VA'S CAREGIVER PROGRAM: ASSESSING CURRENT PROSPECTS AND FUTURE POSSIBILITIES

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VA'S CAREGIVER PROGRAM: ASSESSING CURRENT PROSPECTS AND FUTURE POSSIBILITIES

Wednesday, December 3, 2014

U.S. HOUSE OF REPRESENTATIVES,
COMMITTEE ON VETERANS' AFFAIRS,
SUBCOMMITTEE ON HEALTH,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10:00 a.m., in Room 334, Cannon House Office Building, Hon. Dan Benishek [chairman of the subcommittee] presiding.

Present: Representatives Benishek, Roe, Denham, Huelskamp, Wenstrup, Walorski, Jolly, Brownley, Brown, Ruiz, and Kuster.

OPENING STATEMENT OF CHAIRMAN DAN BENISHEK

Dr. BENISHEK. The subcommittee will come to order. Good morning, and thank you all for joining us today for our oversight hearing entitled "The VA's Caregiver Program: Assessing Current Prospects and Future Possibilities." According to a recent RAND Corporation report, there are approximately 5.5 million military or veteran caregivers providing care to active duty servicemembers or veterans that if provided by home health attendants instead would cost our country more than $13 billion. Though that number is staggering, the real value caregivers provide cannot be quantified.

For veterans who have been severely wounded in service to our country, caregivers are lifelines. For the Department of Veterans Affairs, caregivers are increasingly important partners. They are there when VA cannot be and they function in ways a government bureaucracy will never be able to, filling in gaps, picking up the slack, and supporting the day-to-day recovery and rehabilitation of wounded veterans on a 24-hour, 7-days-a-week basis, often to the detriment of their own physical, mental and financial health and stability.

In recognition of the services caregivers provide and the sacrifices they endure, Congress passed public law 111–163, the Caregivers and Veterans Omnibus Health Services Act of 2010. This law created two programs of comprehensive caregiver support; one general program available to caregivers of veterans of all eras, and one targeted program available to caregivers of post-9/11 veterans only. This targeted program called the Family Caregiver Program will be our primary focus this morning. And through our work, I hope to discuss both where the program is today and where it needs to go tomorrow.

In a report issued in September, the Government Accountability Office found significant issues with the current management of the Family Caregiver Program and by extension, with the services it provides to family caregivers and to severely wounded veterans. According to GAO, VA's initial estimates for the Family Caregiver Program were significantly off base with a number of approved family caregivers in place today, more than triple what the VA originally estimated.

VA's staffing and workload projections for the Family Caregiver Program were similarly inaccurate, leading to caregiver support coordinators at some VA medical centers with caseloads of up to 251 caregivers, and application backlogs numbering in the hundreds in some locations.

Exacerbating these problems, the GAO also found that the Caregiver Support Program office was unable to readily access workload numbers and other important data about the program, making effective oversight of the program nearly impossible.

These issues led the GAO to conclude that after 3 years of operations, it is clear that the VA needs to formally reassess and restructure key aspects of the Family Caregiver Program.

Make no mistake, while challenges abound and must be overcome, the Family Caregiver Program is critical to providing the support of services that caregivers and veterans they serve require, and it must be strengthened and improved, not abandoned or left to fester.

What is more, as our veteran service organizations express so eloquently in their statements for the record, as we examine how to reassess and restructure the current Family Caregiver Program, we must also examine ways to potentially expand it to be more inclusive of caregivers for pre-9/11 veterans. The services these caregivers provide, while different in some important ways, is no less important and no less worthy of our appreciation and our support.

However, it troubles me that the VA's report to Congress last year and potential expansion of the post-9/11 caregiver program stated that estimating accurate participation rates in cost estimates for an expanded version of the program would be challenging and inexact. To proceed with a program expansion without taking all potential costs and resource requirements into account, would pose risk of compromising other aspects of the VA's core mission.

Making the Family Caregiver Program a long-term viable program for those caregivers who contribute so much to the quality of life for our disabled veterans would require diligent effort and close coordination with the VA, our service organization partners and others. This morning's hearing is just the start of that work. I look forward to continuing it in the 114th Congress.

With that, I now recognize Ranking Member Brownley for any opening statement she may have.

OPENING STATEMENT OF RANKING MEMBER JULIA BROWNLEY

Ms. BROWNLEY. Thank you, Mr. Chairman, and good morning. I would like to thank everyone for attending today's hearing. As ranking member of the Health Subcommittee, I certainly take seriously our responsibility to conduct oversight of veterans' health ad-

ministration programs to ensure that they are working as intended, and that is to improve the lives of veterans and their families.

In 2010, Congress passed the Caregivers and Veterans Omnibus Health Services Act, which established the Department of Veterans Affairs Family Caregiver Program. Today, the subcommittee will examine findings and recommendations from two very important reports from GAO and RAND Corporation that were released this year on VA's caregiver program.

I look forward to learning more about how VHA will manage its IT strategic needs and to discussing ways that we can work together to improve caregiver programs at the Department of Veterans Affairs and other Federal agencies.

In my view, the subcommittee should also explore the feasibility and cost associated with expanding the caregiver program to family caregivers of pre-9/11 veterans.

Mr. Chairman, this issue is an important one and I thank you very much for holding this hearing today. However, given the scope of the program and the magnitude of the issue, I would ask that we could possibly have a follow-up hearing. To be held so that we may address other concerns that have been raised by the veterans service organizations and other important stakeholders.

Again, I want to thank our panelists for participating today and I look forward to your testimony. With that, I will yield back the balance of my time.

Dr. BENISHEK. Thank you. Joining us on our first panel is Randy Williamson, Director of Health Care for the Government Accountability Office. Mr. Rajeev Ramchand, Senior Behavioral Scientist for the RAND Corporation. Thank you both for being here this morning.

STATEMENT OF RANDALL B. WILLIAMSON

Dr. BENISHEK. Mr. Williamson, please proceed with your testimony.

Mr. WILLIAMSON. Good morning, Chairman Benishek, Ranking Member Brownley, and members of the subcommittee. I am pleased to be here today to discuss GAO's review of the VA Family Caregiver Program. For many veterans who are severely injured while serving in the military, caregivers are most often family members who provide vital assistance for tasks of everyday living.

My testimony today focuses on how VA has implemented its Family Caregiver Program, including how it has managed the higher-than-expected demand for caregiver services and the resulting impact on VA medical centers, and ultimately on caregiver applicants, and veterans alike.

The VA established its Family Caregiver Program in 2011, and VA is expected to spend over $300 million on this program in fiscal year 2015. In designing the program, VA originally estimated about 4,000 caregivers would be approved for the program by September 2014.

Based on that estimate, VA established a staffing model for the program, which included placing a caregiver support coordinator at each VAMC. In turn, each medical center was expected to provide physicians, nurses and other clinical and administrative staff with

only limited reimbursement from the program to carry out essential functions, such as conducting medical assessments for eligibility and making quarterly home visits.

As of November 2014, over 18,000 caregivers have been approved for their Family Caregiver Program, about 4-1/2 times the original estimate. The unexpected surge of caregiver applications, which has averaged about a 1,000 a month since the program begun, has caused severe workload problems at many VAMCs and has ultimately delayed some caregivers and veterans from receiving timely approval determination and program benefits.

For example, physicians and nurses at many VAMCs who already have heavy patient workloads are not able to timely complete all essential tasks needed to qualify caregivers for the program. Many VAMCs are unable to timely complete the application process for the program in the 45 days it is supposed to take. We found that 65 VAMCs were taking more than 90 days to process applications. At one hospital we visited, they had over 400 unprocessed applications, some stating back to June 2013.

Also, the workload of caregiver coordinators at VAMCs varies widely, ranging from 6 to 251 caregivers served. And at 54 VAMCs, caregiver coordinators had more than 100 caregivers per each coordinator.

Coordinators told us that the—caregivers told us that the amount of time that VA caregiver coordinators can devote to them is often crucial to their success in effectively assisting veterans.

The heavy workload at many VAMCs due to higher-than-expected demand for caregiver services and the time needed to process caregiver applications and appeals, and provide other services is yet another example where VA is stretching available resources at its medical centers to the potential detriment of veterans.

While the VA has taken incremental steps to address problems with the program, many VA facilities still face daunting challenges to best serve caregivers and veterans. At the program level, the VA needs to make major improvements. First, VA program managers need to readily access accurate and complete data to systematically and routinely monitor the effects of the caregiver program on the limited resources at its medical centers and make adjustments where necessary.

Currently, the VA must struggle with the very labor-intensive Web-based system that was developed quickly under then-existing constraints and was designed to manage a relatively low volume of information for what was conceived to be a much smaller program. The VA is uncertain how long it will take before a new system can be developed.

Second, VA's caregiver program managers need to fundamentally reexamine the program and consider modifications that streamline the application and home visit processes, identify ways to improve staffing support for the caregiver program at VAMCs, and assess the overall impact that the program is having in improving the well-being of our Wounded Warrior veterans.

Until these issues are properly addressed and resolved, the quality and scope of caregiver services and ultimately the well-being of veterans served will likely continue to be compromised.

This concludes my opening remarks.

[THE PREPARED STATEMENT OF MR. RANDALL WILLIAMSON APPEARS IN THE APPENDIX]

Dr. BENISHEK. Thank you very much, Mr. Williamson. Mr. Ramchand, please proceed with your testimony.

STATEMENT OF RAJEEV RAMCHAND

Mr. RAMCHAND. Thank you, Chairman Benishek, Ranking Member Brownley, and members of the subcommittee for inviting me to testify today. My name is Rajeev Ramchand, I am a senior behavioral scientist at RAND, and for the past 10 years, I have been studying post traumatic stress disorder and suicides among servicemembers and veterans.

Earlier this year, my colleagues and I turned our attention to the men and women who are caring for our Nation's wounded, ill and injured veterans, our veteran caregivers. Today, I am going to present five key findings from our research and highlight recommendations for better serving this population of hidden heroes.

First, as were mentioned in the opening remarks, our Nation's veteran caregivers are a large group who services save the Nation billions of dollars each year. It is also a diverse group and a most pronounced difference is between those assisting veterans who served before and after September 11th.

There are 4.4 million pre-9/11 veteran caregivers. These caregivers are mostly adult children taking care of their parents who are suffering from conditions associated with aging, like dementia or cardiovascular disease. In contrast, there are 1.1 million post-9/11 veteran caregivers. These caregivers are young men and women taking care of their spouses, neighbors taking care of a friend, or parents taking care of their children. These veterans they are caring for have conditions largely associated with their service in Iraq and Afghanistan, 60 percent have a behavioral health condition like PTSD.

Organizations wanting to serve all veteran caregivers must offer services that meet the needs of both groups. In some cases, it may be better to avoid offering services altogether to certain sub groups, if it is not possible to do so with competence.

Second, while there are over 100 organizations currently offering services to caregivers, not all programs are available to all caregivers. Programs like the VA Program of Comprehensive Assistance for Family Caregivers offers services exclusively to post-9/11 caregivers. However, there are many organizations across the country only available to caregivers assisting people over the age of 60 or with Alzheimer's disease, thereby excluding most post-9/11 caregivers.

In addition, some organizations offer services only to family caregivers, which excludes 25 percent of post-9/11 caregivers who are friends taking care of a buddy.

Third, caregiving affects caregivers' health and economic well-being. Depression is significantly higher among caregivers than among non caregivers, and the time spent performing caregiving duties is directly linked to the likelihood that a caregiver will be depressed. Respite provides temporary breaks from caregiving duties and can directly mitigate the risk of depression among caregivers.

In addition, over half of veteran caregivers have wage jobs, but their caregiving duties frequently require that they take unpaid time off work, cut back work hours or quit working altogether. Employers can adopt policies that protect against discrimination in recruiting, hiring and promoting caregivers. They can also accommodate caregivers by offering flexible work schedules and employee assistance programs. These efforts protect against some of the economic consequences caregivers face, but they also benefit employers to increase productivity and retention.

This leads to my fourth point that supporting veteran caregivers on any—does not rely solely on any single entity, but requires coordinated action. This means that the private sector needs to work with the public sector, local, State, and Federal Governments also need to be coordinated. Within the Federal Government, DoD, VA, HHS and Department of Labor all play prominent roles. Coordination across these entities through things like the interagency workgroups or tasks forces and Federal commissions could enhance the alignment and quality of services to support veteran caregivers.

The final point I would like to make is on the value of research. Very few studies exist or are currently being conducted that evaluate caregiver support services. Continued funding of organizations that serve veteran caregivers should be predicated upon evidence that the services they offer are providing value. This requires research to identify which services reduce caregiver burden and which are ultimately improving veteran care.

There is a need to better support America's veteran caregivers. We may need to expand existing programs, but efforts are also needed to engage entities across the country to play closer attention to these hidden heroes.

Thank you again for inviting me to testify. I am happy to answer your questions.

[THE PREPARED STATEMENT OF MR. RAJEEV RAMCHAND APPEARS IN THE APPENDIX]

Dr. BENISHEK. Thank you very much for your testimony. I yield myself 5 minutes for questions.

Mr. Ramchand, a couple of things you said perked my interest, the first one I want to mention is this coordination of all the sources of available help basically. How does that happen? How would you suggest that that happens? I mean that is a real problem as I see it as well and I am glad you brought it up, but where is that occurring. The VA doesn't seem to be leading in that. What is your idea?

Mr. RAMCHAND. I think this idea of interagency work groups, especially between the DoD and the VA, if we just start there, eligibility requirements for the Scattle program and the VA program of comprehensive assistance to family caregivers, they have different eligibility requirements. So ensuring that people can have seamless continuity between when their caregivers serving as member of the Armed Forces, then a veteran, and then somebody into old age, an older veteran, because many of these post-9/11 veterans who require caregiving support are going to require that support for quite a long time. So I think that the need for coordination across these entities is profound, and I think that there are targeted ways and issues that they can address in that alignment.

Dr. BENISHEK. Tell me how I should make that happen Mr. Ramchand? Explain to me how I can get the DoD and VA to have the same medical record. Do you understand what I am saying? How do I go about doing that, making that happen?

Mr. Williamson, do you have any ideas?

Mr. WILLIAMSON. Well, supposedly they have interagency working groups that would help make that transition, but Mr. Ramchand is correct, the DoD caregiver program has different eligibility requirements, probably more stringent than the VA. The DoD covers more different kinds of injuries and illnesses than VA, but basically making that transition from one program to the other can be difficult. Although, when we looked at both programs we didn't hear that as one of the major problems.

Dr. BENISHEK. Mr. Ramchand, one of the other things you said was you mentioned that some time you thought it would be better if there was no assistance offered, I didn't quite understand what you meant there.

Mr. RAMCHAND. If we can't offer services that meet the unique needs of certain caregiving groups, they can become frustrated by the organizations, lose confidence, stop seeking care altogether. So for example, if a program is currently designed only to serve persons with traumatic brain injury or Alzheimer's disease, including now in that program, a new group of caregivers who are taking care of people with very different injuries, mental health problems, if they can't serve this group with competence, if they don't recognize that this group of caregivers also have unique needs, are we really providing value by then opening the services to that group if we can't meet them where they are.

Dr. BENISHEK. I understand. Do either one of you know exactly what the assessment is that the coordinator provides when they go—I assume that these people are doing home visits on a quarterly basis and then assessing what is going on by talking to the caregiver and the veteran, and trying to assist them with many other assets that they have. How long does that take? I am sure there is a lot of variability, but can you kind of talk about that a little bit?

Mr. WILLIAMSON. Now, are you talking about the application process?

Dr. BENISHEK. I am actually talking about the coordinator who has 251 cases, are these coordinators going to the home and then assessing what is happening and the status of the veteran and the caregiver in recommending changes? What exactly happens in that process?

Mr. WILLIAMSON. Nurses from the VAMCs actually go into homes and make quarterly visits—or are supposed to anyway—and do an assessment, provide counseling to the caregivers and the vets about their particular issues, medical issues.

Dr. BENISHEK. Did you talk to caregivers?

Mr. WILLIAMSON. Yes.

Dr. BENISHEK. What was their——

Mr. WILLIAMSON. Actually, most of them have much trepidation before their first visit because they think the nurse is going to come in and take away their benefits. Actually, the caregivers we

talked to were very complimentary of that service, they thought it was a very valuable services.

Dr. BENISHEK. Were there lots of complaints about not having access to the coordinator?

Mr. WILLIAMSON. That—having access to coordinators is another issue, because—yes, caregivers told us that is a big problem in those areas where the caregivers have a large workload.

Dr. BENISHEK. All right, I am out of time. Ms. Brownley.

Ms. BROWNLEY. Thank you, Mr. Chairman.

Mr. Ramchand, you said in your opening comments that military caregivers are saving billions of dollars. And the VA says that they really can't recommend expanding the program until we really sort of wrestle with and look to expanding resources within the VHA budget.

So my question is to you is does RAND have any indications that the program really will pay for itself, similar to the homeless programs by reducing the needs of medical care, any analysis relative to that?

Mr. RAMCHAND. No, we don't. This was outside the scope of our project primarily we didn't evaluate the VA program, nor did we evaluate any other specific program. But in addition to that, not much research has evaluated those programs to make those conclusions and those cost benefit calculations.

And so, I think that is why research is so important to start evaluating these programs and really showing that they are providing value, whether that is reduced medical visits, improve preventive care among caregivers themselves, because then we can actually start qualifying the savings these programs are having.

Ms. BROWNLEY. Has RAND evaluated any other caregiver programs outside of the VA to evaluate cost effectiveness and perhaps cost savings?

Mr. RAMCHAND. Not to my—I can get back to you on that, but to my knowledge in the past 5 years when I have been heavily involved in this space, I haven't seen any research looking at that.

Ms. BROWNLEY. Okay. Another question, I believe that your study estimated that there are 5.5 million military caregivers. In the VA's 2013 report, they estimate 49,000 to 105,000 veterans eligible for fiscal year 2014, if the program was expanded to all the eras. So can you reconcile those figures for me at all?

Mr. RAMCHAND. Well, our estimate of 5.5 million is a probability sample. We went out to households and looked specifically for military caregivers. Now, our criteria for quantifying the number of military caregivers was a little bit less restrictive than the VA's eligibility requirements for their programs. So for example, the VA it has to be a family member or somebody who is not related but who lives with the veterans or plans to live with the veteran, for example. We didn't impose that requirement, and in fact, many of our post-9/11 caregivers don't live with the veteran.

There is also restrictions on activities of daily living, the amount of time that people spend. We didn't have such requirements when we quantified the number of military caregivers. So we have somewhat of a loser definition than the VA is using to make the calculations of programming utilization.

Ms. BROWNLEY. Thank you very much. And Mr. Williamson, given the VA's IT history that we have heard a lot about in this committee, what challenges do you believe the VHA will encounter in coming up with a strategic IT solution to address this data management issue?

Mr. WILLIAMSON. Well, as you know, our prime recommendation was on developing an IT system that would provide data that would let the program better manage and monitor. We think that is vital.

You are right, the history in the past in VA as far as developing and implementing IT programs has not been good in many respects. I don't think the program knows, we don't know when that new system that we recommended will be rolled out, or when it will be developed.

They have designated a project manager, they haven't got the funding yet, they said they identified funding, but they haven't actually got that funding in hand yet. So——

Ms. BROWNLEY. Do you know if there are any off-the-shelf systems that private industry uses that would be similar?

Mr. WILLIAMSON. I am not an IT expert. I think that is something you could probably ask VA and they could give you a better idea.

Ms. BROWNLEY. Thank you. I yield back, Mr. Chairman.

Dr. HUELSKAMP. [Presiding.] I now yield myself 5 minutes for questions. I would like to follow up on the excellent IT questions for either witness, but a little background, if you would, Mr. Williamson, how did they create the system they have been using for the last 3-1/2 years? Can you describe that? And is it part of a current system that we found in this committee again, again has plenty of difficulties.

Mr. WILLIAMSON. You are talking about the IT system?

Dr. HUELSKAMP. Yes.

Mr. WILLIAMSON. Well, when they designed the program—again, it was designed for 4,000 caregivers—it was a small program and it was a Web-based system that didn't generate data reports that they need on a routine and systematic way. So they rolled that out and then when we came along and started this review in 2013, they realized and recognized, and we recognized that they just didn't have the data. Only recently have they generated a report that will give them an idea at each VAMC where the bottleneck and the problems with timeliness lie.

Dr. HUELSKAMP. Thank you. I am looking at what the VA's reported on that and their health care utilization review for veterans talks about how the program has decreased hospital admissions by 30 percent and hospital length of stay by 2-1/2 days. How do they generate that data if the system is as antiquated or doesn't generate that type of data? Do you know how they are providing that data or getting those numbers?

