180 days after disenrollment from PCAFC, allow the VA to pay caregivers up to $1,000 to maintain professional licensure, study the feasibility of establishing a retirement plan for family caregivers, and study the barriers and incentives to hiring former family caregivers to work for the VA.

While EDF strongly endorses this legislation, we would also suggest an amendment to help alleviate a current inequity related to retirement planning for parents enrolled in PCAFC who care for their service-disabled child, currently approximately 2,500 individuals. The VA offers a program called Dependency and Indemnity Compensation, a monthly tax-free monetary benefit offered to eligible survivors-this program is often a financial lifeline for those who are eligible, and spouse survivors are rightfully not subject to an income threshold. Parent caregivers, however, are subject to an income threshold, in some cases as low as approximately $18,000/year. For example, EDF is familiar with a parent caregiver in Florida whose combat-injured Marine son recently passed away. His single mother was his caregiver for 17 years following his severe injuries, and now at age 73, she is unable to return to work. Because she is a parent, she is subject to the DIC income limit, and her $23,000 annual social security payment exceeds the threshold. With Social Security now her sole source of income, she is in danger of losing the home she shared with her son after his injury.

As the Committee considers S. 3885, EDF requests that the Committee consider abolishing or greatly increasing the DIC income limits for non-spouse caregivers enrolled in PCAFC, allowing them to plan for retirement and leaving them far less financially vulnerable when their caregiving role has concluded.

Conclusion:

While caregivers and Veterans still face significant challenges today, many can be addressed through continued oversight and the legislative initiatives mentioned above. Specifically, the Elizabeth Dole Home Care Act as well as the language included in the larger legislative package would provide, in many cases, immediate relief to those caregivers and Veterans most in need. Therefore, the Elizabeth Dole Foundation calls on Congress to come together, treat this vital legislation with the respect and urgency it deserves, and pass it without delay. Veterans and caregivers cannot wait any longer for its life-changing, and likely life-saving provisions.

Thank you, Mr. Chairmen, and I look forward to your questions.

Questions for the Record

U.S. SENATE SPECIAL COMMITTEE ON AGING

″HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS″

JUNE 5, 2024

QUESTIONS FOR THE RECORD

Peter Townsend

Ranking Member Mike Braun

Question:

In your opening statement you referenced your time staying in a Community Living Center (CLC) for respite while your wife was recovering from knee surgery. Why did you choose to use a CLC instead of an in-home aide?

Response:

When I contacted my primary care provider to discuss respite care in advance of my wife's knee replacement surgery, inpatient respite was what was offered at that time. We did not discuss the use of an in-home aide. After further consideration, I do believe that inpatient respite care at the CLC was the right choice for my situation. Although my stay at the CLC was uneventful, the care was available to me at all times should I need it. Had I experienced an acute exacerbation of my symptoms during that time, scheduling an in-home aide would have been difficult and would likely not have provided the care and assistance that I required at the time that assistance was needed.

Question:

How did you feel about the quality of care you received at the CLC?

Response:

The quality of care that I received during my three weeks of respite at the Community Living Center at the Wilkes-Barre VA Medical Center was excellent.

Senator Kristen Gillibrand

Question:

Veterans whose health is affected by service should be supported in their time of need. My Social Security Caregiver Credit Act provides retirement compensation to individuals who leave the workforce or need to reduce their work hours to care for their loved ones. How would retirement compensation have helped you and your wife?

Response:

My wife, Lisa, left the workforce at age 62 to become my full-time caregiver. Her premature retirement meant that she missed out on Social Security contributions for at least three years, and also missed out on the opportunity to contribute to her retirement account through her employer. Prior to her retirement, Lisa had been employed full-time for her entire adult life, with the exception of the year following the birth of our son. Although we have not attempted to calculate the financial effects of her lost contributions, I would assume that it is significant. Recognizing that caregiving is work and providing the appropriate retirement compensation to caregivers who leave the workforce to care for their loved ones would be a valuable benefit and the right thing to do! I thank you for your question and for your commitment to this important issue.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS"

JUNE 5, 2024

QUESTIONS FOR THE RECORD

Hannah Niekens

Senator Kyrsten Sinema

Question:

How do you believe the VA could better ensure it is accounting for a patient's full medical history to prevent those in need of community care from being at a disadvantage when applying for the PCAFC program?

Response:

To improve the Veteran's Administration's ability to account for a patient's full medical history, especially for those utilizing community care or outside providers, the following steps could be taken:

Integrated Health Information Systems: Develop and implement a more robust and integrated health information system that allows seamless sharing of medical records between the VHA and community care providers. This system should be interoperable with various electronic health record (EHR) systems used by outside providers. The records should also be easily accessible to VHA providers.

Integration of VBA and VHA Records: There are significant discrepancies between Veterans Benefits Administration (VBA) and Veterans Health Administration (VHA) records. Ensuring these records are integrated and accessible across both systems is crucial. This integration would help in providing a complete medical history and prevent misunderstandings and omissions of critical health information.

Reporting and Documentation: Establish reporting requirements for community care providers to ensure they consistently and comprehensively document and share medical records with the VHA. This could include standardized forms and protocols to ensure consistency and completeness.

Enhanced Coordination and Communication: Foster better coordination and communication channels between the VHA and community care providers. Joint case reviews and designated liaisons could help ensure that the VHA receives timely and complete medical information.

Patient Education and Empowerment: Educate Veterans about the importance of sharing their full medical history with the VHA. Provide them with tools and resources to track and manage their community care medical records within existing personal health record apps or patient portals. Additionally, provide the opportunity to self-upload medical records from providers who are not part of the community care network.

Data Analytics and Monitoring: Utilize data analytics to monitor and identify gaps in community care medical records. Implement systems that flag missing or incomplete information based on known community care appointment authorizations and prompt follow-up actions to ensure the patient's medical history is fully accounted for.

Policy and Legislative Support: Advocate for policies and legislation that support the integration of health information systems and mandate the sharing of medical records between the VHA and community care providers. This could also include funding for technology upgrades and training programs.

Comprehensive Care Coordination Programs: Utilize care coordination programs that assign care coordinators or case managers to Veterans, especially those with complex medical histories, to help bridge the gap between the VHA and community care providers, ensuring all relevant medical information is captured and communicated effectively. Examples of programs with case management include VA Patient Aligned Care Teams (PACTs), VA Polytrauma System of Care, Geriatrics and Extended Care (GEC) Services, Mental Health Intensive Case Management (MHICM), Caregiver Support Program, Military Sexual Trauma (MST) Coordinators, Homeless Veterans Programs, VA Transition Care Management (TCM), VA Post-Deployment Integrated Care Initiative (PDICI).