Mr. WILLIAMSON. We didn't look at that report, but I think it was an actuarial-type of study that they did, and while we can't vouch for the numbers, because we didn't look at them, it is not surprising that you would see the benefits of the caregiver program in the sense of having a positive affect on hospital admissions and length of stay.

Dr. HUELSKAMP. The gentleman from RAND, well-known for working with numbers, not yourself but the entity, any information or insight about trying to translate for us as policymakers, this is the impact of the program, and do you have any insight on that and how VA might have generated these particular claims?

Mr. RAMCHAND. No, I don't have—again, like I said, we didn't look exclusively at that VA program. In terms of evaluation, and our comments about research, and the importance of research, it is not just for outside entities to look at organizations, but also continuous quality improvements that agencies can evaluate how they are performing, that is critical for all of these programs.

Dr. HUELSKAMP. I appreciate that and look forward to the VA clarifying where the information and data arrived from. As the committee knows and the witnesses particularly others from the GAO pointed out that difficulties with an IT system. Those of us on the subcommittee and the full committee trusting the data we are given, in this case have no idea where it would come from given the integrated system in which this is continuing to function. So with that, I am going to yield back and next recognize Representative Kuster for 5 minutes of questions.

Ms. KUSTER. Thank you so much for being here today. I am very familiar with the caregiver issue, my father well into his 70s was caring for my mother at home with Alzheimer's and was able to keep her at home for 4 years. But the physical toll on him then landed him in the hospital with hip replacement and other things.

So what I want to focus in on is the cost benefit analysis. And I don't know if you got to this, in the private sector, there has been a lot that has been studied about keeping people in the home as compared to the cost of institutional expense with the 24/7 care. And I am wondering do you have any conclusions or was that outside the parameters of your study, given that we are guardians of the taxpayers funds. I consider myself a frugal Yankee for New Hampshire, how can we be saving going forward by helping to support caregivers and keeping our veterans in the home?

Mr. RAMCHAND. That is an excellent question. It was outside the scope of our study to do such a cost benefit analysis, but what we did was look at the hours caregivers spent providing care and estimate what would that be if it were a home health aide attendant that was providing that level of care and that is where we came up with our estimates in the billions of dollars. And other studies that have looked at caregivers, the value of caregiving has also provided estimates in the billions of dollars of the value.

In terms now of the benefits of programs, again, and I hate to keep saying this, but the research just isn't rich enough that shows—for example, if somebody has respite care, whether that is one day a week or 4 hours a week or a week every year that provides some time away, does that reduce their risk of depression? Does that reduce the risk of some of these chronic conditions associated with actually caregiving? You could start calculating that cost benefit, but the research is really needed to start looking at what these benefits are in real terms.

Ms. KUSTER. I appreciate that. And I think the respite—just from our personal experience, the respite is critical, because without that, it is very difficult to keep going, but with that, I think

you can keep going, you know. And given that particularly the family caregivers, there is a lot of love too that is not calculable.

I am wondering did you look at the cost and I think you had a conclusion that statistically significant decrease in average monthly inpatient utilization by eligible veterans participating in comprehensive programs. Did you look at, again, the savings for, and I think this is your report—I am sorry, about how you are able to keep people from the hospital, from the institutional care, did you look at that issue?

Mr. RAMCHAND. We didn't look at that. I don't know if that is from our report.

Ms. KUSTER. It may be a July 2013, is that—expansion of family caregiver assistance—this may be a VA report.

Mr. RAMCHAND. That may be a VA report, sorry.

Ms. KUSTER. No, no. Do you have any recommendations about that, about eligibility, like in terms of who should be included, how do you make this determination? You said you used a broader definition. Would you recommend expanding the definition?

Mr. RAMCHAND. I think in some cases—as part of our research we did conduct an environmental scan where we talked not just to government organizations, but nonprofits who are operating in this space. And eligibility criteria is something that they definitely struggle with, especially with serving military servicemembers and veterans.

So for example, if an organization is geared toward family members, should they start including in their caregiving support services, neighbors and friends, or extended family or what constitutes the definition of family becomes an issue, does the person need to live with the individual. All these issues of eligibility become—so our recommendation in our report is for alignment and for careful consideration of eligibility. And when possible, it should not be really based on these factors, family membership or age of the person they are caring for, but really what the caregiver is doing, what their day-to-day routines look like in helping that veteran function in society.

Ms. KUSTER. Sure. Thank you so much. My time is up, thank you.

Dr. HUELSKAMP. Congressman, thank you. I now yield to Congressman Jolly for 5 minutes of questions.

Mr. JOLLY. Thank you, Mr. Chairman, I appreciate it. Thank you all for being here this morning.

I belief in the RAND report, you mentioned 120 caregiver organizations, the VA just being one of them. General question—I understand asking an accomplished researcher to answer generally hopefully doesn't offend your senses, but the current performance within the VA, would you consider it a leading model, are there best practices at the VA as currently adopted or other organizations that perhaps you've seen as you have studied the issue for many years.

Mr. RAMCHAND. We didn't evaluate the VA's program so I can't attest to how it is performing, or whether caregivers are satisfied. In terms of the scope of things that they offer compared to some of the other programs, it is one of the more comprehensive by its name.

Respite care, only nine organizations we identified offer respite care. A stipend, only three organizations offer a stipend, the DoD, the VA and one nonprofit, respite services. So it does seem comprehensive relative to the other programs that we identified.

Mr. JOLLY. It appears to be one of the leading models, I would think. The challenges for either one of you would appear to be kind of the traditional challenges in terms of capacity, and resources. And I suppose that also limits some of the eligibility considerations as well. Would you identify those as traditional challenges?

Mr. WILLIAMSON. Right, I think the capacity issues and workload issues getting through that—the cumbersome application process, the time it takes and so on. What I would say to the VA, we have evaluated the program and as far as the benefits it offers, in addition to the stipend and so on, the caregivers who is have no other insurance are eligible for CHAMPVA, which gives them health insurance, reimbursement cost for travel of the caregiver and veteran to medical facilities. There are a number of benefits. It probably is the, or one of the top models out there.

Mr. JOLLY. It is the greatest challenges in resources? So I get that the processing delays for 45 days or 90 days or so forth. Obviously there is always practices that can be improved in any management structure, but is it also a resource limitation for the program?

Mr. WILLIAMSON. It can be, because again, the workload of the caregiver coordinators——

Mr. JOLLY. But is there also resources limitation for the program.

Mr. WILLIAMSON. It can be because the workload of the caregiver coordinators, that is a direct hindrance. If it is a high workload, it is a direct hindrance to the caregiver who is trying to contact him or her about questions they have which they need answered.

Mr. JOLLY. That question of scale, I guess a number of the VSOs have advocated for expansion of the current program, the VFW in particular talking about expanding to others outside of the post-9/11 generation, Wounded Warrior, I believe, or some of the others have talked about loosening some of the eligibility restrictions for making eligibility a little easier—if we are talking about resource limitations currently, those issues of expanded eligibility would seem unfortunately a far stretch right now, right? We would have to talk about a dramatic escalation and investment in the program?

Mr. WILLIAMSON. As you are aware, the CBO last year issued a report, and CBO said if VA increased the eligibility for their Family Caregiver Program to veterans of all eras, that it would result in an additional 70,000 caregivers being eligible and result in $9.5 billion outlay over 5 years. Adding 70,000 eligible caregivers to the current 18 would quadruple. It would in, many areas, caregiver coordinators and the VAMCs are already overwhelmed. So I think before we talk about expansion, it might be good to get VA's house in order of what they have going now.

Mr. JOLLY. And one last question just to clarify. Mr. Ramchand, you said this a few times, we don't actually have data to know if it is a net cost savings or not. Because you could make the argument if it is a cost savings ultimately, then expanding the program pays dividends, but we don't currently have a cost benefit analysis.

Mr. WILLIAMSON. Not that I am aware of.

Mr. RAMCHAND. Nor do we have really a cost saving benefit analysis of any caregiving support program.

Mr. JOLLY. Right. So we would first need that research to then determine whether or not expansion—first step would be the research.

Thank you, Mr. Chairman, I yield back.

Dr. HUELSKAMP. Thank you, Congressman. I yield to my colleague from Indiana for 5 minutes of questions.

Ms. WALORSKI. Thank you, Mr. Chairman.

Just to follow up on this question of resources, and that was my question as well—I love, I love home health care. And I think as we look at an aging baby boomer generation, and I experienced it in my own family of taking care of my father with hospice and with all of these community resources that are available. And my question was, and I appreciate the answer was this is not just a question of resources, because—would it not have to take a change in attitude of the VA itself to want to emerge into something that large? If the resources were available, would the VA do that today? Would they literally say, okay, here is the need, we have 5 million people, we have the resources to match it we are going to quadruple the program, hire the 70,000 providers. Is that something the VA would do or is that anywhere on their priority list from the work that you have done on the question?

Mr. RAMCHAND. So you will have to ask the VA on their priority list. What we know from our research is that this one-size-fits-all approach is not necessarily going to work. The program right now is really geared towards this group of younger veterans who have chronic conditions that will probably persist for a long time, the program may need to be adapted in very critical ways to care for, as you said, perhaps more home health aid. A group of people who may be suffering from conditions associated with aging, which may be very, very different.

Ms. WALORSKI. I also have a question about that, I have a constituent Darryl and Lisa Stump, in my district in Indiana. We just became involved with their case a week ago, and Mr. Stump passed away Saturday. And this is all over this issue of family advocacy, home health care, no other options, and the VA refused to pay virtually every option that would be on the books. They refused, they brought him back home. The wife his been caring for him by herself, had to quit her job, they are living on disability. She has become basically the caregiver, doctor, hospice worker, all of the above just because of being turned down so many times. He died.

But one of the things that we have found in trying to advocate even for constituents is this letter of the law interpretation of HIPPA with the VA's interpretation. So the VA is there to provide all the direction, if they are 100 percent disabled Agent Orange, which this constituent was, wasn't receiving probably even half the services that were available to him just because of lack of knowledge or being turned down once by the VA and being too tired, no respite care, just being turned under by taking care of their loved one.

We have so many issues with this issue if you are not the veteran calling in for help, you get can't get any medical advice, you get can't get any medical services. And basically the answer is I

want to talk to the veteran. If the veteran is suicidal, I still want to talk to the veteran. If the veteran is not mentally competent, I still want to talk to the veteran.

When it comes to this whole issue of somebody advocating for you, say it is your spouse or it is your neighbor, or it is your cousin being the advocate, what have you found it has been like with trying to get information out of the VA to even help the person that they are supposedly helping? Do they get a clearance with the VA to be able to access all the medical information, since oftentimes the spouse doesn't even know their name is on file.

Mr. RAMCHAND. So the VA is probably a better place to answer when they assign somebody a primary caregiver what records that actually permits them to have access to. In our recommendation and our research, we heard the same complaint that you are raising a lot, and we did make a recommendation to make health care environments more caregiver friendly. This means really educating physicians and other health care providers about really kind of what HIPPA allows and doesn't allow to better care for their caregivers, because we know that talking to the caregivers to ensure that whatever is being prescribed for caring for that veteran can be adhered to, because oftentimes it requires the caregiver to actually follow through with the adherence.

Ms. WALORSKI. Right. My concern for the pre-9/11 group is that oftentimes, especially if you are looking at Agent Orange you are looking at senior citizens, you are looking at seniors going from the baby boomer generation with a lot of the same kind of chronic conditions, same kind of chronic symptoms, dying of the same types of conditions because of Agent Orange.

And it seems that—back to your point—if you could almost put groups together that says, you know, this is the kind of care these folks are going to need because quite often they have the same kind of symptoms, they have lung cancer, they have COPD, they have things that become so prohibitive and so they need a lot of the same kind of care. They need oxygen, they need regular interaction with doctors.

I guess my final question is: When it comes to this issue of rural health, and rural telehealth, and the things that the VA is doing fairly well within rural areas, is that something that you see as a benefit, does that kind of roll into this whole thing of family members becoming advocates and trying to help keep them out of long-term facilities?

Mr. RAMCHAND. In our research, we actually couldn't longitudinally look and see who was in a long-term facility and who wasn't. We really didn't see much difference between caregivers who live in rural areas and those who live in metropolitan areas, nor were we really able to evaluate whether the organizations currently serving caregivers are more prevalent in kind of rural areas or metropolitan areas.

Ms. WALORSKI. I appreciate your research. I yield back, Mr. Chairman.

Dr. HUELSKAMP. I recognize my colleague from Florida, Ms. Brown, for questions.

Ms. BROWN. Thank you. I guess let me just say that my State of Florida has a program that they work with the families and pro-

vide them like 20 hours of care to help relieve the caregivers. Is there some other programs around the country like this, because it is very helpful to relieve people? They can come in as sitters so they can go to the doctor, the grocery store and other things like that.

Mr. RAMCHAND. Sure, that is respite care. There is around—we identified in our organization, in our research of 120 organizations, nine that are currently offering respite care, but we acknowledge that within States, there are lots of different respite options and respite groups for the State.

So there are definitely programs out there. One of the most underutilized programs among caregivers relative to things like caregiving training or caregiver social support. And we heard in our conversations with people who are caring for individuals with mental health conditions like PTSD, that the respite may be need to be tailored or tweaked a little bit. So that it isn't necessarily that a stranger can come into the house and take care, or a volunteer, even if that person is vetted, can take care of an individual with these cognitive difficulties. It may need to be respite provided by a family member and provisions to pay for their travel to the house so that they can actually provide that care. So that we have to be really conscious—again, it is not this one-size-fits-all program.

Ms. BROWN. The implementation of the bill that we passed, how is that working?

Mr. WILLIAMSON. Excuse me, now?

Ms. BROWN. The bill that just passed the Congress pertaining to caregivers.

Mr. WILLIAMSON. It has—yes, the VA program has, for people that are in the Family Caregiver Program, has 30-day minimum of provision for respite care.

Ms. BROWN. I am trying to find out how is the program working?

Mr. WILLIAMSON. I am sorry, I am not understanding.

Ms. BROWN. Is the program working the way we intended?

Mr. WILLIAMSON. Oh, okay, I got you now, I am sorry. The program, I think, because it has grown so quickly, is not working as efficiently as planned. It has still got a lot of the elements that you put into it, but what I would say is that it has grown so rapidly, and especially as people talk about expansion, that we need to—or the VA needs to think about fundamentally reexamining the process that they have set up, the staffing models, the eligibility requirements, the application process, the workload, benchmarks they have set for their coordinators, a number of things that need to be done.

Ms. BROWN. Are there some other recommendations that you would make?

Mr. WILLIAMSON. Yes, we made several recommendations, and the VA is actually moving out to deal with them. The major recommendation we made was to come up with a new IT system to provide them better data to monitor and manage a program, that is one of the main things.

The other aspect is once you have that data, then you have to have mechanisms and processes in place to analyze that data, identify bottlenecks, streamline, to have a strategy for dealing with

those things. So those things are not, at this point, probably well thought out, because they are still trying to get the data, but I think down the road that is where they will have to go.

Ms. BROWN. Thank you. I yield back the balance of my time.

Dr. HUELSKAMP. Thank you. I yield to Congressman Wenstrup for 5 minutes of questions.

Dr. WENSTRUP. Thank you, Mr. Chairman. Help me understand how this whole program is set up and working. In other words, is there a 1 on 1 between the doctor and the patient periodically to evaluate the level of care that is necessary? What type of care needs to be administered? You know, some people may only need assistance 1 hour a day, and other people may need 24 hours.

Mr. WILLIAMSON. Correct.

Dr. WENSTRUP. So how is that decided? Who is the coordinator? What is the oversight? How often is it reevaluated, assuming some people might get better?

Mr. WILLIAMSON. The coordinator at HVAMC will review applications for eligibility. After that determination has been made, the veteran will see a physician, usually his or her primary physician. And they will evaluate that veteran's needs for caregiving services.

And the veteran then will be—if caregiver services are needed, they are put into one of three tiers, a high which is needing 40 hours a week, and a low which is needing about 10 hours a week, and you get a stipend based on that amount.

Then there is a home visit made to the veteran's residents where the caregiver resides. And that would be to evaluate whether the caregiver is capable, and the house is well equipped, it is safe and so on. So that is kind of the process. And then final determination is made. Training is provided to the caregiver, core training. And then after that, a nurse makes home visits every 3 months or so to evaluate how it is going, to answer any questions and so on. That is how the process works.

Dr. WENSTRUP. So when it comes to the caregivers, whether it is family or friends or whatever the case may be, as the caregiver, why do they need to be so restricted as far as HIPPA violations, et cetera, as far as really being part of the care and maybe calling with a question? Why can't we include them within the loop of being able to know what is going on with the person they are caring for, even though they are not maybe an RN or M.D.?

Mr. WILLIAMSON. Yeah. Well, HIPPA is very strange sometimes in that regard, but 75 percent of the caregivers are spouses, and another 12 percent or so are family members. So where a spouse is involved, one would think that caregivers, if they are the caregiver, they should be involved with their spouse in decisions, and a lot of them have durable power of attorneys and have that kind of right. But we heard the same complaint from caregivers we talked to. I don't know why, there must be some reason perhaps the VA can shed some light on that one when they testify.

Dr. WENSTRUP. But you would recommend that it be addressed?

Mr. WILLIAMSON. Oh, I think so, because a lot of people have mental issues, TBI or PTSD, and they have memory loss. They have real serious issues, and you need somebody there as your advocate, that is usually your spouse in these cases, and they are—the veteran may not be capable of doing that.

Dr. WENSTRUP. What are the maybe extreme differences that you are seeing from pre- and post-9/11 patients besides just aging differences? I know you mentioned Agent Orange effects and things like that. Are there other things that are drastically different between the two populations?

Mr. RAMCHAND. Yes. They are different with respect to the tasks they are providing. So let's start demographically, they are younger, a lot of them are spouses. We also have this new group of parents taking care of their children who have been wounded, ill or are injured. The children are single so they don't have a spouse necessarily, so there are demographic differences. We see the people that they are caring for, the conditions they are caring for are very different, so as opposed to, as you said, the chronic conditions associated with aging. We have high rates of back pain, but also behavioral health conditions. There are differences in the tasks they perform. So they may not be helping as much with the post-9/11 caregivers——

Dr. WENSTRUP. I am thinking more of war-related maladies.

Mr. RAMCHAND. Sure. So the post-9/11 caregivers are generally taking care of somebody who has a condition that is related to service relative to the pre 9/11. So we asked in our report when we surveyed what conditions did the people have, and for each condition they checked, whether it was related to their service. And so, it is not the most precise measure, but at the same time, overwhelmingly, the post-9/11 caregivers are caring for conditions that are war-related and the pre-9/11 caregivers—many of them have hearing loss that they associate with war, chronic pain that they associate with their service, but many are also caring for these comorbid conditions that happen as you age.

Dr. WENSTRUP. True. Just one quick question, you talked about, there has been talk about needing more research. Is most of the research that you think is necessary more of cost benefit type of research? What other things might be included here?

Mr. RAMCHAND. So the cost benefit, the evaluation of programs, make sure that they are providing value and also longitudinal studies of caregivers and veterans themselves. Our study was a cross sectional kind of snapshot, but we think that these things will change. We really talk about a spiraling or a seesaw effect where if a caregiver's health is affected then it affects the care that they provide the veteran, and it worsens their health, and then their demands become greater on the caregiver. So you see it somewhat spiraling out of control without intervention or without stopping.

Dr. WENSTRUP. Thank you, I yield back.

Dr. HUELSKAMP. Thank you, Congressman. Any additional questions of this panel? Ms. Kuster.

Ms. KUSTER. I just want to make a quick comment and it may be more appropriate for the next panel. I don't see why they don't have a medical authorization. There is not a problem with HIPPA. You can sign a medical authorization to authorize any person. It doesn't have to be a family member, it is a legal document, you are entitled to view my records. So we can ask the VA, but I think we can get to the bottom of that.

Dr. HUELSKAMP. Thank you, I appreciate the panel for being here and your hard work, you are now dismissed, or excused.

Now welcome our second and final panel to the witness table, joining us from the VA is Dr. Maureen McCarthy, Deputy Chief, Patient Care Services for the VHA. Dr. McCarthy is accompanied by Michael Kilmer, the chief consultant of Care Management and Social Work, and Margaret Kabat, Acting National Director for the Caregiver Support Program. Thank you for being here.

Dr. McCarthy.

STATEMENT OF MAUREEN McCARTHY, M.D., DEPUTY CHIEF, PATIENT CARE SERVICES, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS, ACCOMPANIED BY MICHAEL KILMER, CHIEF CONSULTANT OF CARE MANAGEMENT AND SOCIAL WORK, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS, AND MARGARET KABAT, ACTING NATIONAL DIRECTOR, CAREGIVER SUPPORT PROGRAM, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS

STATEMENT OF MAUREEN McCARTHY, M.D.

Dr. MCCARTHY. Chairman Huelskamp, Ranking Member Brownley, and distinguished members of the House Committee on Veterans' Affairs, thank you for the opportunity to discuss VA's efforts regarding our Caregiver Support Program. I am joined today by Mr. Michael Kilmer, chief consultant for care management and social work services, and Ms. Meg Kabat, acting national director of the Caregiver Support Program. And thank you, Chairman Benishek.

Caregivers truly are a special group of people, as any one of us who has had a loved one needing caregiver support well knows. Their sacrifices and stresses are many, and they clearly deserve support in their roles.

Central to our mission in caring for those who have borne the battle, VHA recognizes the crucial role that family caregivers play. They are partners in helping veterans as they recover from injury and illness, in the daily lives of veterans in the community, and in helping veterans remain at home.

VA is dedicated to providing caregivers with the support and services they need. The Caregivers and Veterans Omnibus Health Services Act of 2010, also referred to as the Caregiver Law, has allowed VHA to provide unprecedented support and services to approved family caregivers of eligible veterans.

We now have at least one caregiver support coordinator at every medical center, a national caregiver support line, a Web site dedicated to family caregivers, and a peer support mentoring program. Last year we began a Building Better Caregivers program and now even have an alumni group for the program.

For approved family caregivers of eligible veterans who are seriously injured in the line of duty on or after 9/11, the Caregiver Law allows for additional services. These include a stipend of support to the caregiver, enrollment in CHAMPVA health care if the caregiver has no other health care, and, if eligible, expanded respite care benefits, mental health services, and travel benefits.

In this law, caregiver financial assistance is to be provided only if the Secretary determines it is in the best interests of the eligible veteran to do so. That has been key in establishing caregiver support as a treatment decision. The law specifically states the relationship between VHA and the caregiver is not an employment relationship, and it specifically does not create an entitlement to any assistance or support. This is consistent with the intent of maximizing independence of the veteran, and therefore requires ongoing reevaluations of the continued need for caregiver support.

VA has been accepting applications for the program of comprehensive assistance since May of 2011. By the end of fiscal year 2014, there were over 17,500 family caregivers actively participating in the program. Over 20,000 have participated since the program began.

For the role of caregiving, VA has trained more than 22,000 family caregivers of post-9/11 veterans and has provided CHAMPVA medical coverage to more than 4,800 primary family caregivers who did not have other healthcare coverage. By October 31, over 39,000 applications had been processed.

The goal of the comprehensive program for assistance is to help veterans reach their highest level of functioning. GAO was recently asked to examine VHA's implementation of this program. The report examined how VA is implementing the program, and resulted in three recommendations.

In response to the first recommendation, VA identified fiscal year 2015 funding to support the development of a new IT solution. Additional steps are also being taken to stabilize the current system, allowing the field to improve data capture and data integrity. This will permit the program office to better monitor workload across the country and identify needs and best practices.

For the second recommendation, VHA made the policy decision to use home visits to monitor the well-being of program participants, as is contemplated under the Caregiver Law. Due to feedback from veterans, their caregivers, as well as the field, we established a work group to evaluate our policy for monitoring the well-being of program participants. The work group is currently meeting, and we anticipate formal recommendations for changes this spring.

To address the third recommendation, we established a Partnered Evaluation Center. This center reviews the program's impact on the health and well-being of both caregiver and veteran participants. VA anticipates preliminary findings from this group will be available in mid-2015.

As you know, the RAND Corporation submitted its Hidden Heroes report in March. Their recommendations affirm the current services and supports we offer. The valuable input from both GAO and RAND provide us with further insight into the Caregiver Support Program and allow us to better understand how we can strengthen the support and services we provide.

In September 2013, we sent the Expansion of Family Caregiver Assistance Report to the committee, as requested. VHA believes the expansion of the program to caregivers of eligible veterans of all eras would make the program more equitable, but VA would need additional resources to fund the expansion.

In conclusion, Mr. Chairman, caregiving is truly a labor of love, and VA recognizes the crucial role that caregivers play in helping veterans remain in the communities they defended, surrounded by those they love. VA is dedicated to promoting the health and well-being of caregivers who care for our Nation's veterans through education, resources, support, and services. I thank Congress for your support as we continuously improve the services and supports we provide for America's veterans and their caregivers.

This concludes my testimony, and my colleagues and I are prepared to answer any questions you or other members of the committee may have.

Dr. BENISHEK. Thank you, Dr. McCarthy. Appreciate your testimony.

[THE PREPARED STATEMENT OF DR. MAUREEN MCCARTHY APPEARS IN THE APPENDIX]

Dr. BENISHEK. I will yield myself 5 minutes for questions.

So how long is it going to take to get this caseload number for the coordinators into shape here? Two hundred fifty-one seems like an excessive number. So can you give me a date when that is going to be ready?

Dr. MCCARTHY. So as I understand your question, you are saying there is a variety of caseload numbers that the various what we call the CSCs, the caregiver support coordinators manage, and some manage more than others, and you are asking how long it will take?

What we have done is we have monitored the workload, we have increased by over 70 percent the number of caregiver support coordinators, we are working with the individual medical centers and helping with the processing of the applications.

Dr. BENISHEK. What is the plan? I mean, it is very nice that you are here and you stated all very laudable goals in your testimony, but from what I understand the facts, that there is backlogs, at certain centers up to 400 people who have applied and hadn't had a response. There are some coordinators that have 251 people on their caseload. That seems like an excessive amount. And all the things you said are great, but when is this going to get fixed, is the question I am asking.

Dr. MCCARTHY. Well, sir, we did mention that there were over 39,000 applications filed and 18,000 approved. As of November 5, there are 3,400 that are pending. Of those, some are pending less than 45 days. That would be about 36 percent.

What the application process involves and why people perceive delays is that that processing in the application requires the veteran and the caregiver to apply, it requires an evaluation by the caregiver support coordinator, and as I mentioned, it is a treatment team issue. So the treatment team, the primary care team that is involved with the veteran has to make a decision about whether the support for the caregiver would be beneficial to the veteran. So all of that does take a significant amount of time.

There are some applications that are pending, and we are aware of that and we have offered support to the individual facilities that have those delays. But it is a cumbersome process, because we want to make sure that this is consistent with what is best for the treatment for the veteran.

Dr. BENISHEK. According to the VA's report to Congress last year, the potential expansion of the family caregiver program to pre-9/11 veterans under the current resource framework poses the risk of compromising resources needed for its core veteran health mission. And you mentioned too that additional resources may be needed in your testimony today.

Taking that and the findings that we had today from the GAO and the RAND into account, do you still believe that the expansion of the family caregiver program to pre-9/11 veterans is operationally feasible and advisable?

Dr. MCCARTHY. I believe it is operationally feasible and advisable, but I do think it is going to take some time to make it happen. We wouldn't want to set up a program ahead of when we have the resources available to make it happen as seamlessly as possible for the veterans and the caregivers. So it would take additional caregiver support coordinators, but in addition we would really need to look at resources about funding the stipends and the other kinds of support services that are available to them.

Dr. BENISHEK. Did you have an estimate, then, in the number of veterans that would potentially be in the program as it exists today? I mean, because obviously your first assessment for the number of veterans was off by a factor of four, as I understand. So what is the potential for the numbers in the next, say, 4 years?

Dr. MCCARTHY. For our current program as it is right now?

Dr. BENISHEK. Yes.

Dr. MCCARTHY. Well, the number of applications we are getting every month is 500. We had anticipated that the number of applications would eventually reach a plateau, but that hasn't happened. The issue about being really catastrophically disabled, we had anticipated that it would level off, but some of the signature wounds of this war are things that may not really show up till later. We have very many veterans with mental health conditions who are eligible for the caregiver program, and I am not sure we had anticipated that there would be that many.

But nevertheless, that is what we are here to provide, and we are doing what we can. We have IT solutions in the works, we have reorganization of how we will do the evaluations of the program and so forth in the works, and we do have the research ongoing to identify what are the evidence-based treatments that work.

Dr. BENISHEK. Thank you, Dr. McCarthy.

I will yield 5 minutes to Ms. Brownley.

Ms. BROWNLEY. Thank you, Mr. Chairman.

Dr. McCarthy, I wanted to just ask, in the earlier testimony I think it was uncovered that probably the first thing that the VA should probably do is research and to look at the cost-benefit and trying to understand what the potential savings might be vis-α-vis a caregiver-in-home situation versus institutionalization. And so I am just wondering if that is in the plan, to begin to do that analysis?

Dr. MCCARTHY. Yes. Thank you. And I wanted to clarify something. First of all, we do have this partnered research group going on with our QUERI organization, which is part of our Office of Research and Development.

I did want to clarify the source of the data for the information about decrease in admission rates. That was from the Office of the Actuary and it was a retrospective look back for a particular veteran 6 months before the caregiver program served that veteran and the caregiver and 6 months later, and that was actually where the data came from, from that analysis that showed a 30 percent decrease in inpatient admissions and a 2.5 decrease in length of stay for those that were admitted.

But, besides that, yeah, the QUERI program is ongoing, and we are anticipating some information from them in spring of this year.

Ms. BROWNLEY. In spring of this year?

Dr. MCCARTHY. Yes, ma'am.

Ms. BROWNLEY. And some kind of information, what does that mean exactly? Will we have kind of a full assessment and really understand what the cost-benefits are in dollars and cents so that we can begin to evaluate the current program and begin to evaluate expansion of the program?

Dr. MCCARTHY. I will turn to Meg.

Ms. KABAT. Thank you. So we have partnered with VA researchers at the Durham VA, and they are doing this work for us. It will involve looking at healthcare utilization, actually comparing the healthcare utilization of similar veterans who are not in the program to those who are in the program. So there is that comparison group, not just straight pre and post.

I am not a researcher, I am a social worker, but I am told by our researchers that it takes quite a period of time to really have a very strong cost-benefit analysis. But that is one of the goals, is to really begin to look at the full cost, so to look at the cost of all the services that we are providing, but also to look at the cost of time of the staff involved and all those kinds of pieces.

Their full report will be available in the spring of 2016, but in 2015 we will begin to see some of the beginnings of those results. There will be a survey of caregivers participating, so we will be able to get feedback from them as well about what services they believe are the most helpful.

Ms. BROWNLEY. Thank you.

Dr. McCarthy, you mentioned, I think, in your testimony in terms of one of your recommendations in terms of moving forward that you reached out to some VSO organizations. Certainly in our oversight responsibilities here on the committee we have talked a lot about accountability in various VA programs across the spectrum, and I think for all of us the ultimate threshold for a program that is working well is veteran satisfaction.

So I am very curious to know what kind of outreach you are doing to VSOs in terms of monitoring and evaluating and modifying. It sounds like you are making some changes forthcoming. But if you could describe to me exactly what you are doing and how you are integrating working with the VSOs and veteran satisfaction and the veterans that we are serving in this program.

Ms. KABAT. We certainly meet with VSOs on a regular basis, we participate in conferences and work groups with many different VSOs. With the advent of the Elizabeth Dole Foundation, my office is very involved in working with the Elizabeth Dole fellows, and meet with them on a regular basis to get their feedback and talk

to them about various aspects of the program and get their input as well. So we really welcome that kind of interaction, as well as nonprofit organizations who are focused on caregiving, especially for those who are maybe caregivers of older veterans, because we want their input as well as we expand our services, not just the Program of Comprehensive Assistance, but other services that we provide to that group as well.

Ms. BROWNLEY. Thank you.

And I yield back.

Dr. BENISHEK. Dr. Roe, I will yield 5 minutes for your questions.

Dr. ROE. Thank you.

And thank you all for being here today, and I am sorry I missed part of your testimony. But would you, Dr. McCarthy, would you walk me through, if I am a veteran family, for the record, just walk through how I would go about this process of obtaining the family caregiver and how long it actually takes?

Dr. MCCARTHY. So typically this might start if you were still in DoD. We have field-based individuals who assist with the process as it begins in their transition from DoD to VA.

The name of those individuals, Michael?

Mr. KILMER. Our VA liaisons for health care.

Dr. MCCARTHY. Right, they are called our VA liaisons for health care, and they start the process as it goes forward.

What the individuals need to do is complete an application, both the caregiver and the veteran, or servicemember at that point, who needs the care. That application is reviewed by the caregiver support coordinator. The caregiver support coordinator looks at issues such as eligibility, and specifically related to the eligibility as defined in the legislation, and then also refers the case then to the treatment team for the veteran, which makes an assessment if providing this kind of support for the caregiver is consistent with the treatment goals for the veteran. And this is as the veteran is now transitioning into VA. It would be the VA primary care team that would make that assessment.

Dr. ROE. So how long would that take?

Dr. MCCARTHY. I don't have an exact number.

Dr. ROE. Is it a month or 2 months or 6 months, or how long?

Dr. MCCARTHY. It would be several months typically, but there are some that have taken longer.

Dr. ROE. Why does that take so long?

Dr. MCCARTHY. We don't have the actual roadblock kind of plots that we want to have, and our new IT system will help us with that. But what we are aware of is that sometimes there are issues with both the veteran and the caregiver completing the application, and sometimes there are issues with the caregiver completing some online training. But often it is that the treatment team has to actually make the visit and ensure that the veteran and the caregiver, it is a good fit for the treatment plan for the veteran.

Dr. ROE. So if I am a veteran in Pinedale, Wyoming, and I try to get help, and have a family caregiver, it may take me months, may take a year, right?

Dr. MCCARTHY. Well, I am not sure. I am sorry. I don't know where Pinedale, Wyoming, is, but I do know that there is an elabo-

rate kind of telehealth program that reaches out through that VISN, and some of the care is provided directly and some of it——

Dr. ROE. Look my question is, if I am a veteran out there, it doesn't matter, it is 100 percent me. So it is me and my family, I need the help. How long does it take to get help, is what I am saying? It takes a long time, apparently. I think that is what Dr. Benishek was asking. And in one VA, I was noticing there were 400 people, that we have a program here, it is like the Post-9/11 GI Bill, it doesn't do any good if you can't get it. And that got implemented pretty quickly. It is a great program, I think. But if it is not being implemented for veterans, it doesn't do them any good to have a name out there and they can't benefit, utilize it, I mean.

Dr. MCCARTHY. I do to make note that the stipends that are paid to the family members are retroactive to the date of application. And so, yes, there are delays, but the financial support they need, they need at the time——

Dr. ROE. At the time.

Dr. MCCARTHY [continuing]. I recognize that, but we do have the ability to do it retroactively.

Dr. ROE. I know on the homeless program, the coordinators are 25 to 1, it would be 1 coordinator up to 25 homeless veterans that they would see. And I agree with Dr. Benishek on this, is that up to, whatever, is it 250, there is no way in the world that a coordinator could coordinate that care for 250 people, I don't think.

So is it just a lack of hiring people who are qualified social workers, for instance, that are qualified to do this, or there are not enough of them, or what is the hold up on that?

Ms. KABAT. I think there are various pieces. I think it is important to remember that the caregiver support coordinator is not a member of the veteran's treatment team. So the veteran may be receiving assistance from a whole cadre of other providers, case managers and others within the system.

We are also doing other things besides hiring additional caregiver support coordinators. We have expanded access, for example, to our current IT system to administrative staff within VA at the discretion of the medical center so that the caregiver support coordinator is really focused on moving those applications through the process.

The other thing that we have done at the national level is funded caregiver support programming, so building better caregivers that Dr. McCarthy mentioned, our peer support mentoring program, all of those kinds of things that our caregiver support line provides, education and training, so that the caregiver support coordinators can refer caregivers to those kinds of supportive services and continue to focus on that application.

Dr. ROE. My time has expired, but as I understand it, the veterans are very pleased with this once they are in the program. Am I correct on that?

Dr. MCCARTHY. That is our impression.

Dr. ROE. What is the possibility of the capacity of the VA to expand this? Because, look, I am a Vietnam era veteran, and we are getting old, fast, and the World War II veterans are already there, and it is not to them. If you expanded it, do you have any idea the scope of that if it were to be expanded to pre-9/11?

Dr. MCCARTHY. We did this report in September of 2013 that we submitted, and calculating the actual numbers is challenging. We went one route and got one range, and we went another route using a different kind of calculation based on who needs aid and attendance through the VBA program and so forth, got another. We estimated somewhere between $1.8 billion and $3.8 billion, but we don't have an exact number, just like we didn't when we started this program.

Dr. ROE. Okay. Thank you. I yield back

Dr. BENISHEK. Thank you.

Ms. Brown, 5 minutes for questions.

Ms. BROWN. Thank you.

I guess if you have never experienced a caregiver, which I have, their role, like you say, is life saving to the family, whether it is helping a person with their medication, their personal hygiene, making sure they eat their meals on time. It is just all kinds of issues. And I think one of the things, as we go back, and the DoD, starting when you release that person, to make sure that that caregiver is a part of the team. And you indicated that many of the players are the wives, the spouses, or their parents. How come we can't have a training program working with them from the beginning so that there would not be this delay?

And I have to mention that the State of Florida really does have a good program in this area and that the caregivers, they have to meet so often and they go through a certain amount of training. Have we thought about doing something like that?

Dr. MCCARTHY. We do. And we have an excellent program. We partner with Easter Seals, which teaches the program, the main program that orients the caregivers. And then we have the online training, we have all kinds of online resources, caregiver support resources, we have all kinds of things like that.

But, yes, there is access to that training right away. And they don't have to be post-9/11 caregivers to have access to that. If you go to *www.caregiver—all one word—.va.gov*, you can have access to a lot of resources.

Ms. BROWN. I know you all think everybody have online.

Dr. MCCARTHY. I know.

Ms. BROWN. I know. I know everybody has it. But some people are not online——

Dr. MCCARTHY. Right. So I have the phone number to call for caregiver support. And I was trying to figure out why we don't have a mnemonic to make it easier, but I will just read it to you. It is 1–855–260–3274, and that is our caregiver support line. And that is actually a——

Ms. BROWN. Try it again.

Dr. MCCARTHY. Yes, ma'am. I am sorry. 1–855–260–3274. And so that is a great starting point. We get over 200 calls a day in there, and they can help with finding the right caregiver support coordinator.

The online Web site does it by ZIP code, so that would help the family in Wyoming, but also the caregiver support line would help with access to resources.

Ms. BROWN. But you mentioned, someone mentioned earlier that many of the caregivers were spouses or parents, and they are not

a part of the medical team, but they are there from the beginning. So I don't understand why it can't be interfaced at that point.

Dr. MCCARTHY. Well, we have a release of information program. Every medical center has an office, but there are forms that people fill out for release of information.

I am a psychiatrist in the VA, and the patients that I treat, I encourage them up front to have them sign a release of information so I can speak with their family members, and that has worked out extremely well.

I think it takes some planning. It is also part of our application process for caregiver support to have those releases of information signed, which should allow for that kind of communication.

Ms. BROWN. And so you are having that with the DoD from the very, very beginning when they are transferring out of DoD into VA?

Dr. MCCARTHY. I am going to yield to Mr. Kilmer.

Mr. KILMER. That is a very good question. We actually have 43 nurse and social workers embedded at 21 military treatment sites, and they are there to serve as that bilingual bridge between VA and DoD and to serve as that transition from DoD to VA as a member transitions from being an active duty servicemember to being a veteran. So they proactively identify people who are eligible for the Caregiver Support Program, and that application process is a part of that referral process over to the VA.

Ms. BROWN. I guess, when they leave DoD at one point, they don't feel that they necessarily need the Veteran Administration at a certain time, but now we are making it more mandatory, or I don't know how we are doing it.

Mr. KILMER. That is a very good observation, and it is something that we see on a daily basis, because obviously if you are being medically separated from the military, let's face it, you really don't want to leave. As a veteran myself, I know what it is like to be in service. And to leave under conditions where you are being medically separated, probably involuntarily so, you really don't want to go to the VA, you want to stay with your military brothers and sisters.

Ms. BROWN. Right, right, right, right.

Mr. KILMER. So those are conversations that our VA liaisons have quite frequently and are very sensitive to, even as to when to engage in that conversation of talking about coming over to the VA.

Ms. BROWN. Okay. I yield back the balance of my time, Chair.

Dr. BENISHEK. Dr. Wenstrup.

Dr. WENSTRUP. Thank you, Mr. Chairman.

This program, like so many others, always have the best of intentions in taking care of our troops any way we can and things sounds good, and then we encounter problems, whether it is a shortage of providers or whatever the case may be, funding, whatever the case may be. We always want to make sure that it is working. And we talked a little bit today about further research being needed to really evaluate the situation.