Stable Needs: A review of medical records should include all relevant records from any point in time where significant need was established. Veterans who have stable needs were disadvantaged by not having a preponderance of medical records.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS"

JUNE 5, 2024

QUESTIONS FOR THE RECORD

Andrea Sawyer

Senator Kyrsten Sinema

Question:

Your testimony in a previous hearing brought to my attention the healthcare, financial, and employment difficulties veteran family caregivers are facing. Your testimony, the input provided by your organization, the Quality of Life Foundation (QoLF), and input from the Military Officers Association of America have been critical to the formulation of my bill, the Veteran Caregiver Re-Education, Re-employment, and Retirement Act. One of the provisions of my bill mandates a study of allowing caregivers to make contributions to Social Security and other types of existing retirement accounts. What are the QoLF's thoughts on retirement account options that should be available to caregivers enrolled with the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC)?

Response:

Quality of Life Foundation has not taken a stand on the type of retirement accounts which caregivers should be allowed to contribute to. However, caregivers should have some form of account created like that of Social Security or Railroad Benefits so that there is a retirement safety net. Another option would be to create a Thrift Savings Plan for caregivers or to allow them to set up retirement savings. These accounts could be taxed at the time of withdrawal like that of current IRA's, so as not to create a taxation problem for stipend vs. wages with the actual PCAFC stipend.

Question:

Another provision of my bill requires the VA to study the potential challenges and opportunities of hiring additional former PCAFC caregivers to help address staffing shortages. What are the most significant barriers to VA employment that QoLF has identified for PCAFC caregivers attempting to reenter the workforce?

Response:

Caregivers moving out of full-time caregiving and back into the workforce will have the same challenges as new parents returning to the workforce will have. Many studies cite that new parents have problems with child care, balancing career and childcare demands, and continued career advancement. The same are true for caregivers, as caregiving is essentially the same as child-rearing in its impact on careers.

Just because a caregiver is dismissed from PCAFC does not mean that the care recipient does not need care, just that they need care to a lesser extent than before. Caregivers have to find alternative care resources for their loved ones through home health care or other alternative programs. If those care supports fail to show or run late, then the former PCAFC caregiver has to step into that role. This creates absenteeism in the workplace for caregivers and can threaten long-term employability for caregivers. Jobs should allow work-place flexibility options so that caregivers can work from home in order to fulfill caregiving duties simultaneously.

While many workplaces tout flexible work options, caregivers will need workplaces to be extremely flexible. Workplaces that expect caregivers to do nine to five jobs while also having to ferry loved ones to doctors offices and other appointments that are during the traditional work day, are not caregiver friendly. Caregivers will need work places that are focused on task achievement, not on adhering to a traditional schedule. Caregivers have learned to achieve many goals during caregiving, but they do their work during non-traditional hours.

Caregivers will be left behind in career advancement as long as they are caregiving. Because caregivers will not have kept up with the latest advancements, missed out on continuing education, had gaps in licensure, etc., caregivers will fall behind in their fields. When their caregiving duties end, caregivers will be able to make this up, but in the short term, there will be some damage to the caregiver's career advancement. Workplaces that are able to offer return ships that can capitalize on the flexibility that caregivers have mastered will be the workplaces that are able to value and integrate caregivers successfully into their places of work.

Question:

Are there staffing gaps at the VA that former PCAFC caregivers could be helpful in closing?

Response:

VA can integrate caregivers into a myriad of positions that it has. Caregivers come from a variety of fields prior to caregiving, from education, healthcare, finance, structural engineering, etc. VA could potentially give a hiring preference to former caregivers (many of them may already have spousal preference for 100% p and t Veterans) to integrate them into VA careers. VA could use unskilled caregivers as personal care attendants or help them achieve their CNA 1 and CNA 2's to meet staffing HHA needs for Veterans within the VA. Since VA and its contracted agencies are facing a severe shortage of HHA workers, it would only make sense for VA to work out a program to help caregivers achieve CNA licensure and then hire on former caregivers to fill the open roles that VA has in its labor force.

Question:

In your testimony, you also highlighted the requirement that PCAFC caregivers assist their veteran with an activity of daily living each and every time in order to retain eligibility for the Program, which could effectively penalize Veterans for rehabilitating themselves to a point where they do not require assistance every single time. Do you share the concern that Veterans engaging in rehabilitation regimens and treatments could lose their PCAFC eligibility?

Response:

Quality of Life Foundation has always been concerned with the language requiring assistance ″each and every time″ an ADL is performed. We have routinely pointed out the problem with this language in our testimonies and conversations on the Hill and with VA staff. Veterans should be encouraged to participate in rehabilitation and treatment regimens to achieve the highest level of independence possible without it threatening a veteran's level of assistance. No caregiver wants to limit the independence of their veteran through rehabilitation, but the VA threatens a caregiver/veteran dyad's security if a veteran shows even the slightest level of independence, even if such independence is not sustainable.

A veteran who has lost both legs and needs prosthetics to walk may need the assistance of a caregiver while learning to walk again, while suffering from stump sores, and after removing prosthetics in order to shower, toilet, or sleep. Just because the veteran is independent on the prosthetics to walk does not mean they may not otherwise need assistance. The veteran's legs did not magically grow back. Penalizing a veteran for being able to do one thing, one time without assistance, is simply ludicrous.

The best examples of this come with Veterans with conditions like MS that are relapsing and remitting. Veterans can be independent, but at any point in time, their disease may progress and they will need immediate care. Using an ″each and every time″ ADL standard simply does not make sense. Caregivers and Veterans should be encouraged to achieve long-term rehabilitation without the constant short-term threat of having PCAFC withdrawn until the independence achieved has proven to be sustainable.

Question:

I understand that Veterans and their loved ones struggle at times to secure PCAFC eligibility, so I appreciate the work QoLF does to help them enroll with the Program. Do you work with Veteran Service Organizations and other groups to ensure they are equipped to advocate on behalf of caregivers and their Veterans as they navigate the PCAFC application process and, for those denied initially, the clinical appeals process?

Response:

Quality of Life Foundation works with many other organizations in the veteran space to educate those organizations on the issues facing caregivers and Veterans throughout the PCAFC application and appeals process. We do education sessions with multiple VSO's to teach them about how VHA reviews the medical records to determine whether a caregiver is needed. We discuss with them how to appeal a caregiver determination since the appeal is a VHA appeal, which is not the realm in which most VSO's operate. We run education sessions on the process for many veteran supporting organizations such as Semper Fi Fund/America's Fund Visiting Nurses, Neuro Community Care (administrator of Wounded Warrior Project's Independence Program) case managers, Homes For Our Troops case managers, the Elizabeth Dole Foundation Fellows, and other organizations that request those briefings. We do briefings on the actual application process and separate briefings on the types of appeals available for each decision that is made.

Collaboratively, we also hold roundtables with MOAA for the VSO and stakeholder community on the Caregiver and Veteran experience. In 2023, our focus was on caregiver respite. In 2024, our first roundtable was on the state of the pending caregiver regulation.

QoLF has created a PCAFC assessment work group of VSO stakeholders to discuss what needs to be captured in a new assessment for the PCAFC program to make sure that it gauges a veteran's need for assistance and that the assessment is a validated instrument.

What we have found is that QoLF has the expertise to be the thought leader in the very niche space of caregiver. By staying in our lane, we are able to support larger VSO's from having to become masters of all, and to have them support us in our mastery. With our granting organizations, we cross refer. When families need PCAFC help, our grantors send the families to us, and when Veterans needs other assistance beyond PCAFC, we refer to our grantors for assistance.

Senator Bill Cassidy

Question:

Thank you for providing more information during our dialogue at the recent hearing, ″Heroes at Home: Improving Services for Veterans and their Caregivers.″ I want to formally recognize your efforts as the primary caregiver for your husband after he was wounded serving our nation.

Regarding our discussion, I wanted to follow up with you on the questions below about the Program of Comprehensive Assistance for Family Caregivers (PCAFC):

How can we change the VA's interpretation of assistance required for ″activities of daily living″ to include conditions that involve periodic periods of higher disability hardship? And how would ″regular assistance″ provide clarity for these types of conditions - were they initially included prior to Department of Veterans' Affairs reinterpretation?

Response:

Legislate the language surrounding Activities of Daily Living and the level of assistance needed by the veteran to ensure the intent of Congress to allow ″regular assistance with an ADL″ to be the standard for PCAFC eligibility rather than the current assistance standard of ″each and every time a veteran performs an ADL.″ The requirement that a caregiver must assist a veteran with an Activity of Daily Living (ADL) ″each and every time″ it is completed for eligibility in PCAFC was reviewed by the courts. The Veteran Warriors, Inc. v. McDonough ruled that this strict interpretation of assistance with ADL's under VA's regulation was allowed under the legislation creating PCAFC. However, VA Central Office CSP has acknowledged that this strict interpretation is keeping Veterans, especially older Veterans, out of the program and penalizing Veterans for being able to do anything for themselves which impedes progress in rehabilitation and potentially causes patient harm. This language change also impacted those Veterans with diseases with relapsing, remitting patterns. Prior to the 2020 regulation governing PCAFC, the ADL standard for PCAFC was ″regular assistance″ which was in line with the standard for Supervision, Protection, and Instruction and allowed for relapsing, remitting conditions.

While QoLF would not normally ask Congress to legislate this language to such specificity, we do so in this instance. The regulation governing PCAFC has changed four times since the creation of this program in 2011, and we are currently waiting for a new proposed regulation to be published any day now. In order to keep changes from being made each time there is new leadership at the helm of VA, we ask that Congress write the legislation into statute, preventing the legislative language that exists now from being continually re-interpreted by VA and necessitating the constant pauses in PCAFC that have occurred since the programs inception.

Question:

How can we clarify that supervision for ″activities of daily living″ be included as part of the ″each and every time″ standard so that we can provide needed relief to impacted Veterans and their families through PCFAC?

Response:

When guidance was issued to the field after Veteran-Warriors v. McDonough, the field was supposed to address activities of daily living that did not meet the ″each and every time″ standard under supervision, protection, and instruction. Supervision, protection, and instruction, allows CSP to look at each ADL through the lens of needing assistance for safety while performing the ADL on a ″regular″ basis. SPI on a ″regular basis″ for ADL's would meet the SPI standard for qualifying for SPI.

That ADL SPI falls under ″Does the veteran have the physical ability to cope or take action in a changing environment/″; ″What type of support does the veteran need to remain safe in the home?'; ″What type of support does the veteran need to remain safe away from the home?″; ″Is the veteran able to identify his needs?″; and lastly ″Is the veteran able to arrange for his health and safety?″

Since all of necessary guidance for ADL's under SPI exists already in field guidance, Congress could ask VA to take a retroactive look at ADL denials and see if any denials could be accepted under the SPI qualifications. This would impact most denials before June 2022, but after that, corrected guidance had been issued to and implemented in the field, in most cases.

As always, there are certain VISNs that do not comply with field guidance, and VACO CSP has little authority to fix this. VACO CSP has standardized authority, not centralized authority. This means if a VISN chooses not to abide by field guidance, there is little repercussions for the local Caregiver Eligibility Assessment Team, and only the Veteran/Caregiver Dyad suffer. If Congress wanted to fix this issue, Congress could give centralized authority to the Caregiver Support Program so that the VACO CSP staff could actually enforce the directive they are charged with writing and implementing but have only force of will and personality to implement under the current standardized authority granted to CSP.

U.S. SENATE SPECIAL COMMITTEE ON AGING

″HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS″

JUNE 5, 2024

QUESTIONS FOR THE RECORD

Fred Sganga

Ranking Member Mike Braun

Question:

In your opening statement, you mentioned that you run one of only three Adult Day Health Care (ADHC) facilities for Veterans. How long does a Veteran visit you during a day, and what differentiates your ADHC from other independent adult day programs? How do Veterans find out about this program? Who is eligible for this service? Does VA currently contract with your ADHC to provide respite care services for Veterans in VA's CSPs, specifically, PCAFC and PGCSS? Do you believe your ADHC would be able to provide this respite care?

Response:

″At this time, responses are not available for printing. Please contact the U.S. Special Committee on Aging for further updates and to obtain a hard copy, if available.″

Question:

Indiana only has one State Veterans Home. When I met with the Director of the Indiana Department of Veterans Affairs, he suggested it would be more cost effective and beneficial if the state could use existing long-term care facilities-like renting a wing of a nursing home in Evansville or Fort Wayne-as opposed to building an entirely new facility. However, VA doesn't currently allow these kind of satellite operations. Did VA previously allow satellite sites? Do you believe it would be more fiscally responsible if State Veterans Homes had the flexibility to utilize space in this way? During the hearing you were questioned on the impact of the nursing home minimum staffing rule by Senator King. Could you please expand on the following: How does this rule impact your facilities and other SVH directors' facilities? What are some creative staffing alternatives that CMS could consider while ensuring quality patient care standards are upheld?

Response:

″At this time, responses are not available for printing. Please contact the U.S. Special Committee on Aging for further updates and to obtain a hard copy, if available.″

Senator Kirsten Gillibrand

Question:

Living at home or in the community and receiving care during times of need is a basic right, but Veterans deal with long waiting lists and limited options for these services. The HCBS Access Act and HCBS Relief Act reinforces services provided in the home and community and give our Veterans with a disability dignified living choices. How would expanding support for home- and community-based services complement the current services provided by the VA?