And I think on that, we don't necessarily have to research it on a whole nationwide level, but start small, maybe pick a couple of areas or regions where we can actually do an evaluation of the ef-

fectiveness and try and find the flaws and then see if it is nationwide, rather than taking on a research project of the entire Nation, I think would be to our benefit. And we should be looking at the quality of care, the quality of life pre and post the caregiving situation. And we should be able to tell pre and post what the cost is, for example, per patient, per year, per diagnosis, and then what the after cost is once they have gotten the care.

And those are the things that I think we can focus on in a small level, in small regions, and if we push forward in that direction, we can then try to craft and perfect the situation throughout the country. But I would hope that we are not looking at it like, oh, we want to take on this project of research and cross the entire Nation, but maybe take a small section and see how we can make it better.

That is just a suggestion I have, and I will welcome any thoughts you may have on that.

Dr. MCCARTHY. I appreciate that very much. And I also appreciate our colleague from the RAND Foundation who talked about research will require long-term kind of evaluations. I mentioned that we expect a report in the spring, and obviously it is not that kind of long-term evaluation, but I will mention that some of the scales that people use for caregiver burden, the Zarit Burden scale and so forth, are things that are used in this program as well. So there is that kind of data that can be tracked as well.

Dr. WENSTRUP. Yeah, especially capturing what we have before they begin the program too and then what we see afterwards.

Dr. MCCARTHY. Yeah.

Dr. WENSTRUP. Thank you. I yield back.

Dr. BENISHEK. Ms. Kuster.

Ms. KUSTER. Thank you, Mr. Chair.

And thank you, all of you.

I want to start by commending, this sounds like a pretty impressive program to get off the ground, and certainly the goal of it. I had spoken previously about a personal family situation in my family, and my father, a World War II vet, who had cared for my mother at home. So I am very, very familiar with the limitations and the complications of home care, but I think it is significant, and I want to commend my colleagues for recognizing and passing this law, the value of the caregiver. I think previously this was uncompensated entirely.

Having said that, I want to focus in, this is from the Wounded Warrior testimony that we received, or comments that we received, about wide variability in determinations of eligibility and support. I am curious. So 39,000 filed, 18,000 had been approved. That seems like a relatively high rate of ineligibility. Like, a family that has gotten to this place that is asking for this kind of help, I think we want to err on the side of trying to be supportive. I mean, the bottom line to this entire program is that these people have gone off to defend our freedom, and none of these families anticipated this change in their lives.

So I am just wondering, and in particular their testimony is very interesting about the distinction, this is TBI, PTSD, that type of thing, and how that impacts the hours of care that are required, the type of care that is required, supervision. We talk a lot in this

committee about suicide risk. Could you just comment on what the denials were and sort of how we can do better with that?

Dr. MCCARTHY. Certainly. Thank you for that question. Our veterans are sometimes very strong at communicating to us what they want. We have a high rate of denial for pre-9/11 veterans who have wanted to file applications to make the point that they feel like the services should be available to them as well.

Ms. KUSTER. So it is a message to Congress. Well, consider it received.

Dr. MCCARTHY. Yeah.

Ms. KUSTER. Okay. I can certainly understand.

Dr. MCCARTHY. That is our largest group. In addition, we have denials related to—well, let me let Meg handle this, because she analyzes this regularly.

Ms. KUSTER. Sure.

Ms. KABAT. We also have a high number of denials related to illness, because illness is not included in the eligibility.

Ms. KUSTER. So it needs to be service related rather than——

Ms. KABAT. No. The legislation actually states an injury in the line of duty. So a veteran who has a significant illness cannot participate in the program unless they also——

Ms. KUSTER. Even if it is service connected?

Ms. KABAT. Correct. Right.

Dr. MCCARTHY. Could we give an example of that?

Ms. KUSTER. We should make a correction then.

Dr. MCCARTHY. So our PVA organization partners have advanced this and we support what they are saying. The spinal cord injured veterans are allowed to be part of the program, but veterans who suffer terribly with amyotrophic lateral sclerosis, ALS, and multiple sclerosis are not eligible for the program by definition. We would support amending the legislation to include them.

Ms. KUSTER. Okay. That sounds very important. Are there any other categories like that?

Ms. KABAT. No. I mean, certainly there are caregivers who apply, and we spend a lot of time, caregivers and veterans will spend time talking about the importance of really helping veterans get to their highest level of independence. And sometimes caregivers and veterans choose not to participate because they came in with the idea that this was another benefit in the suite of benefits that VA provides and are not interested in the home visits and other kinds of things. So people do withdraw applications as well.

Ms. KUSTER. Thank you. And the other piece of this, and it is connected, but it is the calculation of the stipend. And obviously there is a bottom-line impact, so I am happy to have the VA be frugal with taxpayer dollars, but I am concerned about an issue that they raised with regard to because they have been seeking independence and they have been seeking to manage the activities of daily living and maybe made significant improvement with regard to their physical disabilities so that they don't need assistance, and yet they still have mental health issues, outbursts, suicidal tendencies, depression, whatever, that they need the continuum of care. And it sounds like that issue may need to be addressed in the regulations.

Dr. MCCARTHY. So first off, it is really hard for some veterans to understand that this is not a benefit or an entitlement, but it is part of their treatment plan. And it is also important to keep in mind that the focus is on independence. And so when people drop down one of our three tiers, it is not that we are trying to penalize them or have them be less compensated, have the caregivers be less compensated, but it is more a focus on the increasing independence that the veteran may or may not be acquiring. So if the physical needs change or if the mental health needs change, then that would necessitate, as part of the reevaluation, moving through the tiers.

Now, inherent in the tiers are some problems. We calculate things based on 40 hours. And any one of us that has lived with a situation where a caregiver is required knows that it is many more than 40 hours, particularly for a spouse or a family member with whom the veteran lives.

But that said, we don't want to foster dependence, and so that is why it is a complicated program as a treatment decision fostering independence and yet supporting caregivers. The whole goal is to keep the folks out of institutions and at the same time encouraging independence.

And so we may get into disagreements about it, but when we reviewed the legislation and reviewed the implementation, it really is focused on the independence of the veteran and fostering that independence and providing the caregiver support to help keep them as independent as possible.

Ms. KUSTER. I am just suggesting a balance. But my time is well over. I apologize. And thank you.

Dr. BENISHEK. Ms. Walorski.

Ms. WALORSKI. Thank you, Mr. Chairman.

And, Dr. McCarthy, I appreciate you all being here. And I just wanted to ask you the follow-up that I was talking with Mr. Rand about. It seems like there are many cases in my district where the VA does not appropriately communicate with the caregivers in citing HIPAA, the privacy laws. It seems like VA is being overzealous in the application of HIPAA, which then the domino effect creates difficulty with the caregiver to know what to do, any kind of direction.

Can you just talk about or shed light on if the VA is doing anything to improve education on privacy laws so that caregivers given appropriate information regarding the treatment so nothing slows the process down? And I appreciate, again, the RAND Corporation's research into that.

And I just wanted to read one little quick story. We have a handout from Wounded Warriors, and I just want to read this, because it goes right in hand with the things we hear in our district, it is this kind of a story. It says, "My husband was interviewed by his VA physician, but I was not allowed to go in and assist him and help him remember things and help give an accurate picture of his functioning and health." Goes on to say, I am the caregiver, and I am blocked out of all this information.

In our district, we have a lot of cases where the answer from the VA comes back and says, well, they are not listed on the form as an approved person to get that information, but then they are. So

could you just shed light on is there information going on, on privacy laws?

Dr. MCCARTHY. So there is a lot of education that VA staff are required to do, and every year there is intense education about privacy, and our computer access is restricted if we don't do it. It is a very strong education requirement.

That very well describes the purposes of release of information and so forth. The caregiver application process, the releases are signed. My suggestion is carry it with you, make a copy and carry it with you and have it be set up that it is in an ongoing way. That is how it best works.

I too am the relative of a veteran and had to navigate the system, and so appreciate what you are talking about. But fortunately it was for my father and I was allowed to have access to what I needed to advocate for him for.

But I apologize for what happened with the family that you spoke of, and we are happy to take that for the record and look into it if you want.

Dr. MCCARTHY. But nevertheless, the issue is the release of information is really the bottom line, and my advice to the caregivers would be carry it with you.

Ms. WALORSKI. Can I ask you this, though? And I appreciate that, and that is a good idea and we can certainly recommend that. But a lot of times when a physician calls back and wants to speak to the veteran, in some cases they, if there is not a speaker phone available or something like that, just say, having to put you on speaker, a lot of times we have situations where spouses are fighting for their—in many cases these are husbands fighting for wives, wives fighting for husbands—and you are on a telephone. And they say, look, I have got the signed paper, I have got this, I have got that. What do they do then?

And then also my question, on that 800 number, that caregiver 800 number, is that something that we can give out to a spouse that——

Dr. MCCARTHY. Absolutely.

Ms. WALORSKI [continuing]. Who is in the middle of that hassle——

Ms. KABAT. Yes.

Ms. WALORSKI [continuing]. With a family member, so they call that customer hotline, the caregiver hotline?

Dr. MCCARTHY. Yes. The caregiver support line, yeah. Yes.

Ms. WALORSKI. Okay.

Dr. MCCARTHY. And we are fielding 200 a day.

Ms. WALORSKI. Yes.

Dr. MCCARTHY. Go ahead.

Ms. KABAT. I would add that in my work with other organizations like the Caregiver Action Network, even in some preliminary work that the Institute of Medicine is doing on caregiving as a national issue, this issue of HIPAA really cuts across all of caregiving, not just for veterans. And certainly my office, the Caregiver Support Program, we really believe that part of our role is to provide additional education about the role of caregivers to our providers and to ensure that they do become part of the treatment team.

One of things we are talking about is in our residency programs and some of our other medical services talking about caregivers when folks are part of VA's training programs to ensure that they begin to understand, whether or not they stay within VA, how important it is to include that caregiver on the phone or in the appointment.

Ms. WALORSKI. I appreciate that. And my final question is just to get an idea, back to this whole IT issue and looking and searching and being able to get this new database management system, what is the time line on that? When will you be up and running with the type of a system that you needed to manage this program?

Dr. MCCARTHY. So the system that was developed was kind of piggybacked on another system that was working for something else, and anticipated 4,000 and we are at way more than that. So at the same time that there was recognized the need to expand, there was recognized also a need for a new system. So we have two processes going on kind of simultaneously, one to is kind of fix what we have while we are developing a new system, and the two are being rolled up, there is money that has been allocated. I don't know if you are familiar with the PMAS system and all that for the IT approvals, but it is past the first phase, it is now at the point of the next approval, and then we will go into planning and development as part of that.

Ms. WALORSKI. What does that put us at? Does it put us at 2015, 2016, 2017?

Dr. MCCARTHY. Go ahead.

Ms. KABAT. So the current goal is to have the fix, or the rescue as we are currently calling it, in place by the end of this year and then a new system in fiscal year 2016.

Certainly this is work that we have been doing now for several years. We had an initial document with all of the requirements completed even before we started taking applications in 2011. So at this point, what we have been able to do is garner some support around specific reports that we need and really focusing in on workload and targeting, being able to identify sites where the application process is taking longer than 90 days. And I actually have some staff working fairly diligently with specific medical centers to improve that time it takes to take applications.

Ms. WALORSKI. Okay. I appreciate it, Mr. Chairman. I yield back.

Dr. BENISHEK. Thank you for your questions, Ms. Walorski. And it is sort of similar to the same question I asked, is that when you ask them for a date, it is very hard to get a date out of the VA. And all the stuff you say is great, but it is hard to hold you guys to a date, and that is one of the frustrations that we have here in this committee.

So I want to thank you for being here today.

Ms. BROWN. Mr. Chairman, I have just one question.

Dr. BENISHEK. Yeah. Absolutely. Go ahead.

Ms. BROWN. Yeah. I do have one follow-up question, because as far as the caregivers are concerned, you indicated it is a physical ailment or a condition related to the war.

Dr. MCCARTHY. An injury, but it can be like a traumatic brain injury or post-traumatic stress disorder or a mental condition as well as what we traditionally think of physical injuries.

Ms. BROWN. Well, we have 22, we talk about it, veterans committing suicide. How does that fit into identifying that person that needs that particular kind of care and training? I mean, to me that is a major question as to how we are going to stop this major problem that we are experiencing in the country.

Dr. MCCARTHY. And we wouldn't disagree with you, and we have been before the committee before talking about suicide prevention. And caregivers are key in this for so many of our veterans. I certainly have treated many veterans whose spouses have been responsible for helping them to stay alive for 40, 50 years after the war, and sometimes they see me together and sometimes I see them individually, but nevertheless, I talk to the spouses about what they go through as well. And just like people talk about the emotional numbing that people feel with PTSD, the spouses feel the same. And the spouses will say things to the effect like that veteran is not the only one in the house that has PTSD. As a result of that person's PTSD, I have some. And certainly that is the case.

So a program like this provides things like specific education about PTSD for the caregiver, which is really valuable for them to know, to know, oh, it is not that they are mad at me, it is not this, it is not that; it is that condition. Maybe it is an anniversary date. Maybe there was a trigger when we went to the grocery store. The spouses will ask why does someone with PTSD have to go to Wal-Mart at 3 in the morning. And it is really that they can't stand the crowds, and that is why they go. And so the paint gets picked out and the spouse gets upset that it is not the color that they wanted.

I am sorry. I am just giving you an example of what the families are going through. And so having caregivers around to prevent the suicide is really, really important, because they are partners, and they are our partners, but more importantly, they are their spouse's partner in addressing the unknown that comes back to them after the war.

Ms. BROWN. Well, my question is, are they a part of the denial? No?

Ms. KABAT. No. The law actually states injured in the line of duty on or after September 11, including traumatic brain injury, psychological trauma, and other mental health disorders. So certainly if someone is experiencing anxiety or depression to the point where they require the assistance of another caregiver for supervision and protection.

And I do want to clarify that we, in terms of the scoring that goes on, the physical issues around activities of daily living and the issues around supervision and protection, mood regulation, those kinds of things, are treated equally, they are not weighed separate—well, they are weighed separately, but they are balanced in terms of the ability. So we certainly have many veterans in the program who are completely capable of all of their activities of daily living, but really can't be left in the home alone because of safety reasons, poor judgment, short-term memory, who qualify for the program as well.

And I just want to add one thing. One of the things we have been able to do with this program is to provide really specific training on specific areas. So, for example, we have used the VA TV system. We had groups of caregivers all over the country gather in their

local medical center, about 300 participated, and we had a subject matter expert on post-traumatic stress in our TV studio here in D.C. and so the caregivers watched live a presentation about PTSD and then the caregiver support coordinators would call in and ask questions live.

And so they were really questions, as Dr. McCarthy is saying, on things like, when he wakes up in the middle of the night screaming, do I touch him, and really getting the kind of information that they needed. And we were able to record those sessions, and so now we can provide them on DVD to other caregivers who were not able to attend in person.

Ms. BROWN. Okay. Thank you.

Thank you, Mr. Chairman.

Dr. BENISHEK. Well, if there are no other questions, you are excused.

Ms. KABAT. Thank you, sir.

Dr. BENISHEK. I ask unanimous consent that all members have 5 legislative days to revise and extend their remarks and include extraneous material. Without objection, so ordered.

Dr. BENISHEK. I would like to thank all the witnesses and the audience members for joining us this morning at today's hearing. And the hearing is now adjourned.

[THE STATEMENTS SUBMITTED FOR THE RECORD APPEAR IN THE APPENDIX]

[Whereupon, at 11:50 p.m., the subcommittee was adjourned.]

United States Government Accountability Office

Testimony
Before the Subcommittee on Health, Committee on Veterans' Affairs, House of Representatives

For Release on Delivery
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VA HEALTH CARE

Improvements Needed to Manage Higher-Than-Expected Demand for the Family Caregiver Program

Statement of Randall B. Williamson
Director, Health Care

GAO-15-245T

Chairman Benishek, Ranking Member Brownley, and Members of the Subcommittee:

I am pleased to be here today to discuss improvements needed to manage the higher-than-expected demand for caregiver support services provided by the Department of Veterans Affairs (VA). My statement today is based on our September 2014 report that examined how the Veterans Health Administration (VHA)—which operates VA's health care system—is implementing its Family Caregiver Program, including the types of issues that have been identified during initial implementation and our recommendations for improvement.[1] Since the beginning of the Iraq and Afghanistan conflicts in 2001, advancements in medical care and body armor have reduced fatality rates, allowing more servicemembers to recover from catastrophic physical and psychological injuries, including multiple limb loss, traumatic brain injury, and post-traumatic stress disorder. The cumulative number of post-9/11 veterans who were wounded in action was 1.3 million in 2012—nearly triple the 482,000 veterans who were wounded in action in 2001.

Given the increased number of recovering veterans, the need for caregivers has grown substantially. Family members most often serve in this role and are referred to as "family caregivers." These caregivers assist with the tasks of everyday living—as well as making and keeping appointments, helping navigate complex health care systems, serving as advocates, and making decisions on medical, legal, financial, and benefit issues. Caregivers enable those for whom they are caring to live better quality lives and can contribute to faster rehabilitation and recovery; however, time spent caregiving can lead to the loss of income, jobs, or health care insurance and can exact a substantial physical, emotional, and financial toll, according to RAND and others. To the extent that family caregivers' well-being is compromised, they may become unable or unwilling to fulfill their caregiving role, leaving the responsibilities to be borne by other social institutions.

To provide greater support for caregivers of post-9/11 veterans, Congress passed legislation requiring VA to establish a program to assist

[1]GAO, *VA Health Care: Actions Needed to Address Higher-Than-Expected Demand for the Family Caregiver Program*, GAO-14-675 (Washington D.C.: Sept. 18, 2014).

caregivers with the rigors of caring for seriously injured veterans.[2] In May 2011, VHA established the Program of Comprehensive Assistance for Family Caregivers (Family Caregiver Program) at each of its VA medical centers (VAMC) across the United States. In accordance with applicable requirements, the program provides approved primary family caregivers with a monthly financial stipend, the amount of which is based on the amount and degree of personal care services—such as assisting with bathing and eating—provided to the veteran, and geographic location. The program also provides caregivers with other types of assistance, including training, referral services, counseling, some mental health services, and respite care. Additionally, primary family caregivers approved for the Family Caregiver Program may be eligible for medical coverage through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) if they have no other coverage. As of May 2014, about 15,600 caregivers were approved for the Family Caregiver Program, and the estimated obligations for fiscal year 2014 are over $263 million.

For our September 2014 report, we met with officials from VHA's Caregiver Support Program office—the office responsible for managing and overseeing the Family Caregiver Program. We obtained and reviewed the program's authorizing legislation and implementing regulations as well as relevant policy and management documents, including the program's implementation plan, policy guidebook, and the orientation manual for caregiver support coordinators (CSC), who administer the program at the medical facility level. In addition, we obtained and reviewed information on the numbers of CSCs and approved caregivers for each VAMC, and other program statistics from the Caregiver Support Program office, including aggregate data from weekly reports on the numbers of applications and caregiver approvals as of May 2014. We spoke with Caregiver Support Program officials about these data, and they explained that data from their information technology (IT) system is not reliable unless additional steps have been taken to verify them. We confirmed that the data we obtained from program officials had been verified, and therefore, we determined that these data were sufficiently reliable for the purposes of our report. Additionally, we applied federal standards for internal control related to capturing

[2]See Caregivers and Veterans Omnibus Health Services Act of 2010, Pub. L. No. 111-163, 124 Stat. 1130 (May 5, 2010) (codified at 38 U.S.C. § 1720G).

information and monitoring performance to assess the ability of the Caregiver Support Program office to oversee the program as well as internal control standards for efficiency and effectiveness of operations.[3]

To assess program implementation at the medical facility level, we interviewed officials at five VAMCs, including the directors, selected staff such as departmental leaders, clinicians, and CSCs. We also interviewed program officials from the five Veterans Integrated Service Networks (VISN) who oversee the program at these facilities. However, the information we obtained from interviews with VAMC and VISN officials cannot be generalized. We selected a nonprobability sample of VAMCs based on geographic dispersion and a range of CSC-to-approved caregiver ratios. The VAMCs we selected were Washington, D.C. (VISN 5); Fayetteville, North Carolina (VISN 6); Temple, Texas (VISN 17); Fort Harrison, Montana (VISN 19); and Palo Alto, California (VISN 21). We also interviewed a non-generalizable sample of 11 caregivers of veterans who were approved for VHA's Family Caregiver Program at some of the VAMCs we contacted to obtain their experiences and perspectives on this program. Additional information regarding the scope and methodology of our work is available in our report.

We conducted the work in accordance with generally accepted government auditing standards.