Response:

″At this time, responses are not available for printing. Please contact the U.S. Special Committee on Aging for further updates and to obtain a hard copy, if available.″

U.S. SENATE SPECIAL COMMITTEE ON AGING

″HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS″

JUNE 5, 2024

QUESTIONS FOR THE RECORD

Meredith Beck

Ranking Member Mike Braun

Question:

In your testimony you mentioned Veterans simply do not know about critical benefits like the Caregiver Support Program. I am concerned that without sufficient outreach, education, and support, too many Veterans will never be able to use these services. How can the Veterans Administration make sure that every veteran eligible for these important benefits knows about and can use them?

Response:

″At this time, responses are not available for printing. Please contact the U.S. Special Committee on Aging for further updates and to obtain a hard copy, if available.″

Question:

It is important for the VA to ensure that Veterans are aware of the opportunities available to them. The VA posts information on many of its programs online. However, Aging Committee oversight found that the VA has not consistently made its websites and other technology accessible for people with disabilities, as required by law. Including people with disabilities in VA oversight could help. Senator Scott and I introduced a bill, S. 2516, the Veterans Accessibility Act, to give Veterans with disabilities a role in overseeing the VA's compliance with all federal disability laws, which the Elizabeth Dole Foundation has endorsed. How does noncompliance with federal disability laws limit access to VA programs? How would the Veterans Accessibility Act help ensure that the VA's programs are accessible for all Veterans and their caregivers?

Response:

″At this time, responses are not available for printing. Please contact the U.S. Special Committee on Aging for further updates and to obtain a hard copy, if available.″

Senator Kirsten Gillibrand

Question:

Five and a half million caregivers providing vital care for our nation's Veterans experience high levels of burden, distress, financial strain, and other negative consequences like depression. I am pushing to pass the Elizabeth Dole Home Care Act, which would provide these workers the support they need. Thank you for your testimony. This bill requires VA to conduct a review of the use, availability, and effectiveness of respite services. In what ways would an expansion of respite care better support the care and quality of life of caregivers?

Response:

″At this time, responses are not available for printing. Please contact the U.S. Special Committee on Aging for further updates and to obtain a hard copy, if available.″

Senator Kyrsten Sinema

Question:

I appreciate the Elizabeth Dole Foundation's endorsement of my Veteran Caregiver Re-education, Re-employment, and Retirement bill and your suggested amendment to eliminate annual income caps for dependency and indemnity compensation (DIC) payments to non-spouse PCAFC caregivers. Of the 2500 PCAFC parent caregivers cited in your written testimony, about how many would be eligible for DIC payments at their current annual income levels? Do payments from the PCAFC monthly stipend from within twelve months of a veteran passing count towards the

DIC eligibility income caps, even though the stipend payments are considered unearned income?

Response:

″At this time, responses are not available for printing. Please contact the U.S. Special Committee on Aging for further updates and to obtain a hard copy, if available.″

Statements for the Record

U.S. SENATE SPECIAL COMMITTEE ON AGING

″HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS″

JUNE 5, 2024

STATEMENTS FOR THE RECORD

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) Testimony

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging and Senate Committee on Veterans' Affairs joint hearing on ″Heroes at Home: Improving Services for Veterans and their Caregivers.″ The Association and AIM thank the Committees for their continued leadership on issues important to the millions of Veterans living with Alzheimer's and other dementia and their caregivers. This statement highlights the importance of services to meet the needs of our nation's Veterans living with Alzheimer's and other dementia, as well as their caregivers.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's and other dementia through the advancement of research; to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. AIM is the Association's advocacy affiliate, working in a strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

Nearly half a million American Veterans are living with Alzheimer's - and as the population ages, that number is expected to grow. In 2022, an estimated 451,000 Veterans were living with Alzheimer's. The U.S. Department of Veterans Affairs (VA) has projected the number of Veterans living with Alzheimer's dementia will increase by 8.4 percent through 2033 to more than 488,000. For Veterans, the prevalence may grow even faster in future years because they have a higher risk of developing dementia, as they are uniquely exposed to certain risk factors. For example, evidence indicates that even mild traumatic brain injury (TBI) increases the risk of developing certain forms of dementia. A recent meta-analysis estimated the increase in dementia risk from any form of TBI was nearly 70 percent. The significant increase in the number of Veterans with Alzheimer's and other dementias will place a heavy burden on the VA health care system, and in particular, nursing home care.

The Alzheimer's Association is deeply grateful for the VA's comprehensive approach to dementia and the people it affects: its extensive research, its care and support services within the Geriatrics and Extended Care program, and its participation on the Advisory Council on Alzheimer's Research, Care, and Services. We are particularly appreciative of our joint pursuits, including the Alzheimer's Disease Neuroimaging Initiative (ADNI) and the Partners in Dementia Care program, and we are glad to serve as a resource to the VA as it continues to balance the protection of its aging Veterans while encouraging the availability of high quality care.

Home-and Community-Based Services: The Impact on Family Caregivers and Needs of the Alzheimer's and Dementia Community

We are grateful for the VA's commitment to supporting Veterans living with Alzheimer's and other dementia by offering an array of long-term care and support services, such as assisted living, residential, as well as adult day and home health care.

Home-and community-based services (HCBS) allow people with dementia to remain in their homes while providing family caregivers with much-needed support. These services empower caregivers to provide quality care for their loved ones while allowing them to manage and improve their health. While 83 percent of care provided to older adults in the United States comes from family members, friends, or other unpaid caregivers, nearly half of these caregivers do so for individuals with Alzheimer's or other dementia. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families - either through out-of-pocket health and long-term care expenses or from the value of unpaid care. In 2023, caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours of informal - that is, unpaid - assistance, a contribution valued at $346.6 billion.

Several states are implementing innovative solutions to address Alzheimer's by developing critical, cost-effective, dementia-specific HCBS programs. These programs are allowing people with dementia and their caregivers to access services and support that are uniquely tailored to meet their needs, allowing them to remain in their homes and communities longer and enjoy a greater quality of life. Building off of innovative solutions by several states, the VA through the Veterans Health Administration (VHA) should consider adopting a core set of home-and community-based services that are specifically designed for people with dementia. A core set of HCBS, in addition to other services, will allow people with Alzheimer's to continue to remain in their communities and be independent for as long as possible.

Supporting Veterans' Access to High Quality Long-Term Care Services

While people living with Alzheimer's and other dementia and their caregivers often prefer to keep the individual living in the home for as long as is manageable, they make up a significant portion of all long-term care residents. More than 60 percent of the VA's costs of caring for those with Alzheimer's are for nursing home care. Given our constituents' intensive use of these services, the quality of this care is of the utmost importance.