In brief, our September 2014 report stated that

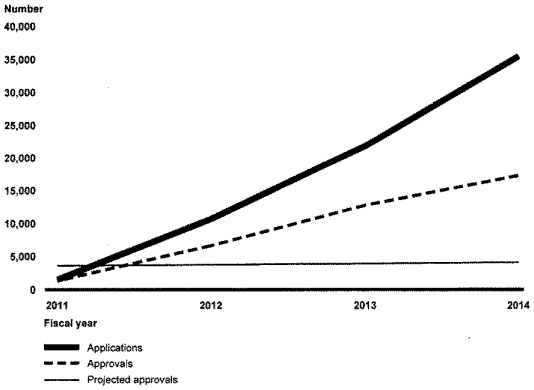
- VHA significantly underestimated caregivers' demand for services when it implemented the Family Caregiver Program. As a result, some VAMCs had difficulties managing the larger-than-expected workload, and some caregivers experienced delays in approval determinations and in receiving program benefits. VHA officials originally estimated that about 4,000 caregivers would be approved for the program by September 30, 2014.[4] However, by May 2014 about 15,600

[3]GAO, *Standards for Internal Control in the Federal Government*, GAO/AIMD-00-21.3.1 (Washington, D.C.: November 1999).

[4]This estimate was based on the number of expected post-9/11 veterans and servicemembers who have serious medical or behavioral conditions involving impairment in at least one activity of daily living or who require supervision or protection, using available data from the Veterans Benefits Administration and the Department of Defense. VA's interim final rule explains the basis for this estimate. See 76 Federal Register 26148, at 26160.

caregivers had been approved—more than triple the original estimate. (See fig. 1.)

Figure 1: Number of Actual Applications and Approvals Compared to VHA's Initial Estimates of Projected Number of Approvals for Family Caregiver Program, Fiscal Years 2011-2014



Source: GAO analysis of VHA information. | GAO-15-245T

The program's staffing was based on VA's initial assumptions about the potential size of the program and consisted of placing a single CSC at each VAMC. In addition, each VAMC was to provide clinical staff to carry out essential functions of the program, such as conducting medical assessments for eligibility and making home visits. This led to implementation problems at busy VAMCs that did not have sufficient staff to conduct these program functions in addition to their other duties. As a result, timelines for key program functions, such as those for processing applications for new caregivers within 45 days and making quarterly home visits to caregivers, were not being met. VHA has taken some steps to address staffing shortages; however, some VAMCs have not been able to overcome their workload problems because the program continues to grow at a steady rate—about 500 approved caregivers were being added to the program each month. A Caregiver Support Program official stated

that program officials recognize the need to formally re-evaluate key aspects of the Family Caregiver Program, including program staffing and the processes for eligibility assessments and home visits, in light of the fact that the program was designed to manage a much smaller caregiver population. This is consistent with federal internal control standards, which emphasize the need for effective and efficient operations, including the use of agency resources such as human capital.[5]

- The Caregiver Support Program office, which manages the program, does not have ready access to the type of workload data that would allow it to routinely monitor the effects of the Family Caregiver Program on VAMCs' resources due to limitations with the program's IT system—the Caregiver Application Tracker. Program officials explained that this system was designed to manage a much smaller program, and as a result, the system has limited capabilities. Program officials also expressed concern about the reliability of the system's data, which they must take steps to validate. Outside of obtaining basic aggregate program statistics, the program office is not able to readily retrieve data from the system that would allow it to better assess the scope and extent of workload problems at VAMCs. This is inconsistent with federal standards for internal control, which state that agencies should identify, capture, and distribute information that permits officials to perform their duties efficiently.[6] A Caregiver Support Program official told us that the office becomes aware of workload problems at some VAMCs through various informal information channels, such as CSCs' requests for application extensions and communication with the CSCs and VISN CSC leads. The lack of ready access to comprehensive workload data impedes the program office's ability to monitor the program and identify workload problems or make modifications as needed. This runs counter to federal standards for internal control which state that agencies should monitor their performance over time and use the results to correct identified deficiencies and make improvements.[7] Program officials told us that they have taken initial steps to obtain another IT system, but they are not sure how long it will take. However, unless the program office begins taking steps towards

[5]See GAO/AIMD-00-21.3.1.

[6]See GAO/AIMD-00-21.3.1.

[7]See GAO/AIMD-00-21.3.1.

identifying solutions prior to obtaining a new system, VAMCs' workload problems will persist and caregivers will not be able to get the services they need.

In conclusion, after 3 years of operation, it is clear that VHA needs to formally reassess and restructure key aspects of the Family Caregiver Program, which was designed to meet the needs of a much smaller population. This would include determining how best to ensure that staffing levels are sufficient to manage the local workload as well as determining whether the timelines and procedures for application processing and home visits are reasonable given the number of approved caregivers. To accomplish this, the Caregiver Support Program office will need to take a strategic, data-driven approach that would include an analysis of the program's workload data at both the aggregate and VAMC levels. It will therefore be necessary for VHA's Caregiver Support Program office to obtain an IT system that will facilitate access to the types of data that would allow it to more fully understand the program's workload and its effect on VAMCs, CSCs, and caregivers. However, without a clear time frame for obtaining another IT system, workload issues will persist unless the Caregiver Support Program office starts to identify solutions to help alleviate VAMCs' workload burdens, such as modifications to the timelines and procedures for application processing and home visits, and the identification of additional ways to provide staffing support. If the program's workload problems are not addressed, the quality and scope of caregiver services, and ultimately the services that veterans receive, will continue to be compromised.

To ensure that the Family Caregiver Program is able to meet caregivers' demand for its services, we recommended that the Secretary of the Department of Veterans Affairs expedite the process for identifying and implementing an IT system that fully supports the program and will enable VHA program officials to comprehensively monitor the program's workload. We also recommended that the Secretary of the Department of Veterans Affairs direct the Undersecretary for Health to (1) identify solutions in advance of obtaining a replacement IT system to help alleviate VAMCs' workload burden, such as modifications to the program's procedures and (2) use data from the IT system, once implemented, as well as other relevant data to formally reassess how key aspects of the program are structured and to identify and implement modifications as needed so that caregivers can receive the services they need in a timely manner.

VA concurred with our recommendations and identified actions planned or underway to address them. However, in concurring with our last recommendation to use data from the IT system, once implemented, as well as other relevant data to reassess the program, VA did not mention using data from the new IT system as part of its evaluation. As a result, we are concerned that VA's proposed actions only partially address this recommendation. A VHA official explained that no one knows how long it will take to develop the new IT system, or how long it will be before data from the system are available, and as a result, VHA developed its response based on actions it knew it could accomplish. However, the substance of our recommendation is focused on using comprehensive workload data from the new IT system as the foundation of a data-driven program analysis. Without such data, VHA will not be positioned to make sound, well-informed decisions about the program, potentially allowing it to continue to struggle to meet the needs of the caregivers of seriously wounded and injured veterans.

Chairman Benishek, Ranking Member Brownley, and Members of the Subcommittee, this concludes my prepared remarks. I would be pleased to respond to any questions you or other members of the subcommittee may have at this time.

For questions about this statement, please contact Randall B. Williamson at (202) 512-7114 or williamsonr@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this statement. Individuals making key contributions to this testimony include Bonnie Anderson, Assistant Director; Fred Caison; Jacquelyn Hamilton; and Giao Nguyen.

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Testimony

Hidden Heroes

Caregivers to America's Ill, Injured, and Wounded Service Members and Veterans

Rajeev Ramchand

RAND Office of External Affairs

CT-421

December 2014

Testimony presented before the House Veterans' Affairs Committee, Subcommittee on Health on December 3, 2014

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Hidden Heroes
Caregivers to America's Ill, Injured, and Wounded Service Members and Veterans [2]

Before the Committee on Veterans' Affairs
Subcommittee on Health
House of Representatives

December 3, 2014

Chairman Benishek, Ranking Member Brownley, and members of the Subcommittee, thank you for inviting me to testify.

Earlier this year, RAND released *Hidden Heroes: America's Military Caregivers.* Funded by the Elizabeth Dole Foundation, the study shed new light on the number and needs of the men and women caring for our nation's wounded, ill, and injured service members and veterans. For the rest of my testimony today I will refer to these individuals as **military and veteran caregivers**. In addition, our study identified the services available to support these military and veteran caregivers. By collecting data on both caregivers and the organizations that serve them, we were able to identify unmet needs and make policy recommendations on areas for improvement. Today, I will share with you highlights from this research with a specific focus on the need to expand services to military and veteran caregivers, and important considerations we should keep in mind when doing so.

The Burden of Caregiving

Our study was one of the first that provided an accurate estimate of the number of military and veteran caregivers living in the United States today. We estimate that there are 22.6 million adults – or 9 percent of the adult population – currently serving as caregivers to other adults. These caregivers are taking care of aging parents, ill and injured spouses, adult children living with disabilities, or neighbors in need of help to keep them living in the community. Of this group, 5.5 million are military or veteran caregivers, providing care and assistance to someone who either

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[2] This testimony is available for free download at http://www.rand.org/pubs/testimonies/CT421.html.

currently serves or previously served in the United States military, regardless of whether that individual's injury or illness resulted directly from military service. Of these 5.5 million military and veteran caregivers, 20 percent – or 1.1 million – are caring for someone who served in Iraq or Afghanistan, a group I'll refer to as **post-9/11 caregivers**. The remaining 4.4 million I'll refer to as **pre-9/11 caregivers**.

Caregivers provide a range of support and assistance that includes helping those they are caring for to eat, bathe, and walk; assisting them with paying bills, buying groceries, and completing chores around the house; and importantly, for persons with mental health or cognitive difficulties, helping them cope with or manage stressful situations. Were the country to replace the time that caregivers spend performing these tasks with the services of home health aide attendants, the total cost would be more than $10 billion for pre-9/11 and more than $3 billion for post-9/11service members and veterans.

In addition to this economic value, the critical support provided by caregivers facilitates the overall health and recovery of those service members or veterans for whom they are caring. However, caregiving duties take a significant toll on these military and veteran caregivers. Relative to the non-caregivers we surveyed, caregivers report worse overall health. They also report that their health affects their ability to perform physical tasks. Their mental health suffers as well: Our study found that the number of hours a person spends providing caregiving duties relates directly to the likelihood that they meet symptom criteria for depression. Their romantic relationships suffer, especially if the person they are caring for is their spouse. Those who are parents report that caregiving negatively affects their relationships with their children, as well. Finally, many caregivers also have waged jobs outside of their caregiving responsibilities, and these caregivers report having to take unpaid time off of work, cut back their work hours, or quit working altogether as a result of caregiving. While both civilian and military and veteran caregivers suffer these same outcomes, those most profoundly affected are post-9/11 caregivers.

Threats to Informal Caregiving

If our nation were to stop supporting military and veteran caregivers, it would leave a cadre of wounded, ill, and injured service members and veterans without the support they need to live or to live in the community in a non-institutional setting. Without caregivers, this group could suffer increased homelessness, morbidity, and even mortality. These concerns are exacerbated in light of what we identify as three critical threats to our nation's caregivers, specifically among the children, parents, and spouses serving in this role:

1. **Children as Caregivers.** In 2013, the AARP Public Policy Institute highlighted that the number of adult children able to care for their parents over age 80 is shrinking, from seven adult children to one aging parent in 2010 to a projected 4-to-1 ratio in 2030 and 3-to-1 ratio by 2050. A large portion of this aging group in need of caregiving support is the pre-9/11 veterans who currently rely on caregivers, plus an unknown additional number of veterans who will need such support as they age.
2. **Parents as Caregivers.** Of the 1.1 million post-9/11 caregivers, 25 percent are parents. As these parents age, who will be available to continue to provide caregiving support to their wounded, ill, and injured sons and daughters?
3. **Spouses as Caregivers.** Thirty-three percent of post-9/11 caregivers are spouses. Caregiving strains these marriages, many of which are quite young, and some are likely to dissolve. Without a caregiver, it is unclear who and what services will be available to provide the assistance that the wounded, ill, or injured veteran needs.

Services Available for Caregivers

We identified 120 organizations currently offering services that directly support military and veteran caregivers. One of these organizations is the Department of Veterans Affairs. The VA offers a wide array of services to caregivers, including those offered through the VA Program of Comprehensive Assistance for Family Caregivers. This program is similar to those of many other organizations that offer services to military and veteran caregivers in that it offers caregiver training and structured social support. However, it is unique in many ways as well. It is one of the few programs to offer a financial stipend to military and veteran caregivers, respite to those who need a temporary break from caregiving duties, health insurance to those who do not have access through other means, and health care to caregivers who need it. Another aspect that makes it unique from the programs of other organizations is that it serves the caregiver directly. Many organizations target most of their services to wounded, ill, and injured service members and veterans, serving caregivers only as an incidental population. For example, the Department of Defense's Special Compensation for Assistance with Activities of Daily Living, or SCAADL, provides its stipend to the service member who qualifies, whereas the VA program provides its stipend directly to the caregiver.

Aside from the VA program, we identified 13 other government-sponsored programs that serve military and veteran caregivers, most of which are in the Department of Defense and serve wounded, ill, and injured service members while offering complementary services to their caregivers. And then aside from a few private, for-profit organizations that serve caregivers directly, the vast majority of the remaining 106 programs are nonprofit organizations that either

serve military families or serve all caregivers and serve military and veteran caregivers incidentally as a subset of both.

Two-thirds of these nonprofits are less than 10 years old, and their longevity is threatened in two ways. First, there is evidence of waning public interest in supporting military and veterans' issues, which may threaten the financial resources needed to sustain these organizations. Second, there is a lack of empirical evidence and evaluation studies showing that the programs they offer actually work, which may dampen funders' enthusiasm for support. This is why research is urgently needed to identify which services being offered are reducing caregiver burden and distress, improving the caregiving support that is being provided, and ultimately improving service member and veteran well-being.

Although there are 120 organizations offering services to military caregivers, not all military and veteran caregivers can access all of them. In addition to the VA Program of Comprehensive Assistance for Family Caregivers, 12 organizations offer services exclusively to post-9/11 caregivers. Other programs may offer services only to individuals who are exclusively caring for a family member or to those caring for someone with a VA disability rating or with a specific condition, such as traumatic brain injury or Alzheimer's disease.

Caregiver Use of Services

Perhaps because there are more services available to them, post-9/11 caregivers tend to use caregiver support services more commonly than pre-9/11 caregivers. For example, nearly three-quarters of post-9/11 caregivers report accessing some form of caregiving support from the Department of Veterans Affairs, though not all are accessing the Program of Comprehensive Assistance for Family Caregivers. This compares to only 38 percent of pre-9/11 caregivers. While this may appear to be a marker of underutilization, our data suggest that most of those not using VA or any other services indicate that it is because they do not want to use them. Among the roughly 20 percent of military and veteran caregivers not using – but who would want to use – a specific service, most reported that they were not using the service because they were unaware of the resource or that it was difficult to find information about it.

A Heterogeneous Group

Caregivers are a diverse group, and differences are perhaps most pronounced between the two groups of military and veteran caregivers that I referenced earlier in my testimony.

- Post-9/11 caregivers tend to be young men and women taking care of their spouses, neighbors taking care of a friend, or parents taking care of their children. Of those service members or veterans in their care, 58 percent have a VA disability rating; most are suffering from back pain; and more than 60 percent have a mental health or substance use disorder, like posttraumatic stress disorder.
- By contrast, the pre-9/11 military and veteran caregivers look similar to non-military and veteran caregivers: They tend to be adult children or grandchildren taking care of an aging parent or grandparent. The veterans in their care commonly experience back pain and tend to suffer from chronic conditions like hypertensive vascular disease or neurological conditions like dementia.

Organizations wanting to serve all military and veteran caregivers must cater to this diversity of caregivers and care recipients. For example, training that educates caregivers regarding how to help an aging parent bathe and dress may not be relevant to post-9/11 caregivers who need to learn how to help their spouses cope with stressful situations to mitigate the risk of a panic attack. Similarly, the type of respite care required for someone with Alzheimer's or another form of dementia may be very different from respite care for someone with symptoms stemming from a traumatic brain injury. To be effective, programs must account for and offer services to a range of caregivers; it may be better to avoid offering services to certain caregiving groups if it is not possible to do so with competence.

Caregiving as a National Priority

Caregivers face unique needs that programs specifically designed for them can certainly address. Research suggests that structured support from other caregivers is beneficial and that caregivers similarly benefit from training provided specifically to them. Respite is the only service that directly reduces the hours spent caregiving, and the time spent performing caregiving duties is the primary contributor of negative outcomes among caregivers – including risk for depression – so we consider respite to be a critical service for caregivers. Accordingly, some military and veteran caregivers are unable, ineligible, or unwilling to access respite offered by the VA, so reauthorizing and fully funding the Lifespan Respite Care Act will broaden the respite services available to all types of caregivers.[4]

[4] The Lifespan Respite Care Act (P.L. 109-442) was signed into law in 2006 and authorized Congress to spend $288 million between FY2007 and FY2011 to provide high-quality respite at state and local levels; allocations have been approximately $2.5 million per year since 2009.

There are other policy vehicles through which all caregivers, including military and veteran caregivers, can gain access to specific support. The Department of Health and Human Services, for instance, oversees the National Family Caregiver Support Program and Medicaid's Home and Community-Based Services (HCBS) Waiver Program, both of which offer services specific to caregivers. However, it should be noted that not all military and veteran caregivers are currently eligible to access these services. The National Family Caregiver Support Program, for example, is geared largely toward caregivers of people over age 60 and of those with Alzheimer's; thus, while many pre-9/11 caregivers will qualify for services offered under this program, most post-9/11 caregivers will not. Likewise, states interpret eligibility for Medicaid's HCBS Waiver Program differently. Some of them may restrict services to those caring for people over age 60 or to family caregivers – thus excluding neighbors and friends, who account for between 10 and 25 percent of all caregivers. This is why we recommended that eligibility for programs be determined by the tasks and duties that caregivers perform rather than the age of those they are caring for or their relationship to the caregiver.

Because between half and three-quarters of military caregivers are also employed, employers have a role to play as well. Some provisions of the American Disabilities Act prevent discrimination against individuals related to persons with a disability, which may include some – but not all – caregivers. The Family Medical Leave Act (FMLA) also protects the jobs of caregivers who have to take time off of work to attend to caregiving duties. In 2008 and 2010, the National Defense Authorization Act expanded the injuries and illnesses covered for military caregivers and the period of time that military and veteran caregivers could take leave under the FMLA.

In addition to adhering to these legal requirements, employers themselves can take proactive roles in supporting military and veteran caregivers. In 2007, the Equal Employment Opportunity Commission published for employers best practices for supporting employed caregivers. While many were related to preventing caregiver discrimination in recruiting, hiring, and promoting, other best practices encouraged work-life balance and strategies to accommodate caregivers, such as offering flexible work schedules or employer-sponsored services like Employee Assistance Programs to mitigate some of the stressors caregivers may face.

Given that the Departments of Health and Human Services, Labor, Veterans Affairs, and Defense all have a role in supporting military and veteran caregivers, it is critical that efforts to serve this population be coordinated. While there is some evidence of collaboration between departments, gaps and inconsistencies in eligibility criteria and program definitions remain. Efforts to facilitate interagency coordination, such as through interagency working groups or task forces and federal

Commissions, could enhance the alignment and quality of services to support military and veteran caregivers.

Conclusion

Honoring and serving our current and former members of the armed forces, particularly through periods of illness or when recovering from injuries and wounds, is a national priority. Our report makes it clear that honoring and serving this group requires that we attend to their family members and friends who provide the informal care that is critical to keeping them alive and thriving. We titled our report "Hidden Heroes" because this group often stands in the shadows of its disabled service members and veterans and is rarely the focus of policy attention. I commend Congress for taking it upon itself to learn more about what it can do to support these hidden heroes. This hearing will prompt an emerging and much needed national dialogue on how the nation can better support its caregivers, and I hope that our data are helpful in informing this discussion. As I have noted, understanding the diverse nature of their characteristics and needs is critical because a one-size-fits-all approach will not be effective in serving all military and veteran caregivers simultaneously.

Thank you, Chairman Benishek, Ranking Member Brownley, and members of the Subcommittee for inviting me to testify before you today to be part of this dialogue. I look forward to answering your questions.

STATEMENT OF DR. MAUREEN MCCARTHY

DEPUTY CHIEF PATIENT CARE SERVICES

DEPARTMENT OF VETERANS AFFAIRS

BEFORE THE

HOUSE COMMITTEE ON VETERANS' AFFAIRS

DECEMBER 3, 2014

Chairman Benishek, Ranking Member Brownley, and distinguished Members of the House Committee on Veterans' Affairs, thank you for the opportunity to discuss with you the Department of Veterans Affairs' (VA) efforts regarding our Caregiver Support Program.

VA recognizes the crucial role that family caregivers play in helping Veterans recover from injury and illness and in the daily lives of Veterans in the community. VA values the sacrifices caregivers make to help Veterans remain at home. Caregivers are our partners in the care of Veterans, and VA is dedicated to providing them with the support and services they need. The Caregivers and Veterans Omnibus Health Services Act of 2010, also referred to as the Caregiver Law, has allowed VA to provide unprecedented support and services to approved family caregivers of eligible Veterans. After the law was enacted, VA established a comprehensive National Caregiver Support Program, with a prevention and wellness focus, which includes the use of evidence-based training and support services for family caregivers. In fiscal year (FY) 2014, VA obligated approximately $350 million for VA's Caregiver Support Program.

The Caregiver Law establishes additional support and services for approved family caregivers of eligible Veterans (including eligible Servicemembers undergoing medical discharge) who were seriously injured in the line of duty on or after September 11, 2001 under the Program of Comprehensive Assistance for Family Caregivers. Additional services and supports include (1) a stipend paid directly to the designated primary family caregiver, (2) enrollment in VA's Civilian Health and Medical Program (CHAMPVA) for the designated primary family caregiver, if eligible, (3) an expanded

respite care, (4) mental health services, and (5) travel expenses for the eligible family caregiver when receiving initial training and during the eligible Veteran's medical appointments. Required Family Caregiver training is provided as part of the application process through VA's collaboration with Easter Seals.

VA has been accepting applications for the Program of Comprehensive Assistance for Family Caregivers since May 9, 2011. Since the Program began, 20,109 family caregivers have participated. At the end of FY 2014, there were 17,572 family caregivers participating in the Program. VA has trained more than 22,000 family caregivers of post 9/11 eligible Veterans and provided CHAMPVA coverage to more than 4,800 eligible primary family caregivers who did not have other health care coverage.

In partnership with VA's Office of the Actuary, the Caregiver Support Program reviewed the health care utilization of approximately 9,000 Veterans participating in the Program of Comprehensive Assistance for 6 months prior to participation and for the first 6 months of their participation. Inpatient hospital admissions decreased by 30 percent. When a Veteran was hospitalized, their length of stay decreased by 2.5 days. While these findings do not take into account other factors that may have contributed to health care utilization, they are exciting and build the foundation for additional evaluation.

VA's Caregiver Support Program

In addition to the Program of Comprehensive Assistance for Family Caregivers, VA offers a variety of services and resources to caregivers of Veterans of all eras. One valuable resource for caregivers is their local Caregiver Support Coordinator. These individuals serve as the clinical experts on family care giving issues and are experienced social workers, nurses, and psychologists. VA requires each medical center to employ at least one full-time Caregiver Support Coordinator (CSC). They provide support and programming to caregivers, link caregivers to community and VA resources, and respond to referrals from the Caregiver Support Line. At the end of FY 2014, VA was funding 259 full-time CSC positions in the field, with 8 additional temporary positions being funded to meet demand as requested by medical centers.

An important service VA established in February 2011 is the National Caregiver Support Line, which is staffed by licensed social workers. The support line is available to respond to inquiries about caregiver services, as well as serve as a resource and referral center for caregivers, Veterans, and others seeking caregiver information. As of the end of FY 2014, VA's Caregiver Support Line had received 149,654 calls, averaging more than 200 calls each day. Callers represent Veterans of all eras of service, with most calls about Vietnam era Veterans, followed by Veterans who served Post 9/11, World War II Veterans, and Korean conflict era Veterans.

Another highly utilized resource is VA's website dedicated to family caregivers, www.caregiver.va.gov. It provides caregiver stories, resources, and a zip code locator feature that allows caregivers to identify their local Caregiver Support Coordinator. The site also has a list serve function which currently has more than 42,000 subscribers.

In addition, the Caregiver Support Program launched a Peer Support Mentoring Program in January 2012, to decrease the isolation that many caregivers feel by providing a more formal support mechanism for social networking. The program matches seasoned caregivers with less experienced caregivers to receive guidance, and to share their experiences, wisdom, and skills with one another. At the end of FY 2014, 240 caregivers had participated in this program.

Caregiver Training and Education

In addition to the support services previously mentioned, VA offers a menu of training and education opportunities for caregivers of Veterans of all eras. In January 2013, VA launched Building Better Caregivers in collaboration with the National Council on Aging (NCoA). Building Better Caregivers is an evidence-based online workshop that groups caregivers of Veterans together to learn about problem-solving, dealing with difficult behavior and emotion, and taking care of themselves. At the end of FY 2014, more than 3,000 caregivers had been referred to Building Better Caregivers. In addition, based on feedback from caregiver participants, VA launched an alumni group, allowing alumni of Building Better Caregivers to continue their discussions and on-line relationships with one another. More than 450 caregivers are currently a part of the community.

VA also provides in-person training of caregivers on a variety of topics related to self-care including *Managing Stress, Taking Care of Yourself, Problem Solving and Effective Communication,* and *Utilizing Technology.* These courses were developed in collaboration with Easter Seals and have been provided to more than 1,200 caregivers of Veterans of all eras across 51 VA sites. In November 2014, more than 500 caregivers were registered to attend classes at more than 30 sites as VA celebrated National Family Caregivers Month.

Beginning in November 2012, VA's Caregiver Support Line began offering Telephone Education Groups to caregivers of Veterans of all eras. In FY 2014, VA offered 29 Telephone Education Groups, with more than 480 caregivers participating in at least one call. After receiving feedback from caregivers regarding the times the calls were offered, VA added a third call to each month, held in the evening, to allow caregivers who work during the day to attend the calls. More than 95 new caregivers were able to join these calls due to the change in time.

VA also provides specialized training services for caregivers that are specific to a diagnosis. Resources for Enhancing All Caregivers Health for Veterans, otherwise known as REACH VA, is a national program run out of the Memphis VA Caregiver Center, located at the Memphis VA Medical Center (VAMC). It is an evidence-based, skills-building intervention, including individual sessions with an option for telephone support group meetings designed to provide support, education, and skills-building to eligible caregivers of Veterans with Alzheimer's disease or other related dementias. While REACH VA began as a 12-session intervention, it is currently implemented in four core sessions, with the option for additional sessions based on caregiver need and clinician judgment.

The intensive one-on-one intervention between an eligible caregiver and a VA clinician addresses five main care giving risk areas including: safety; social and emotional support; problem solving; caregiver well-being; and, both caregiver and Veteran health. The intervention focuses on problem solving around behavioral topics, stress and coping techniques, as well as step-by-step strategies to assist caregivers in everyday problems they may encounter. In research on effectiveness, REACH caregivers show significant improvements in reported burden, depression, social support, health care behaviors, caregiving frustrations, and a number of reported

behavioral problems. Caregivers often spend time providing hands-on care, as well as spending time "on duty," which is defined as time spent providing supervision of the care recipient, time that cannot be spent relaxing, socializing, or doing other household or personal tasks. Caregivers who have participated in REACH report spending one hour less per day providing hands-on care, and two hours less per day of "on duty" time.

Through the end of FY 2014, more than 550 VA clinical staff across the country were trained in REACH VA. At the end of FY 2012, REACH VA was adapted for use with caregivers of Veterans experiencing spinal cord injury or disorder as a pilot program at three VA sites. The Caregiver Support Program is currently funding additional expansion to include amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS).

A program called Spouse Telephone Support (STS) is also offered through the Memphis Caregiver Center. VA has long provided support in person and via telephone through the use of support groups to eligible family members who serve as caregivers of Veterans. In October 2011, based on successful outcomes demonstrated by a Department of Defense research study, VA expanded support services by initiating STS. STS is designed to improve resilience, prepare spouses, significant others, and intimate partners to cope with reintegration difficulties, to serve as a support system, and to ease the post-deployment transition. In January of 2015, an adaptation of STS will be available for all caregivers of Veterans.

In October 2014, the Caregiver Support Program expanded its training to caregivers using an on-line platform historically used to train VA staff – VA's eHealth University or VeHU. In October, a VA subject matter expert provided on-line training on domestic violence and intimate partner violence to more than 180 caregivers. The training is now available at MyVeHU On Demand and can be viewed at any time by caregivers.

Public-Private Collaboration

In addition to the many services and supports that VA provides to Caregivers, VA has collaborated with the Fisher House Foundation, which provides Hero Miles to support family caregivers and eligible Veterans participating in the Program of Comprehensive Assistance for Family Caregivers. Family members and friends can

use Hero Miles to fly to the Veteran's home to assist in the care of the Veteran, providing a much needed break to the family caregiver. Since launching this collaboration, Hero Miles has provided more than 2,600 flights to support family caregivers and eligible Veterans participating in the Program of Comprehensive Assistance at a cost savings of more than $4.5 million to caregivers and Veterans.

GAO Report Recommendations

GAO was recently asked to examine VA's implementation of the Program of Comprehensive Assistance for Family Caregivers. The report examined how the Veterans Health Administration (VHA) is implementing the program, including the types of issues that have been identified during the initial implementation of the program. VA agreed with GAO's three recommendations:

1) Expedite the process for identifying and implementing an IT system that will enable program officials to monitor workload data;
2) Identify solutions to help alleviate VAMCs' workload burden in advance of obtaining a new IT system; and
3) Use data from the new IT system once implemented, and other relevant data, to re-assess the program and implement changes as needed.

In response to GAO's first recommendation, VA has identified FY 2015 funding to support not only the development of a new IT solution to support the Caregiver Support Program, but also funding to stabilize the current system, allowing the Program Office to better monitor workload, including data on the status of each application. This will allow the Program Office to identify the best practices of high-performing facilities and target lower performing facilities for improvement. Stabilizing the current IT system will also allow VA to provide accurate data to key stakeholders regarding the status of applications across the country.

Regarding GAO's second recommendation, VHA has been providing the Program of Comprehensive Assistance for Family Caregivers for more than 3 years. When the program was first established, VHA made the policy decision to use home visits as the way to monitor the well-being of program participants as is contemplated under the Caregiver Law. Due to feedback from the field, as well as caregivers and Veterans, the Caregiver Support Program Office has established a workgroup of subject

matter experts as well as Caregiver Support Coordinators and VA staff who currently complete home visits to evaluate VA's policy for monitoring the well-being of program participants. The workgroup is currently meeting weekly and we anticipate recommendations from the workgroup by Spring 2015.

Lastly, to address the third recommendation, the Caregiver Support Program Office, in collaboration with VHA's Health Services Research and Development office, has established a Partnered Evaluation Center. This center will review the impact of both the Program of Comprehensive Assistance for Family Caregivers and the Program of General Caregiver Services on the health and well-being of both Caregiver and Veteran participants and build on the data received from VA's Office of the Actuary discussed earlier in my statement. VHA anticipates preliminary findings from this study will be available in mid-year of 2015.

Conclusion

Mr. Chairman, caregiving is truly a labor of love and VA recognizes the crucial role that caregivers play in helping Veterans remain in the communities they defended, surrounded by those they love. VA is dedicated to promoting the health and well-being of caregivers who care for our Nation's Veterans, through education, resources, support, and services. I thank Congress for your support as we work to make things better for all of America's Veterans and their caregivers.

This concludes my testimony. My colleagues and I are prepared to answer questions you or the other Members of the Committee may have.

STATEMENT OF
ADRIAN ATIZADO
DAV ASSISTANT NATIONAL LEGISLATIVE DIRECTOR
SUBMITTED FOR THE RECORD TO THE
SUBCOMMITTEE ON HEALTH
COMMITTEE ON VETERANS' AFFAIRS
UNITED STATES HOUSE OF REPRESENTATIVES
December 3, 2014

Chairman Benishek, Ranking Member Brownley and Members of the Subcommittee—

On behalf of the DAV and our 1.2 million members, all of whom are wartime wounded, injured and ill veterans, I am pleased to present our views for this oversight hearing. DAV is dedicated to a single purpose: empowering veterans to lead high-quality lives with respect and dignity. For many severely ill and injured veterans, such lives would be difficult to achieve without the love, support and daily sacrifice of their family caregivers. Therefore, DAV is grateful that the Subcommittee is turning its attention to the Department of Veterans Affairs (VA) Comprehensive Assistance for Family Caregivers Program, and is reviewing the feasibility of expanding this program to family caregivers of veterans who were injured, wounded or became ill before September 11, 2001.

According to a recent report by the RAND Corporation, *Hidden Heroes: America's Military Caregivers*, the loving assistance provided by family caregivers saves the United States government many millions of dollars each year in health care costs, and enables millions of veterans to live at home rather than in institutions.[1]

Enactment of Public Law 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010, required VA to create and implement across VA's vast health care system an entirely new, comprehensive and integrated program designed primarily for a population it had not served in such a manner before—and DAV was under no illusions that nationwide implementation of the caregiver support program would not encounter its share of obstacles along the way. Those obstacles have emerged, but we believe VA has done a creditable job with the tools it possesses to implement this important program.

As a September 2014 Government Accountability Office (GAO) report points out, thousands of caregivers and their families' wounded and injured veterans are benefiting today from VA's Comprehensive Assistance for Family Caregivers Program. However, the report also describes how the VA health care system has been slow to react to the needs at the front lines of this program and to the caregivers it is charged to assist.[2]

DAV agrees with GAO's findings and recommendations, and we look forward to VA's reporting whether it met its self-established goals due in January, April, and June of this year, as well as to learn the status of VA's identifying, developing and deploying a new IT system for the caregiver support program.

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[1] http://www.rand.org/pubs/research_reports/RR499.html
[2] http://gao.gov/products/GAO-14-675

The GAO's report, unfortunately, did not discuss other aspects of concern to DAV regarding the caregiver support program. Among our concerns, currently a single individual is serving as both the Acting Director and Deputy Director of the caregiver program in VA Central Office. Thus, the program and the caregivers of severely injured veterans participating in both the Comprehensive Assistance for Caregiver Program (post-9/11) and VA's general caregiver services (pre-9/11) are not being effectively represented in higher organizational policy and priority discussions. Further, unlike other clinical programs under the Veterans Health Administration's (VHA) current organizational structure, the caregiver support program office has no "clinical operations" counterpart office with which to work collaboratively to support consistent field operations across the VA system.

With a disadvantaged program office trying to implement and integrate a new national program, including the development of a more robust IT system, among other competing priorities within VA, successful program management is proving to be extremely challenging. As validated by the GAO report, without reflective program data, DAV is rightly concerned about VA's ability to project the resources needed to address the backlog of pending applications and continue supporting the growing caregiver population and their family veterans who were severely disabled from military service.

In addition, the DAV continues to have other concerns regarding the VA Caregiver Support Program such as delay in the agency's response to our comments made to the interim final rule for the program, the apparent lack of due process and transparency in the decision and appeal process for program applicants, and the lack of a publicly accessible program handbook or directive that would shed light on program policies and processes.

Irrespective of whether because of inadequate staffing for the caregiver support program from VA Central Office to local VA facilities, or not having the right tools and sufficient resources or support to properly manage, evaluate and improve the program, caregivers of and injured veterans themselves are being adversely affected and are not receiving the full benefits intended by Congress.

DAV urges Congress and the Administration to work together to overcome these weaknesses while continuing to support thousands of caregivers and their family veterans who need these services. In light of the current situation, this Subcommittee should look closely at the Administration's FY 2015 budget request and the flat-line FY 2016 advance appropriations request for caregiver support programs. The unmet needs of severely ill and injured veterans and their family caregivers deserve your close attention.

Ending the Inequity: Eligibility for Comprehensive Assistance for Caregivers Program

DAV thanks the Subcommittee for working with us to begin a discussion on how to reasonably and responsibly end the current inequity of denying participation by caregivers of severely ill and injured pre-9/11-veterans in the Program of Comprehensive Assistance for Caregivers. Our members and their family caregivers look forward to having a seat at the table in any future discussions this Subcommittee will sponsor on this crucial topic.

Today, many veterans' family caregivers remain unserved or underserved. Research published by RAND in October 2014, *The Opportunity Costs of Informal Elder-Care in the United States,* estimated the value of informal family-based care at $522 billion per year. As the report states, "[r]eplacing that care with unskilled paid care at minimum wage would cost $221 billion, while replacing it with skilled nursing care would cost $642 billion annually."[3]

Moreover, RAND's *Hidden Heroes: America's Military Caregivers* report estimates that of the current adult caregiving population in the United States, 24.3 percent (over 5.5 million) support wounded, ill or injured military or veterans. More specifically, the report points out that over 80 percent of the 5.5 million caregivers of veterans, or approximately 4.4 million caregivers of veterans severely ill and injured, ***are not eligible*** to participate in the Comprehensive Assistance for Caregivers Program.

Given that the purpose of RAND's *Hidden Heroes* report was to identify the systematic differences between post-9/11 military caregivers and other military caregiver groups, and to recommend tailored approaches to meet the unique needs and characteristics of post-9/11 caregivers, it is encouraging that the report validates the need for integrated and coordinated services and supports as is currently provided through VA's caregiver support program.

Perhaps it is because of its focus that the RAND report inadvertently suggests VA's general support services program is comparable to the Comprehensive Assistance for Caregivers Program. By law and in reality, however, they are far from equal. For example, the RAND report ascribes a monthly financial stipend under the general caregiver support services as the "Aid and Attendance program."[4] First, Aid and Attendance (A&A) is not a program; it is a compensation benefit and has no formal connection to the general caregiver support services.[5] Second, the A&A benefit is awarded to a veteran, not a caregiver. Third, the veteran must present a higher level of disability to meet the eligibility criteria for A&A compensation discussed in the RAND report, compared to the eligibility criteria for the monthly financial stipend available under the Comprehensive Assistance for Caregivers Program.

There are similarly significant differences that apply to the eligibility criteria for the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) health coverage for general caregivers versus primary caregivers under the Comprehensive Assistance for Caregivers Program.[6]

Primary caregivers in the Comprehensive Assistance for Family Caregivers Program, who are not otherwise insured, are provided CHAMPVA coverage. Uninsured caregivers of pre-9/11-injured veterans in the General Caregiver Support Program must also meet the following

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[3] http://www.rand.org/pubs/external_publications/EP66196.html

[4] Hidden Heroes: America's Military Caregivers. The RAND Corporation. Pg. 220

[5] Aid and Attendance is not administered by the Veterans Health Administration (VHA), which is responsible for VA's Caregiver support program, but by the Veterans Benefits Administration (VBA)

[6] According to the RAND report, "ensuring that caregivers have health care coverage is critical for their health and well-being, and as many as 40 percent of post-9/11 military caregivers do not have such coverage. Also alarming is that 20 percent of pre-9/11 and civilian caregivers do not have such coverage."

criterion: (1) the veteran must be rated permanently and totally disabled due to a service-connected condition(s); (2) the caregiver can only be the veteran's spouse or child (not parent, step-family member, or extended family member, etc.), and; (3) if the designated caregiver is the veteran's dependent child, the eligibility for CHAMPVA ends at the age of 18, unless that individual is enrolled in an accredited school as a full-time student until the age of 23. If he or she marries, or is a stepchild who no longer lives in the household of the CHAMPVA sponsor, eligibility for CHAMPVA coverage is lost.

In the view of DAV, any discussion purporting that the General Caregiver Support Services program (pre-9/11) is somehow equivalent to the Program of Comprehensive Assistance for Family Caregivers (post-9/11) must simply consider the plain differences in the law discussed here. Addressing the differences mentioned above and others—such as including "illness" in the eligibility criteria for the Comprehensive Assistance for Caregivers Program and addressing the eligibility differences with the Department of Defense's Special Compensation for Assistance with Activities of Daily Living—need to be adjusted legislatively to correct current inequities and provide comprehensive and coordinated caregiver support and services for caregivers of all severely ill and injured service members and service-disabled veterans.

DAV recommends the Subcommittee consider whether there is any difference in status or needs between a service member injured or ill on September 10, 2001 and one injured or ill on or after September 11, 2001. We see no difference at all, despite the symbolism since embraced by Congress that 9/11 was an important demarcation date for eligibility for VA services and benefits. DAV vigorously and firmly disagrees with such a two-tiered and unjustified policy. If a veteran is severely injured or ill due to active military service, his or her needs should be fully addressed by the government, without equivocation, and without respect to when a particular illness or injury occurred.

Veteran-Directed Home- and Community-Based Services Program

Mr. Chairman, the *Hidden Heroes* report also highlighted several existing federal caregiver support programs, but only mentions one other VA program—the Veteran-Directed Home- and Community-Based Services Program (VD-HCBS).