While much of the training for long-term care staff is regulated at the state level, we encourage the Committees to consider proposals that support state VHA Medical Centers in implementing and improving dementia training for direct care workers, as well as their oversight of these activities. Training policies should be competency-based, should target providers in a broad range of settings and not limited to dementia-specific programs or settings, and should enable staff to (1) provide person-centered dementia care based on a thorough knowledge of the care recipient and their needs; (2) advance optimal functioning and high quality of life; and (3) incorporate problem-solving approaches into care practices.

We also urge the Committees to support VHA Medical Centers in the following efforts: (1) any training curriculum should be delivered by knowledgeable staff that has hands-on experience and demonstrated competency in providing dementia care; (2) continuing education should be offered and encouraged; and (3) training should be portable, meaning that these workers should have the opportunity to transfer their skills or education from one setting to another.

Conclusion

The Alzheimer's Association and AIM appreciate the Committees' steadfast support for Veterans and their caregivers and the continued commitment to advancing issues important to the millions of military families affected by Alzheimer's and other dementia. We look forward to working with the Committees and other members of Congress in a bipartisan way to advance policies to support the growing population of Veterans living with dementia and their caregivers.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS"

JUNE 5, 2024

STATEMENTS FOR THE RECORD

Jack Evans Testimony

Good afternoon. I am providing my written statement to you because I cannot attend this important hearing.

My name is Jack Evans, III. I am a retired major in the US Army Reserve, having served in the Reserve Program from May 1983 to May 2008. I live in Enola, Pennsylvania, and have been married to DiAnn Evans for approximately 35 years.

In 1991, I was diagnosed with diabetes and served the majority of my military career with this condition. In 2011, I was diagnosed with kidney failure and started hemodialysis shortly after this. In 2014, I began doing hemodialysis at home after my wife, who was a schoolteacher, received training on how to administer my treatments.

In 2021, my wife and I first applied for the VA Caregiver Support Program and were subsequently denied. We appealed the decision, and the VA has yet to respond as of today, June 11, 2024. Following the VA's suggestion, we reapplied for the program in the spring of 2023, receiving approval. My wife's and my circumstances did not change between our 2021 and 2023 applications, but the VA's assessment method did. The VA reviewed my 2021 application through video and voice calls, while they reviewed my 2023 application through an at-home visit, allowing them to comprehensively understand my needs.

Due to these discrepancies in assessment, the program manager at the VA in Lebanon, PA, suggested that we file a separate clinical appeal regarding the payments we should have received if the VA had approved us initially. Last week, the VA denied this appeal, more than two years after our original application to the VA Caregiver Support Program. In their denial letter, the VA included incomplete and inaccurate documentation that they reviewed to make this decision.

For instance, I received surgery in the fall of 2020 and underwent extensive rehabilitation for two weeks. However, according to the VA's documentation, I never had surgery then and only spent one day in rehabilitation. Furthermore, the VA did not consider my medical records before the fall of 2020, records from non-VA facilities, or any of my dialysis records, even though I have received dialysis treatments multiple times a week for a decade. We are patient, but my wife and I are entitled to the arrears from this program. That is why we will appeal this denial until we can access the benefits we deserve.

In saying this, I want to emphasize the following:

- The caregiving program's stipend is helpful to my wife, who facilitates my care. We do not collect a substantial sum for the time and effort she puts in daily, but spousal recognition is essential. My wife supported me throughout my 25 years in uniform, and we appreciate the VA's assistance.
- Through this program, my wife and I have access to a group of professionals who can discuss complex medical and emotional concerns with us, which is significant. A few times, we used this support system to make difficult decisions regarding my treatments.
- My wife has participated in videoconferences, and she tells me that these help her learn coping skills and hear from others with similar issues.
- However, finding out about this program and whether we were eligible was difficult. Like the VA Dialysis Program I participate in, I learned about the caregiving program via "word of mouth." It would have been beneficial if the VA had provided information about this program when my VA Disability Rating went up to 100%. Depending on how the VA would have evaluated my situation, I could have been eligible as a full-time dialysis patient as early as 2014.

In closing, I thank Senators Casey and Tester for their interest and attention to this critical and consequential support program.

Respectfully,

Jack O. Evans, III

U.S. SENATE SPECIAL COMMITTEE ON AGING

"HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS"

JUNE 5, 2024

STATEMENTS FOR THE RECORD

Jacob Johnson Testimony

My name is Jacob Johnson, and I live in Saylorsburg, Pennsylvania. I'm a native of Russiaville, Indiana, over 650 miles away. I have no family in Pennsylvania other than my 10-year-old son.

I joined the Marine Corps in 2002 and served until I was medically separated in 2014. After this, I followed my then-wife and our 4-month-old son to her hometown in Oregon. We moved to Pennsylvania in 2016 to be close to her mother, who lives in Scranton, Pennsylvania. I've had various health issues related to my service, much of which I believe is burn pit related, and I have primarily used the VA for my healthcare. My wife and I separated in 2018, and I've been divorced since then. I have several disabilities, with extensive PTSD and mental illness, as well as a brain injury, which I will discuss later.

In March of 2022, the VA hospital in Wilkes Barre, Pennsylvania, instructed me to go to the closest emergency room because I was pretty sick. I was diagnosed with necrotizing pancreatitis, and my body had begun to shut down. I was in kidney failure, my lungs were full of fluid, and I was septic. My doctors didn't think they were going to be able to save my life, and I spent the next seven months or so in and out of the hospital. I had drains in my abdomen, requiring flushing and tracking the amount of infected fluid coming out of my body twice a day. I was on a plethora of medications for infections, several other enzymes to keep me alive, and pain medicines that had to be regulated.

The VA hospital trained my then-girlfriend, Celeste, how to take care of me. She regulated my meds and kept a logbook of my drained fluid measurements, which she gave to the home care nurse, who came once a week to check on us. Celeste bathed me because I couldn't get my drains wet. Additionally, I could barely move around or reach anything below my waist. She wiped my backside because I couldn't even do that due to the drains from my abdomen and the 100 pounds of fluid I had gained from my kidneys not working correctly. Celeste forced me to eat because it was so difficult and painful for me to ingest food. She would take care of my son, who was eight at the time, which allowed me to spend time with him.

Celeste also took me to multiple weekly appointments because I could barely walk or drive. She would pick up my daily needs and medications because it was too painful for me to ride in a car. I was unable to communicate my health concerns to doctors and healthcare professionals due to the medicines I was on and the effects that sepsis and fevers had on my brain so Celeste would do this for me. I was a full-time project, and she took time off from her realtor profession to take care of me.