The mission of VD-HCBS is to provide flexible care that respects veterans' choices and desires in how they receive needed health care services. It uses state-of-the-art, person-centered planning coupled with a flexible service model that puts veterans in the driver's seat in making their own choices about the types of services they receive, and when they receive them. This is truly a veteran-centric approach to obtaining long-term services and supports. In addition, studies conducted by four different VA medical centers (VAMC) demonstrated VD-HCBS can keep veterans at home in their communities, rather than be placed in nursing home beds, saving funds in both VA nursing home and in acute care program spending, thus freeing up precious resources to serve more veterans in communities and reduce VA waiting lists. Equally important to DAV, other studies have shown that veterans are extremely satisfied with this program.

Since 2008, the VHA has been collaborating with the Department of Health and Human Services (HHS) through the HHS Administration for Community Living, to allow states and

local aging and disability network agencies to serve, through VD-HCBS, at-risk veterans of all ages who are candidates for nursing home placements. The DAV applauds this innovative and cost-effective partnership.

Since its inception, approximately 1,900 veterans have received VD-HCBS services across 48 VAMCs in 27 States and the District of Columbia. This program provides one-on-one counseling to veterans, their caregivers, and their family members, and helps affected veterans to determine how to use a flexible budget to meet long-term service and support needs, goals, and preferences using local community resources.

As it relates to this hearing, because veterans are more comfortable having family caregivers provide the personal care services they require on a regular basis, and in this program veterans can use their VD-HCBS monthly spending budget to hire and pay their caregivers, veterans have largely hired and paid their spouses, children or other family members who live with or near them to provide personal care services to maximize their own independence, allowing them to remain safely in their homes.

For example, 60 percent (139 of 231) veterans participating in 10 VD-HCBS programs in five states reported using their monthly spending budgets to pay 205 family caregivers (an average of 1.47 family caregivers per veteran) for personal care services. These veterans used on average 72 percent of their VD-HCBS monthly budget for personal care to hire family caregivers, which equates to receiving an average of 94 hours of personal care services per month. Unfortunately, because the law now only allows VA to use provider agreements with Medicare- and Medicaid-certified providers, it appears that 26 local aging and disability network agencies that were established under the Older Americans Act and the Rehabilitation Act would no longer be able to serve veterans under this VD-HCBS program.

That is, access to the VD-HCBS program will soon start to cease for over 400 veterans served by these 26 organizations in the states of Florida, Idaho, Illinois, Louisiana, Maine, Massachusetts, Michigan, Minnesota, New York, Oregon, South Carolina, Texas, and Wisconsin. Without a resolution, veterans currently being served by these agreements would be forced into institutional care or to use provider-driven home health care services. Neither of these options reflects the personal choices or preferences of veterans.

The DAV recognizes VA is working to resolve this provider agreement issue within existing authorities. However, in the absence of a clear and timely resolution to this challenge, multiple VA medical centers with established VD-HCBS programs are beginning to curtail veterans' access to this program while other VA medical centers ready to start a program to help local veterans and their caregivers are left waiting.

DAV urges this Subcommittee to author, and the Congress to pass legislative language to allow local aging and disability network agencies to be made eligible recipients once again for provider agreements with VA and facilitate veterans' access to VD-HCBS nationally.

Conclusion

Congress has before it numerous legislative options it can take to fully recognize and support caregivers of all severely ill and injured veterans and service members, from fully funding the Lifespan Respite Care Act; reauthorizing the Older Americans Act and the Rehabilitation Act; eliminating the inequity in the eligibility for VA's Program of Comprehensive Assistance for Family Caregivers; and, amending VA's provider agreement authority as discussed above.

Despite the weaknesses identified by GAO in VA's Program of Comprehensive Assistance for Family Caregivers, the RAND report validates the need for integrated and coordinated services and supports as is currently provided through VA's caregiver support program. Moreover, VA's recent report to Congress on the feasibility of expansion of family caregiver assistance, required by Public Law 111-163, provides information about program effectiveness in supporting primary caregivers and reducing VA's direct health care costs. We call the attention of the Subcommittee to this important report.

VA's report describes the merit in resolving the inequity created by the current eligibility requirements, and would further recognize the sacrifice and the needs of the family caregivers of all severely ill and injured veterans.

> "VA believes, apart from resource issues… such an expansion is operationally feasible. There would be challenges in a surge of new applications upon an expansion. VA estimates an additional 2,000 full-time equivalent staff would need to be in place to assist with the workload of an expanded program. With planning, the increased workload could be managed. Additionally, the application of eligibility criteria for serious injuries that occurred decades ago may take more time and analysis than we experience today and the availability of evidence for those decisions may be limited. This, too, can be mitigated with planning and preparation."

In light of VA's statement, we turn to a March 2011 letter to VA from a Congressional leader that asserted—

> "Further delay of this program hurts veterans and caregivers in need of these critical benefits and services. Further, limiting eligibility to arbitrary and stringent criteria… creates undue hardship for veterans and family caregivers meant to be helped by the new program."

While this letter was penned to address VA's delay in implementing the Comprehensive Assistance for Family Caregivers program, as well as VA's proposed actions at that time to severely limit access of family caregivers to the then-new benefit, it is a fitting letter speaking to the current inequity faced by caregivers of veterans who became severely ill and injured before September 11, 2001.

Mr. Chairman, this concludes DAV's submission of testimony for the record of this hearing. Should this statement prompt questions by you or other Members, please forward them and DAV will supply our written responses to better inform the record of this important hearing, or to meet with you to discuss them. Also, DAV would be pleased to work with your professional staff to craft legislation to remedy the issues DAV has raised in this statement or others that may be discussed during today's hearing. Thank you for accepting this testimony.

STATEMENT FOR THE RECORD

OF

PARALYZED VETERANS OF AMERICA

PROVIDED TO THE

HOUSE COMMITTEE ON VETERANS' AFFAIRS

SUBCOMMITTEE ON HEALTH

CONCERNING THE DEPARTMENT OF VETERANS AFFAIRS'

FAMILY CAREGIVER PROGRAM

DECEMBER 3, 2014

Chairman Miller, Ranking Member Michaud, and members of the Committee, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to submit our views pertaining to the Department of Veterans' Affairs Family Caregiver Program. PVA appreciates the Committee's interest in improving this program so that it can ultimately be viable for all generations of veterans.

The intent of P.L. 111-163, the "Caregivers and Veterans Omnibus Health Services Act of 2010" is to improve caregivers' skills and well-being while lessening the financial burden of their role. Similarly, the law ensures that veterans with catastrophic injuries receive caregiver support that is so critical to their own independence and health. The law offers services to three groups of family caregivers

i. **General Caregivers**: includes caregiver education and training, use of telehealth technologies, restricted counseling and mental health services, and respite care.

ii. **Secondary Family Caregivers**: includes all General Caregiver supports, monitoring veterans quality of life, instruction and training specific to their veteran's needs, paid travel expenses while accompanying veterans to appointments, information and assistance to address the routine, emergency, and specialized caregiving needs and individual and group therapy, counseling and peer support groups.

iii. **Primary Family Caregivers**: includes all General Caregivers and Secondary Family Caregivers supports, a monthly caregiver stipend, at least 30 days a year of respite care, and CHAMPVA healthcare coverage, if they have none.

Information from the recent GAO report "VA Health Care: Actions Needed to Address Higher-Than-Expected Demand for the Family Caregiver Program," (GAO-14-675) highlight many issues that require immediate attention. PVA concurs with the findings of the report and we likewise support the recommendations presented by GAO. Members of PVA, veterans with spinal cord injury or disease, generally have a much higher need for caregiver support than the rest of the veteran population. As such, we would like to share our observations, frustrations,

and suggestions to ensure this program provides the best services possible to those veterans with the greatest demonstrated needs.

No 22 year-old husband or wife prepares to become a caregiver for their spouse. They are often thrust into this responsibility, sometimes over night. As a result, the completion of a college degree or the pursuit of a career is diverted into being the sole provider and caregiver for his or her loved one. Often these partners are already juggling childcare and attending to elderly parents. The well-being of a caregiver is an absolutely critical factor in the well-being of the catastrophically injured veteran and their family.

Unfortunately, not all severely disabled veterans with a service-connected injury or illness have full access to the Family Caregiver Program administered by the Department of Veterans Affairs (VA). The Caregiver Program applies only to veterans with an injury that occurred after September 11, 2001. To amend this inequality, PVA recommends Congress remove the post-9/11 injury requirement for the caregiver program and include "serious illness" as a criterion.

The needs of catastrophically disabled veterans are not different because they became injured or ill prior to September 11, 2001. PVA's members would benefit from this program more than any other population of veterans. And yet, because of an arbitrary date, most of them are denied a critically needed service. No reasonable justification can be provided for why veterans with a catastrophic service-connected injury or illness incurred prior to September 11, 2001 should be excluded from the caregiver program.

Moreover, the need for a caregiver is not lessened simply because a veteran's service left him or her with a catastrophic illness, rather than an injury. For PVA's members, a spinal cord disease is no less catastrophic than a spinal cord injury. Veterans that have been diagnosed with Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS) will eventually experience unrecognizable changes to their daily activities, and unquestionably become dependent on a caregiver. So why are these families less important than those who currently have access to the Family Caregiver Program?

The cost of the services the VA Caregiver Program currently denies to veterans who became catastrophically injured or severely ill prior to September 11, 2001 will ultimately be paid for by society as a whole. The well-being of a family inevitably declines without essential supports. Ensuring that a veteran is able to reside at their home, in their community, has been shown time and again to reduce medical complications, hospital stays and costs. At the same time, the veteran and their family maintain a psychosocial wellness that is impossible to achieve in an institution.

VHA officials originally estimated that around 4,000 caregivers would be approved for the program by September 30, 2014. By May 2014, about 30,400 caregivers had applied for the program, and 15,600 caregivers had been approved. The GAO report explains, "Caregiver Support Program officials told us that after 3 years of operation, demand for the Family Caregiver Program remains high: system-wide there has been no appreciable decrease in the number of caregivers submitting applications for the program."

Additionally, the report reveals that several thousand post-9/11 veterans and caregivers are not benefiting from the program. They are waiting in the application process or waiting on services for months after they have already been approved. The reasons for these failures are not a mystery. The VA failed to consider that an increase in injured soldiers would be reflected in an increased number of caregiver program applicants. This miscalculation, whether the result of genuine naiveté on the part of the VA or willful disregard for catastrophically disabled veterans and their caregivers, is unacceptable.

Moreover, the GAO report highlights a staggering level of information technology (IT) underperformance. The program is unable to fully realize the comprehensive workload data that would effectively support oversight and management. Lack of an integrated IT system that can offer workload data is a startling admission of incompetence in the 21st century. The report captured stories of manual data entry and ad hoc retrieval of any data not contained within a preprogrammed report.

The Caregiver Application Tracker is a stand-alone system that is not integrated with other VHA systems. This means in order to determine how many veterans in the program are using respite care, staff need to individually "download their data into a spreadsheet and then upload this information to the IT system for respite care use in order to crosswalk the information." VA medical center requests for additional Caregiver Support Counselor positions are based on informal feedback. The Caregiver Support Program has no means of assessing its own progress or impact without a functioning IT system. It is critical that VA properly address these IT problems as it moves forward with the Family Caregiver Program. This means that VA must

request fully sufficient resources to manage and staff this program and develop the appropriate IT architecture to administer the program, and Congress must ensure that those resource needs are properly met.

With regards to education and training, PVA believes that the law should be amended to meet the caregiver where they are in their skill development (assuming they already have some skills as a caregiver), instead of requiring that they start at the beginning. Many PVA members with spinal cord injury also have a range of co-morbid mental illnesses. We know that family counseling and condition specific education is fundamental to the successful reintegration of the veteran into society.

In an earlier version of the Caregiver Act, Congress would have authorized VA and the Department of Defense to contract for a national survey of family caregivers of seriously disabled veterans and service members, with a report to Congress. Without this information, it is difficult for VA to honestly provide recommendations on funding the caregiver program to Congress. VA estimates the survey would cost approximately $2 million. PVA strongly recommends that such a national survey be authorized

Caregivers often drop out of school to care for their veteran. Those that manage to work are forced to strategize around the critical and unpredictable needs of their loved ones. Absenteeism, reduced work schedules, and unreliability are inevitable in cases where medical emergencies compete with job demands. The Rand study found civilian caregivers reported missing nine hours of work on average, or 1 day of work per month. By comparison, Post-9/11 caregivers

reported missing 3.5 days of work per month. The lost wages from work in addition to costs associated with providing medical care result in serious financial strain for these veterans and their families.

Intending to alleviate some of the financial burden, the program offers Primary Caregivers a tax-free stipend based on the amount of hourly assistance the veteran requires. The law designates 40 hours a week as the maximum number of hours to receive a stipend. The reality is many caregivers provide services for the veteran more than 40 hours a week and in many cases around the clock. However, there is an unintended negative consequence as a result of the tax-free consideration of the stipend. The tax-free nature of the stipend means caregivers cannot claim stipend payments as income since they are not considered wages. Assuming the caregiver provides a minimum of forty hours a week of service for the next 40 years, that work and its accompanying stipends are not considered earnings for the purposes of Social Security eligibility. The long-term income security of that caregiver after working age could then be put at risk. We believe that Congress should consider the need to change the law in such a way so as to allow these family caregivers who have sacrificed so greatly to support their catastrophically disabled veterans to be eligible for Social Security once they have reached the eligibility age.

As the veteran community is aware, family caregivers offer more than physical assistance. They provide mental health support for veterans dealing with the emotional, psychological, and physical effects of combat. The service of these caregivers and the sacrifices they make in order to care for those who serve cannot be deemed less worthy of support because they wore a uniform prior to September 11, 2001.

Simply put, the Caregiver Program excludes families in need. The current inequities in the law are unfounded and unacceptable. We cannot emphasize enough the need for Congress to reexamine this demarcation in order to better serve all catastrophically disabled veterans and their loved ones.

We would like to thank the Committee for the opportunity to provide a statement for the record, and we look forward to working with you to ensure our catastrophically disabled veterans and their families receive the support they have earned and deserve.

Information Required by Rule XI 2(g)(4) of the House of Representatives

Pursuant to Rule XI 2(g)(4) of the House of Representatives, the following information is provided regarding federal grants and contracts.

Fiscal Year 2014

No federal grants or contracts received.

Fiscal Year 2013

National Council on Disability — Contract for Services — $35,000.

Fiscal Year 2012

No federal grants or contracts received.

WOUNDED WARRIOR PROJECT

STATEMENT FOR THE RECORD

SUBCOMMITTEE ON HEALTH
COMMITTEE ON VETERANS AFFAIRS
U.S. HOUSE OF REPRESENTATIVES

VETERANS AFFAIRS' CAREGIVER PROGRAM: ASSESSING CURRENT PROSPECTS AND FUTURE POSSIBILITIES

DECEMBER 3, 2014

Chairman Benishek, Ranking Member Brownley, and Members of the Subcommittee,

Thank you for inviting Wounded Warrior Project (WWP) to provide our perspective regarding the Department of Veterans Affairs' (VA) Family Caregiver Program. Having led the charge for Public Law 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010, we remain committed to serving this generation of injured veterans and their caregivers through advocacy and programmatic supports and are dedicated to ensuring the vital support and compensation provided under the program is strengthened and that flaws in the VA's implementation of that law are resolved.

Maintaining very close ties with disabled veterans and their families, WWP has seen how profoundly a warrior's injury changes an entire family's life. One of the many family members with whom WWP has worked described it well in a previous hearing in front of this Committee:

> *Confronted by severe, life-threatening injuries sustained by a spouse, fiancé, child or other loved one, families must make sudden life-altering changes. Family members may be forced to take extended leaves of absence or permanently leave their jobs to be at the service-member's bedside, beginning a journey of what may become years-long or even a lifetime of committed care. These are acts of love and self-sacrifice. But as the sister of a profoundly disabled veteran, and as a friend of many, many caregivers across the country, I can tell you that, while the decision to care for a loved one may come easily, caregiving can take an extraordinary toll – emotionally, physically, and economically.*[1]

Working daily with family members of warriors who have sustained severe or catastrophic injuries and need ongoing care or assistance, WWP saw the profound toll and the lack of

[1] *Meeting the Needs of Family Caregivers of Veterans*: Hearing before the Subcomm. on Health of the H. Comm. on Veterans Affairs, 111th Cong. (June 4, 2009) (Testimony of Anna Fresc).

assistance for the caregiver. While caring for severely disabled warriors – sometimes for years and without assistance – many caregivers have left their jobs, exhausted savings, and suffered tremendous strain to their own health in order to provide the very best care for their loved ones. The need to provide caregivers access to mental health services, respite options, health coverage, and some modest financial support has been real and pressing. Government programs and services have almost exclusively focused on recovery, rehabilitation, readjustment, and compensation for the warrior. However, caregivers' needs were not addressed until passage of the caregiver-assistance law.

Over four years ago, this Committee helped craft historic legislation that established the framework for a VA program that now provides critical supports to family caregivers of seriously disabled veterans. This legislation recognized the risk that the extraordinary toll of caregiving could overwhelm the caregiver – whether physically, emotionally, or financially – and result in unwanted, but very costly institutionalization. This legislation proposed, therefore, that VA provide support services to help shore up those vulnerabilities. Specifically, we advocated for a program that would provide caregivers with needed training, technical support, mental health counseling, health care coverage, respite care, and a modest financial stipend.

This Committee has played a critically important role – not only in shaping the caregiver law – but in jump-starting and accelerating a process that over the last several years has provided long-awaited help to over 16,000 families. This Committee's oversight of the program to ensure VA complies fully with the law is equally important.

A year after the law was enacted VA finally implemented the program with the adoption of interim final regulations. Although we and other advocates raised concerns about those implementing regulations in formal comments, VA has yet to answer – let alone remedy– problems with the program by promulgating final regulations. Several of these unresolved issues are sources of real frustration for caregivers. Vagueness and ambiguity in those regulations have resulted in wide variability in determinations of eligibility and support, with evidence of clearly erroneous decisions creating hardship.

Additionally, the interim final regulations leave "appeal rights" unaddressed (including appeals from adverse determinations of law). They set unduly strict criteria for determining a need for caregiving for veterans with severe behavioral health conditions, including veterans with Traumatic Brain Injury (TBI). In addition, the vagueness of the regulations, in terms of clinical decision-making, also invites arbitrary, inconsistent implementation. These are serious issues. We ask your help in resolving these long-outstanding concerns, as well as in easing detailed the Veterans Benefits Administration (VBA) reporting and oversight requirements on Veterans Health Administration-recognized (VHA) caregivers who are also fiduciaries for their loved ones.

To illustrate the point, one caregiver of a veteran who is rated 100% disabled for Post-Traumatic Stress Disorder (PTSD) and who needs his wife's assistance because he cannot manage safely on his own, cannot drive, and cannot manage his own funds (VBA has designated his wife his guardian and the fiduciary for his funds). Yet a VA psychiatrist, apparently with no input from

any other VA staff, unilaterally determined that the veteran's wife is not eligible for caregiver-assistance because the clinician's goal for the veteran is to become more independent. That would certainly also be his wife's goal, but the issue is that the warrior needs caregiver-assistance now, and the possibility that he might one day achieve greater independence cannot be a basis to deny a family caregiver the support she and the veteran need now.

VA's regulations also include deeply flawed criteria for assessing the extent of needed caregiver-assistance. In a WWP-conducted survey of caregivers, more than one in four (28%) respondents expressed disagreement with the VA's assessment of the number of hours of caregiver-assistance their veteran required.[2]

As the lead advocate for the caregiver-assistance law, WWP will continue to press for regulatory change, or pursue other avenues as needed. WWP will also work to ensure that the support provided to caregivers under this new law is not compromised (in the case of caregivers who serve as fiduciaries for a disabled veteran) by unreasonable demands under the VA's fiduciary program. There is an appropriate place for fiduciary oversight. From the perspective of family members who for years have sacrificed to care for a loved one and also take on responsibilities as a fiduciary, oversight under that program can be not only confusing, but demeaning. WWP will work to ensure that the VA's fiduciary program better accommodates the needs of these warriors and their families.

Overall, it is clear VA faced challenges in implementing this new program, and that many dedicated staff worked hard to launch it. The process has gone relatively smoothly for numbers of families, while some have encountered problems. We have worked with many others who are still in limbo, waiting for applications to be processed and unsure of what comes next.

But we are most concerned about VA's implementing regulation (which governs the determination and delivery of benefits to caregivers) because it still fails to get some issues right. As a result, some families will likely be shut out; others will likely not get the level of help the law requires. What is quite clear is that the rules discouraged many from even applying.