As I said, regarding the months and months Celeste spent caring for me, I was in no mental capacity to make sound medical decisions. Furthermore, I was in no mental capacity to advocate for our needs or perform research on which programs within the VA we might qualify for. Around October of 2022, I started researching potential health insurance programs for my kids as I realized I probably wouldn't be on my feet and working for quite some time. During my research, I stumbled upon the caregiver support program. My family applied for the program but was denied because they didn't recognize the level of care I needed. I still disagree with their assumption as I look back at where I was mentally and physically.

The VA also denied us any back pay. They told us they would not retroactively approve any service requests, which is astonishing. How do you deny a person something they qualified for when they weren't in any capacity to apply for it? Celeste's bills and house payments-none of that went away. Those were all still waiting for her even though she was taking care of me.

I tried to challenge the decision, but the caregiver support program manager at the Wilkes-Barre VA Clinic told me she would have to deny us again because none of my information had changed. She stated that she wanted to assist, but her hands were tied due to the legislative nature of the denial. The VA denied my family something we qualified for because I wasn't in the mental capacity to research or speak on my behalf due to a severe illness.

I thought we were doing the right thing in getting me out of the hospital to heal at home, saving taxpayers thousands of dollars a day for my care. Veterans are promised help and assistance from the VA, but they never back up their promises.

I'm not the only person in my area who has dealt with this very same issue, and it's extremely sad.

Another thing I should note is that the caregiver support manager told me that each VA clinic has a team of social workers who are supposed to push this information out, but this has yet to happen. My family didn't hear from any social workers until I contacted the caregiver support program manager in Wilkes-Barre. It was too little too late, though, and she couldn't do anything for us either. This is a program where Veterans' caregivers are constantly denied compensation, and there is nowhere or no one to advocate to for change. It's a dead-end road.

I was told to call my Senators and Congressmen, so I did that. I have been fighting this issue for over a year, and it is just now receiving attention from elected officials. I understand that you all are extremely busy people, and I can respect and appreciate that. What I don't understand is the massive overreach for these small programs. People die and lose their homes, cars, and electricity, waiting to be heard on these issues even though the government and VA hires program managers to address these concerns.

Furthermore, I would say these program managers are more than capable of making case-by-case decisions for Veterans and their families who are in need. Taxpayers are left to assume that their money funds excellent programs through the VA and that the VA listens to and promptly assists each veteran and their family. I can tell you this is not the case from my experience as a veteran trying to utilize the resources I need. The VA already has the necessary tools and personnel, but they can't make common-sense, case-by-case decisions for anyone to access their programs.

I also think ″retroactive″ processes need to be addressed if we aren't going to utilize our social workers in a way that could benefit every veteran. I don't understand how it is so difficult to notice if a veteran has an illness that could potentially kill them or leave them and their family in a bad spot for months on end. It makes us, as Veterans, wonder why tax dollars go to pay these social workers if no one even knows they exist, and they don't reach out to families who are in obvious need of extra services.

Fast forward a year or so - in October of 2023, I had to call the VA crisis line. I had a mental breakdown and began contemplating suicide. I was tired of feeling like I was holding my family back from their lives with everything I had going on. The fact that Celeste was behind on her mortgage and other bills had taken its toll on my mental health. I felt as though the very government that I went to battle for, receiving injuries in the process, had turned its back on me, my family, and my loved ones. I also felt that this was my fault, and I wanted to take myself out of the picture so everyone around me could move forward with their own lives. I called the crisis line, but I waited six weeks to receive proper mental health care.

We hear politicians say, ″Twenty-two a day is way too high.″ They say, ″How do we get that down?″ However, to Veterans, it's more than a campaign slogan. I know more Veterans who have taken their own lives than I can count on one hand, but we can change this. Often, it comes down to us feeling as if we are holding back our loved ones from reaching their full potential for one reason or another, which is precisely how I felt.

It is hard watching another human being stress over finances when you know in your heart and mind that you are the cause of that stress. Celeste is still digging herself out of the hole she's in, and no one has reached out to her, saying, ″Hey, we owe you this for taking care of one of ours.″ She's never even received a thank you for how she has helped me and my kids. If it weren't for her, I wouldn't be here today, and my kids would be suffering as a result. As I close with this portion of my letter, I ask again that she receive the compensation she earned while taking care of me, which would allow her to catch up on mortgage payments and other bills from when she could not work.

You all have to understand that many Veterans are in my shoes as they don't move back to their hometowns once they exit the military and instead follow their spouses and kids to a new home. You also have to understand that the divorce rate for veteran families is exceptionally high. With that being said, many Veterans are divorced, living hundreds of miles away from their families and friends so they can be close to and have a hand in raising their kids to be successful in life. We date new people who aren't familiar with how the VA works, as we're not that familiar with it until we need to use it. There is an encyclopedia of programs the VA offers, and no one can ever memorize all of them. We sometimes can't advocate for ourselves, and no one steps in to do that for us. There has to be some way to advocate for the other side of things once we have our capacities back, and unfortunately, there isn't.

As far as recommendations for improvements:

- Implement retroactive approvals for Veterans and their families in situations where the veteran cannot research programs during a time of need due to health reasons.
- Look at why families are being denied the caregiver support program at an alarming rate.
- If we want to change the suicide rate in the veteran community, listen to what the Veterans are saying. It seems from our perspective that many things are assumed and not discussed.
- Ensure VA social workers reach out to Veterans and their families, especially those outside hospitals, to address their needs through community care. The Veterans in outside care facilities are often forgotten about by their VA team.

I hope this information makes sense and you consider it when drafting legislation significantly affecting veteran service members and their loved ones. These programs are designed to do great things for the veteran community, but we need to ensure they're accessible and that the application processes are sensible for everyone. I appreciate you all reaching out to me and hearing my story. Thank you for all that you do for us and our loved ones.

Respectfully,

Jacob Johnson

U.S. SENATE SPECIAL COMMITTEE ON AGING

″HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS″

JUNE 5, 2024

STATEMENTS FOR THE RECORD

Jerry Hromisin Testimony

My name is Jerry Hromisin. My wife, Mary Ellen, son, Thomas ″TJ,″ and I live in Pittston, Pennsylvania. Mary Ellen and I are sharing TJ's story as his sole caregivers.

In 2005, TJ graduated from the University of Scranton at the top of his ROTC class and then joined the U.S. Army. In May of 2007, while leading a platoon of soldiers, he was shot by a sniper. TJ lost both of his eyes and one-third of his brain, but he survived against all odds.

When TJ returned home, he was barely functioning. He could not sit up or walk, and he depended on a feeding tube for nutrition. TJ also underwent extensive rehabilitation while recovering from numerous surgeries. At one point, doctors replaced his skull with polymer, but the procedure failed, leading to infection, and requiring another complex operation with years of recuperation.

Mary Ellen and I revolve around TJ. He is the center of our lives, and we take care of his every need. Because of TJ's severe brain injury, his life is built on uniformity - every task must be repeated in the same way and at the same time. For instance, each morning, I lay out breakfast materials, arranging dishes and silverware so that TJ won't struggle to find his food. I check that his shampoo and soaps are on the correct shelves in the shower, and I arrange his clothes according to their patterns and colors.

Mary Ellen carefully organizes TJ's many seizure medications and supplements in containers with dots and Velcro, but TJ still cannot take them on his own. She is the only one who knows how to clean, remove, and replace TJ's prosthetic eyes.

In the time since TJ's injury, we have made many friends at the VA in Wilkes-Barre, Pennsylvania. They notified us of their caregiving program, which compensates those caring for their loved ones full-time. We enrolled, and Mary Ellen began receiving a small stipend, which was cut by a third after TJ's first yearly evaluation. Due to the most recent assessment, our family will be dismissed from the program in September 2025.

The evaluators of this program made their decision after asking TJ misguided questions over the phone without attempting to understand his care needs. They said, ″TJ, can you walk 10 feet alone?″ He answered yes, so they assumed he could call a taxi, use mass transportation, and travel to his doctor's appointments alone. In reality, TJ doesn't leave our home without either Mary Ellen or me at his side - if he did, he would wander Pittston aimlessly.

Our family's efforts to appeal this decision have failed. As a result, we will lose our monthly stipend in addition to support services, such as caregiver teleconferences for managing stress and book club meetings. The stipend itself is not much - if the VA had to provide care within a facility for all of the individuals in the program, their combined stipends wouldn't cover the cost. However, with this money, I can buy a few things for Mary Ellen to brighten her day or pay a couple of our bills.

After September 2025, my family will still eat and provide constant care for TJ, but receiving the stipend is a matter of principle. If the VA were ending the program, we would understand. If the program exists, and there are families enrolled, while TJ, who lost his eyes and one-third of his brain in service to our country, is disqualified, then we are left wondering who truly qualifies.

The VA's caregiving program supports countless families of injured service members. Please protect and strengthen access to this program for caregivers like Mary Ellen and I providing life-saving care to Veterans like TJ.

Thank you for reading our testimony.

Respectfully,

Jerry Hromisin

U.S. SENATE SPECIAL COMMITTEE ON AGING

"HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS"

JUNE 5, 2024

STATEMENTS FOR THE RECORD

Mark O. Rosensteel Testimony

I joined the U.S. Air Force right out of high school on February 19, 1980, and went to basic training at Lackland Air Force Base in Texas for approximately eight weeks, graduating on April 1, 1980. Then, I went to a technical school in Denver, Colorado, for three months of intense training in electronics and optics. I learned how to maintain and operate high-altitude reconnaissance cameras for RF4C Phantom II Jets.

My unit used RF4C Phantom II Jets, which were flown extensively during the Vietnam War, for photography, topographical map-making, and bomb damage evaluation. From 1980 to 1983, the Air Force trained pilots to continue assessments with these jets and provide photographic reconnaissance of numerous conflicts, including Desert Storm in Iraq. Several times, the U.S. Forestry Service commissioned us to use a special film capable of distinguishing between living trees and those that had died due to fire, insects, or other causes.

The RF4C Phantom II Jets had six cameras, including one for infrared photography. These jets also carried magnesium cartridges, which acted like giant flashbulbs, lighting up the night sky and allowing us to use standard film cameras.

We had problems from time to time, which you may have seen in the news. At Shaw Air Force Base in Sumter, South Carolina, I reviewed film of a plane crash during pilot training. Two of our pilots had an in-flight emergency and could not return to base, so they ejected from their aircraft over the ocean. Usually, search and rescue would find pilots in a matter of hours, but on this particular day, it was not so.

We flew planes 24 hours a day for ten days, searching for the pilots, but only found one. On the tenth day, the base commander called off the search. Even now, putting these words to paper hurts thinking of that lost pilot and his family. My unit developed close friendships working with pilots daily and ensuring their equipment properly functioned for each flight. However, sometimes, it just didn't work out.

I was at Shaw Air Force Base for approximately eighteen months before the Air Force transferred my unit to Bergstrom Air Force Base in Austin, Texas. I worked there until the day of my injury.

One weekend, we organized a cookout for a friend heading overseas for a one-year assignment. Everything was going great until I dove into a swimming pool unmarked for depth. I immediately snapped my neck, and my new story began.

Paramedics soon rushed me to the hospital. I immediately spoke with my surgeon, and we worked everything out, or so I thought. Unbeknownst to me, after putting me on pain medication, my doctors made decisions without my consent, causing more damage to my spinal cord. To give you some context - anytime you are injured, you are covered by the military if you are wounded within 25 miles of your duty station or on leave, making my injury 100% service-connected.

If the doctors in Austin, Texas, had fully operated on me, removing the damaged bone chip from my spinal cord, it would have reduced the severity of my injury by 90 percent. Instead, I was transferred to Wilford Hall in San Antonio, Texas, where I waited two weeks before moving to Cleveland, Ohio. There, at the nearest spinal cord injury center, I finally had a second operation to remove the bone chip causing my paralysis.

The next day after surgery, I started to get movement back in my arms and wrist. Even though I went to therapy five days a week for the next year, I was never able to move my fingers or legs again. I tried everything I could to no avail.

Now, I use V.A. facilities for medical care when needed. Through one of their services, the Homemaker Health Aide Program, I receive care five days a week, which is a tremendous help.

The Elizabeth Dole Home - and Community-Based Services for Veterans and Caregivers Act of 2023, or the Elizabeth Dole Home Care Act of 2023, compensates Veterans' family members for their tireless work providing essential care. These programs save money, keeping Veterans out of expensive nursing homes. About ten years ago, I had a friend living in a nursing home who paid $6,000 monthly for a double room. She lived with a patient who continuously set off alarms all night long, trying to get her out of bed. The misery she went through in that nursing home was not fit for a dog. I could discuss this more, but it would take another two pages. If you have never had the chance, visit a few nursing homes, which will tell you all you need to know about how the staff care for their patients.

The VA caregiving program is vital for Veterans with ALS - amyotrophic lateral sclerosis - and MS - multiple sclerosis. ALS is highly debilitating, and in most cases, Veterans with this condition rarely last long enough to receive care before their paperwork is done. Therefore, I believe these programs must be reformed and expanded so Veterans can receive fast-tracked care. It is debilitating for family members left behind to watch their loved one's health, in some cases, deteriorate before their eyes.

I have suffered from my condition for 41 years and now rely on a wheelchair, still doing the best I can to help my fellow Veterans wherever I go. Over the past few years, an organization I am involved with, Five Plus with Paralyzed Veterans of America, has advocated with our legislative dignitaries, trying to explain how important it is to care for our fellow Veterans. I understand there is only so much that can be done at once, but we need to do all we can.

Thank you for this opportunity, Senator Casey.

Respectfully,

Mark O. Rosensteel

U.S. SENATE SPECIAL COMMITTEE ON AGING

"HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS"

JUNE 5, 2024

STATEMENTS FOR THE RECORD

Rob Grier Testimony

My name is Rob Grier, and I am the son of a United States Air Force disabled veteran and civil rights pioneer. I reside in Pittsburgh, Pennsylvania. Since 2010, I have been a caregiver for my parents, who are aging and have had significant health challenges.

My mother, an early childhood educator who obtained her PhD from the University of Pittsburgh, passed away in 2016 after being diagnosed with Alzheimer's. My father is a proud Air Force veteran who served our country with honor and now faces service-connected disabilities. This journey has been both rewarding and challenging, and I am grateful for the support we have received from various Veteran Administration (VA) programs and initiatives.

I would like to extend my deepest appreciation to Senator Bob Casey and his dedicated staff for their leadership and unwavering commitment to supporting caregivers and aging Pennsylvanians. Senator Casey's efforts have significantly impacted the lives of Pennsylvanians and the rest of the country, mainly through the Senator's role as Chairman of the Special Committee on Aging.

I am also profoundly grateful to Senator Elizabeth Dole, CEO Steve Schwab, and the entire staff at the Elizabeth Dole Foundation for their relentless advocacy for veteran caregivers. The Honorable Denis McDonough, leading the Department of Veterans Affairs, has shown exceptional leadership in improving VA services. I give special thanks to Donald Koenig, Director of the VA Pittsburgh Healthcare System, and Jamie DaPos from the VA Pittsburgh Caregiver Support Services for their outstanding work. I also give a heartfelt thank you to Dad's long-time primary care physician, Dr. Maria Venegas Ortiz. Dad may not be here with us without her care and professionalism.

Furthermore, I extend my heartfelt thanks to President Joe Biden for his leadership and dedication to the welfare of Veterans and caregivers. His commitment to addressing the needs of our nation's Veterans has been instrumental in driving positive change. Additionally, I am grateful to Secretary of Defense Lloyd Austin for his awe-inspiring leadership and support of initiatives that enhance the lives of service men and women, Veterans, and their families.

The United States is facing a caregiving crisis exacerbated by an aging population, a shrinking healthcare workforce, the impacts of COVID-19, and insufficient funding for social services. According to the US Census Bureau, by 2050, the number of Americans aged 65 and older is expected to increase by 47%, with at least half needing caregiving. This situation demands urgent attention and action to support caregivers and their families.

The Pittsburgh VA Healthcare System provides world-class care for thousands of Veterans across the United States, setting a benchmark for the nation. Programs like the VA Caregiver Support Program have been invaluable in allowing me to care for my father at home. This support has included training, technical assistance, and access to a network of professionals dedicated to the well-being of Veterans and their families. Additionally, the VA's Program of General Caregiver Support Services (PGCSS), CPR Training, Aid and Attendance, and respite care have been a tremendous help.

The collaboration between the VA and the University of Pittsburgh Medical Center (UPMC) is a model of innovation. It enables clinicians to rotate through different departments and share best practices, enhancing the quality of care provided to Veterans and the general public. UPMC practices inclusive care daily, exemplifying the commitment to integrating caregivers into the healthcare team. This ensures comprehensive and holistic care for our Veterans and the public.

Family caregivers can improve the quality of life for disabled Veterans and help them recover and rehabilitate. A 2015 National Library of Medicine study found that the VA's Caring for Older Adults and Caregivers at Home (COACH) program helped Veterans with dementia live longer at home and leave institutional care more quickly. The Program of Comprehensive Assistance for Family Caregivers (PCAFC) also supports caregivers of post-9/11 Veterans who need help with daily activities or supervision.

The National Institutes of Health research has shown family caregiving has significant benefits for patients and health systems because it reduces nursing home stays, inpatient visits, and formal home care use. Caregivers who care for Veterans with trauma-based comorbidities reported intensive caregiving and significant levels of distress, depressive symptoms, and other negative consequences. These caregivers require comprehensive support services, including access to health care, financial assistance, and enhanced respite care. The planned expansion of VA caregiver support has the potential to provide positive benefits for this population and serve as a model for caregiver support programs outside the VA healthcare system.

Caregiving is critical in reducing loneliness among Veterans and patients in need. Loneliness is a significant risk factor for suicide, particularly among Veterans. According to the National Institutes of Health, the suicide rate for Veterans is 1.5 times higher than that of the general population. The suicide rate is 2.5 times higher for female Veterans compared to their non-veteran counterparts. In 2017, the veteran suicide rate in the United States was just over 27 suicides per 100,000, compared to 14 suicides per 100,000 among civilians. Loneliness and social isolation are closely linked to these alarming statistics.

Research has shown that caregiving helps reduce loneliness and improve social connections, which are vital in preventing suicide. Caregivers provide emotional and social support, creating a sense of belonging and community for those they care for. By fostering these connections, caregivers can significantly lower the risk of suicide among Veterans and other individuals in need.

Caring for my parents has been a deeply personal and transformative experience. Now, having the ability to support my father at home means that he can age in a familiar and loving environment, surrounded by family. This improves his quality of life and provides a sense of dignity and respect for his service to our nation.

The programs and resources provided by the VA, the Elizabeth Dole Foundation, and UPMC have been crucial in navigating this journey. From training and education to financial and emotional support, these initiatives have empowered me to be a better caregiver and advocate for my father's needs.

These are my recommendations to improve the VA caregiver program -

•Expand Proven Programs: The successful programs that were most beneficial to us, like inclusive care, home health aides, respite, and the Post Acute Recovery Clinic (PARC) at the VA Pittsburgh Healthcare System, should be extended to other Pennsylvania VA hospitals and hospitals nationwide, ensuring that all caregivers have access to the best practices and resources.

•Increase Funding and Resources: Social services and medical care programs need increased funding to meet caregiving's rising costs and demands.

•Promote Private Sector Partnerships: Leveraging the support of private sector partners like UPMC, Comcast NBCUniversal, USAA, and AARP can provide additional resources and innovative solutions to support caregivers.

•Support Legislative Initiatives: The Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act, which would make federal funding available for the first time to local governmental veteran service officers, would help Veterans navigate the VA benefit landscape in their local communities.

The caregiving crisis in the United States requires immediate and sustained action. I am encouraged by the efforts of Senator Casey and the collaborative initiatives between the public and private sectors. Together, we can create a future where caregivers are supported, and aging individuals receive the care and respect we all deserve. Thank you for the opportunity to share my journey and advocate for improved caregiving policies.

Respectfully,

Rob Grier

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