Let us acknowledge that VA's implementing rule is a marked improvement over its initial implementation plan. Unfortunately that regulation needs a lot more work. Let us illustrate by discussing several of our concerns with VA's eligibility criteria, inconsistency in how eligibility is determined, appeals process, and how the stipend is calculated.

Eligibility Criteria & Mental Health

As is well recognized, TBI and PTSD are the signature wounds of this war. Many of the problems we hear regarding VA's implementation are from the families of warriors with those invisible wounds. Typically, because of the severity of one or both of those conditions – these family members feel they can't leave their warrior alone. As one caregiver put it succinctly,

[2] Wounded Warrior Project Survey of Caregivers of Wounded Warrior Alumni (2012). With more than 330 caregivers participating, the survey respondents reported that the principal condition or conditions requiring caregiver-assistance for their veteran were a mental health condition (66%) and/or traumatic brain injury (62%).

"[My warrior] does not need care around the clock, but I have to be available 24/7." Each case differs. Often, the warrior lacks full cognition or judgment to be fully aware of danger. In other instances, a warrior's behavior may be erratic, marked by lack of impulse-control, or even reflect a level of anxiety such that the individual sleeps with a weapon under his pillow or otherwise leaves family fearful of possible suicide-risk. In these kinds of instances, a family member typically stays with the veteran for much of the time to ensure the warrior's safety. Where those behaviors are due to traumatic brain injury, VA's eligibility rule appears to cover such circumstances. In instances where that same safety risk or other similar problem is due to PTSD, depression, or anxiety, however, it seems much less likely that VA will provide caregiver assistance under its new rules.

In contrast, the law very clearly addresses circumstances involving the veteran's safety or related vulnerability. It states that a need for caregiver assistance can be based on a veteran's "need for supervision or protection." That criterion would address the full range of situations we have described. But in the case of a veteran who has PTSD, depression, or anxiety, VA has unnecessarily established a separate, much more restrictive rule. In the case of a veteran with PTSD or other war-related mental health condition, VA's rule says the veteran must be bedridden, delusional, or virtually suicidal to be eligible for caregiver-assistance. And unlike a veteran with a physical impairment, who may be eligible if only a few hours of help daily are needed, a veteran with a mental health condition must require "constant supervision." This kind of disparity is not only unfair, it is inconsistent with the provisions of the caregiver law which draw no distinction between TBI and PTSD.

Additionally, the law's exclusion of support for service-connected illnesses has resulted in depriving veterans with significant caregiving needs of caregiver-support and services. Many of these illnesses, like amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS), are profoundly disabling and denying caregiver support and compensation for these conditions compels congressional action.

Clinical Determinations

A second area of concern is how VA's eligibility criteria are being applied at medical centers around the country. WWP conducted a survey to understand the experience of families who have applied for assistance under the caregiver program. Among the findings, the survey responses suggest that there is variability from facility to facility as to who determines a veteran's need for caregiver assistance, as well as frequent failure to communicate to caregivers how these eligibility determinations are made. Asked their understanding of who determines a veteran's need for caregiver-assistance, more than one in five caregivers expressed the understanding that it was the primary care physician; one in four responded that it was the clinical team; while more than four in ten were unsure. Almost one in five respondents indicated that VA has not explained the process or criteria they will use to determine the veteran's need for caregiving assistance. Feedback from caregivers going through the application process suggests that the breakdown in communication occurs between VA and veterans and their caregivers, and also between VA Central Office and the field.

Let us share one example. For the past several years, a caregiver has provided almost constant care and supervision for her husband who suffers from PTSD, TBI, and persistent short-term memory stemming from injuries. The caregiver submitted an application for caregiver assistance and was contacted shortly afterwards by a nurse practitioner and advised that the application had been denied. The nurse, without either reviewing the veteran's medical records or consulting the veteran's longstanding care team, "determined" on the basis of the veteran's compensation and pension examination records that he didn't need assistance in performing activities of daily living – and thus concluded, accordingly, that he was not eligible. Among the many errors involved was to overlook the fact eligibility could be based solely on a need for supervision or protection, and that these decisions are to be made by an interdisciplinary team.

The veteran's occupational therapist was surprised by the decision and lack of dialogue, and drove to the VA Medical Center for an in-person meeting with the nurse practitioner, after which the eligibility decision was ultimately reversed. While this story ended favorably, it offers a stark illustration of problems other families have encountered with vague VA rules on clinical eligibility determinations. In this instance, but for a very dedicated and well-informed occupational therapist and psychiatrist, this certainly could have ended differently, with much greater distress and headache for the caregiver and veteran.

Another survey respondent's experience highlights the risk of error in what may be a too-brief clinical assessment:

> *My husband was interviewed by his VA physician, but I was not allowed to go in and assist him and help him remember things and help give an accurate picture of his functioning and health. His physician had only seen him a couple of times, we were told this was the reason he was going in for an interview/assessment. The assessment was supposed to provide the understanding of my warrior's needs. Since I was not there, and my warrior does not recall the entire interview, I do not know if the doctor really got a good understanding of the situation.*

Appeals

While the above-cited cases may be outliers, they do raise the question, how can a veteran or caregiver appeal an adverse medical or legal decision? The current review opportunity, for stipend purposes, following a denial of benefits or Tier level is only subject to review by the VHA Medical Center Director. VHA physician staff conducts a clinical assessment review, yet prohibits a private physician's involvement or review of other medical opinions regarding the veterans' need for care. In contrast to decisions administered by VBA, VHA caregiver decisions are denied the opportunity for a personal hearing to bring forth additional evidence or provide sworn testimony under the guidance of an accredited representative. No other such decisions under VBA are afforded this exclusion. All decisions by the VBA are given specific due process and appellate rights. We believe VHA decisions regarding caregiver benefits should not be exempt from this review.

The implementing regulation is completely silent on this important issue. Yet it is essential that VA establish systematic recourse for those caregivers and disabled veterans who may be unduly denied benefits. Feedback WWP has received from caregivers indicates that they are unaware of where to turn in the event that they disagree with a VA determination. This is an issue VA must address as more veterans and their caregivers apply for this benefit, particularly given the potential for error.

Respite

Our survey also showed that while almost three quarters of caregivers were aware of VA opportunities for respite care, a remarkable 93% had not used VA-furnished respite. While respite may be available, it is clear that current options do not meet the critical need for this kind of care. Families with whom we work have shared concerns about safety and respite environments that don't provide a stimulating or engaging atmosphere for the warrior or is not suited to their disability. Opportunities for caregiver-respite should be expanded to provide care that these families will actually use.

Loss of Caregiver Benefits

The interim regulations provide direction for determining the amount of a stipend award and for revoking caregiver benefits. In the case of a revocation, caregiver support may continue for 30 days. Despite the regulation's silence on the matter, we have heard VA medical centers sometimes reduce caregiver stipend amounts, even though the regulation provides no such direction. A sudden, sharp reduction or termination of stipend support can cause a caregiver severe financial hardship. Additionally, the interim regulations provide that in the case of caregiver-status being terminated, VA is to assist the individual to transition to alternative health coverage. The regulation makes no allowance, however, for circumstances where the burden of caregiving itself is a substantial factor in the individual's inability to sustain the role of caregiver. These issues need to be considered to prevent undue hardship and to more effectively plan for the long-term needs of warriors and their families.

Stipend Calculations

Another particularly problematic area relates to determining the amount of a stipend VA will provide a family member designated as the primary caregiver. Since many caregivers can no longer work outside the home and often care for their loved ones on a full-time basis, the stipend was to provide some modest level of financial assistance (tied to the area wage rate of a home health aide).

The law directs VA to develop a methodology for calculating the amount of a stipend, which is to be based on the amount and degree of personal care services the family member provides. But the scoring methodology VA has developed is deeply flawed, particularly for those whose need for caregiving is based on a need for supervision and protection. In other words, the methodology does not provide a reliable tool for gauging the caregiving needs of a veteran with traumatic brain injury, PTSD, or depression.

Specifically, under VA's criteria, a veteran's need for caregiver assistance is rated on a scale of 0-4 for each of seven criteria associated with need for assistance with activities of daily living and the need for supervision. With respect to each criterion (such as need for assistance in performing a particular activity of daily living; having difficulty with planning and organizing; or posing a safety risk), VA clinicians are to assess the degree to which the veteran needs assistance in that particular domain, from having no need for assistance (scored as "0") to needing total assistance (scored as "4"). The number of hours of caregiving-assistance a warrior needs is determined based on how high they score on these measures.

A couple illustrations may be helpful. Take the case of a veteran who sustained a severe TBI in an IED blast, but after a lengthy rehabilitation is able to independently perform all activities of daily living and has no serious cognitive deficits. In this case, the lasting impact of his TBI manifests itself in severe mood swings and sometimes aggressive and violent outbursts. Because he is unable to control these behaviors, even with the assistance of medication, he is unable to work and his wife accompanies him everywhere. She helps him avoid the problems his behavior may cause, get to his medical appointments and maintain some level of social interaction.

In another case, a veteran has lost several friends after multiple tours to Iraq, and suffers now from severe chronic depression. While he has no physical limitations, he is utterly without energy, has difficulty even getting out of bed, cannot concentrate on tasks, and experiences feelings of hopelessness. Medications have not alleviated his symptoms, he is largely homebound, and his mother maintains virtually full-time watch to be sure he that he doesn't harm himself.

Applying VA's current rating scale, in both cases the veteran might score a "4" based on total inability to self-regulate, perhaps another "4" based on safety risk, and another "4" based on inability to plan or organize. In each case, though, with no other pertinent areas of needed assistance, the total score would be "12." The VA rule, however, states that a veteran with an aggregate score between 1 and 12 is presumed to need only 10 hours/week of caregiver assistance. The rule makes no allowance for rebutting that presumption.

These examples are real; let us share the frustration expressed by one of the respondents in our caregivers' survey as she explained that the scoring system fails to take into account the gravity of her husband's needs:

> *I was told that my husband scored in the low Tier level I, with an 11. This only allows 10 hours [of caregiving] a week, approximately $426 a month. I don't agree with this because my husband needs continuous supervision due to his TBI, PTSD, mental health and also sometimes 2-3 days a week requires bed rest due to physical pain. So 10 hours a week is like about 1.42 hours a day. I have to help him remember to take medications 3 times daily, assist with cooking, driving, medical appointments, just overall supervision for his safety. 10 hours a week is nowhere near the time I spend caring for him.*

These scenarios clearly reflect how important it is that VA revise the current stipend-calculation methodology. What is clear is that requiring a high aggregate score across multiple criteria makes no sense when a single deficit or impairment may dictate a need for total care. Does it make any sense, for example, that a veteran who cannot be left alone at all for safety reasons – and has no other limitations – should be deemed to need only about an hour and a half of caregiving help daily?

It is not unusual that a veteran who has sustained a severe TBI, for example, may regain lost function in many domains, have no physical limitations, and may still need to have a loved one close by on a more or less full-time basis because of a single issue – whether it is erratic behavior, severely impaired judgment, or safety. In the case of a veteran whose condition creates a need for supervision or protection it makes little sense for VA to assume that a need for full-time caregiving can only exist when the veteran has multiple needs. This system reflects a fundamental underestimation of both TBI and mental health conditions like PTSD.

The problems with the stipend actually go deeper. Even in circumstances where a veteran is deemed to need total assistance, VA sets a cap on the stipend amount–limiting any caregiver's stipend based on the presumption that 40 hours a week of care would be provided. VA's rule does not address the fact that our disabled veterans' needs rarely conform to a 9-to-5 business day, and makes no provision for those additional hours of likely needed caregiving.

We understand that the intent of this cap is that caregivers shouldn't have to work unreasonably long hours, and that additional care would be provided by others, such as home health aides. Yet the rule is silent on this. Can caregivers count on it? Even if VA were generally to provide such assistance, veterans and caregivers who reside in rural areas are not likely to have access to such sources of care. Given these realities, we have urged VA to revisit the issue and lift the cap where needed so that the stipend amount more reasonably reflects the hours of caregiving actually provided.

Caregiver Program's strengths and weaknesses

While WWP believes that VA must make changes to its final regulation (and submitted extensive recommendations in response to VA's Federal Register notice regarding its VA's interim final rule), we also recognize the progress VA has made in launching this multi-faceted program.

Many caregivers who responded to our survey commented favorably on the ease of filing the initial application and the timeliness with which VA had made contact with caregivers and veterans after the initial submission. Among those surveyed who had reached the stage of a VA home assessment, many respondents commented that VA employees had been professional, thorough, and appeared to be genuinely invested in the health of both the veteran and the caregiver. One respondent characterized the home visit as the most positive interaction she has had with VA employees to date.

Yet despite these positive experiences, caregivers tended to have greater frustration with what appears for many to have been regarding the different steps involved in processing their application, who is making decisions, how decisions will be made, and how erroneous decisions can be reviewed and reversed. We commend VA for the substantial improvements they have made, but also urge the Department to carefully consider the issues we have raised today as well as the much more detailed comments WWP submitted to the Federal Register. VA must still correct serious flaws in its interim regulation in order to ensure that this program fulfills the intent of the Congress and the promise of the law.

In closing, WWP looks forward to working with VA and with this Committee in bridging these gaps.

STATEMENT OF

ALEKS MOROSKY, DEPUTY DIRECTOR
NATIONAL LEGISLATIVE SERVICE
VETERANS OF FOREIGN WARS OF THE UNITED STATES

FOR THE RECORD

VETERANS' AFFAIRS SUBCOMMITTEE
ON HEALTH
UNITED STATES HOUSE OF REPRESENTATIVES

WITH RESPECT TO

VA's Caregiver Program: Assessing Current Prospects and Future Possibilities

WASHINGTON, D.C. December 3, 2014

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE:

On behalf of the men and women of the Veterans of Foreign Wars of the United States (VFW) and our Auxiliaries, I would like to thank you for the opportunity to submit for the record regarding the Department of Veterans Affairs (VA) Family Caregiver Program.

Family caregivers who choose to provide in-home care to veterans who were severely disabled in the line of duty truly epitomize the concept of selfless service. They choose to put their lives and careers on hold, often accepting great emotional and financial burdens. They do so recognizing that their loved ones benefit greatly, both in terms of health outcomes and quality of life, by receiving care in their homes as opposed to institutional settings. The VFW strongly believes that contributions of family caregivers cannot be overstated, and that our nation owes them the support they need and deserve.

For this reason, the VFW strongly supported the *Caregivers and Veterans Omnibus Health Services Act of 2010* which provided a monthly stipend, respite care, mental and medical health care, and the necessary training and certifications required for caregivers of severely disabled Post-9/11 veterans. We have consistently maintained, however, that eligibility must be expanded to include veterans of all eras. Severely wounded veterans of all conflicts have made incredible sacrifices, and all family members who care for them are equally deserving of our recognition and support. The fact that caregivers of previous era veterans are excluded from the full complement of program benefits implies that their service and sacrifices are not as significant, and we believe this is wrong.

One of the requirements of the Caregiver Act was for VA to submit a report to Congress examining the feasibility of expanding eligibility for comprehensive caregiver benefits to those who care for severely injured veterans of previous eras. That report, issued in September 2013, estimated that between 32,000 and 88,000 Pre-9/11 veterans would become eligible for the program at a total estimated cost of $1.8 to $3.8 billion. VA stated that such an expansion would be operationally feasible, so long as Congress gives them the necessary funding to administer the programs and hire the required additional staff. Accordingly, we strongly support H.R. 3383, the *Caregivers Expansion and Improvement Act of 2013*, which would expand the Family Caregiver Program to all eras by striking "on or after September 11, 2001" from title 38 USC section 1720G(a)(2)(B). We feel that this legislation would correct a great and clear injustice, and we urge Congress to pass it swiftly and ensure that it is fully funded.

The VFW hears from our members often about this issue, and their message is clear: they strongly support expanding full caregiver benefits to veterans of all eras. As an intergenerational veterans service organization that traces its roots to the Spanish American War, this is not surprising. Our members are combat veterans from World War II, the wars in Korea and Vietnam, the Gulf War, and various other short conflicts, in addition to the wars of the current era. They rightly see no justifiable reason to exclude otherwise deserving veterans from program eligibility simply based on the era in which they served.

Recently, we received correspondence from a caregiver in Wisconsin whose husband was shot 18 times in Vietnam, resulting in the amputation of his left leg above the hip, his left thumb, and severe neuropathy of the left arm from a gunshot wound to the wrist. Due to his extreme physical injuries, she has been assisting him with his activities of daily living for more than 25 years. Another caregiver of a Vietnam veteran from Pennsylvania shared with us that he requires 24/7 care due to his severe PTSD which manifests as psychotic episodes, putting him at risk for suicide. She is a registered nurse who was forced to quit her job in order to care for her loved one. Both of these spouses have chosen to accept the task of serving as caregivers rather than see their family members institutionalized, even though both veterans would qualify for full nursing home benefits. They believe, as we do, that the veterans they care for experience a much greater quality of life by living at home, despite the massive challenges they face. The VFW strongly believes that caregivers like these should not be forced to choose between placing their family members in institutional care settings and exposing themselves and their families to severe financial hardship.

Additionally, the VFW strongly believes that program eligibility must be expanded to include caregivers of veterans who suffer from severe service-related illnesses. The Department of Defense provides support to family caregivers of members of the armed forces who are catastrophically disabled through its Special Compensation for Assistance with Activities of Daily Living (SCAADL) program, which includes disability caused by illnesses in its eligibility requirements. Although service-related diseases affect veterans of all eras, we note that this issue is of particular importance to Gulf War veterans who continue to suffer at high rates from horribly debilitating diseases associated with Gulf War Illness. The VFW believes that it is necessary to fully align VA caregiver benefits with the SCAADL program, creating a more seamless transition for the most severely disabled veterans, and ensuring that those who care for them receive the support they need. For this reason, we strongly support H.R. 3672, the *Support*

our Services to Veterans Caregivers Act, introduced by Representative Raul Ruiz, which would expand eligibility for the Family Caregiver program to veterans who suffer from serious illnesses incurred or aggravated in the line of duty.

The VFW is aware of the findings of the September 2014 Government Accountability Office report entitled," Actions Needed to Address Higher-Than-Expected Demand for the Family Caregiver Program," and that improvements are needed to ensure the program is properly administered. We strongly agree with the recommendations contained in the report. VA must implement a staffing model that ensures that facilities are able to meet the demand for services, and adopt an IT system that is capable of supporting the program. We believe that addressing these shortcomings is obviously the right thing to do and should be non-negotiable. We do not, however, believe that these very fixable problems should be viewed as a reason to deny or delay expanding program eligibility to caregivers of veterans of previous eras or with service-related diseases. These family caregivers have already been without the support they need for far too long. Some have been providing care for severely injured loved ones to their own financial and emotional detriment for decades. The VFW believes that making them continue to wait to receive benefits while relatively minor issues are resolved does them an extreme disservice and is completely unnecessary.

The VFW is also aware that there would be a significant cost associated with expanding program eligibility to all eras, and that the Congressional Budget Office (CBO) estimate that full expansion would cost $9.5 billion over the next five years may sound prohibitively expensive to some. We contend, however, that this estimate is misleading in terms of the overall impact on the VA budget. It seems logical to us that the ability of veterans to remain in their homes receiving care from family members would allow them to avoid nursing home care which is far more expensive. We do not believe that CBO has taken this into account. According to VA's Fiscal Year 2015 Budget Request, VA spent more than $5 billion providing institutional care to more than 40,000 veterans in fiscal year 2013. The average per diem cost for a VA Community Living Center was $971.97, totaling over $350,000 per veteran, per year. At contracted community nursing homes, VA spends over $90,000 per veteran, per year. The VA contribution for a veteran at state-run nursing homes averages over $45,000 per veteran, per year. On the other hand, CBO estimates that the average cost of benefits to a primary caregiver would total only $33,000 per year. The VFW realizes that CBO is not able to take potential savings into account when calculating cost. We believe, however, that a small technical change to the legislation that has been introduced could make a difference. By inserting a non-duplication of benefits provision such as, "An individual entitled to nursing home care and the Family Caregivers Program may not receive assistance under two such programs simultaneously, but shall elect (in such form and manner as the Secretary may prescribe) under which chapter or provisions to receive such care," we believe that CBO would be induced into scoring the bill more dynamically.

The VFW recognizes that many in Congress may be hesitant to support a large expansion of any VA program at this time, instead choosing to focus on oversight to ensure VA is able to properly administer the programs it currently provides. This is understandable, given the many failures of the Department exposed by the revelations originating in the Phoenix VA Health Care System earlier this year. The VFW notes, however, that the reform bill brought about by that scandal,

the *Veterans Access, Choice and Accountability Act (VACAA)*, dealt in large part with the problem of access by establishing the $10 billion Veterans Choice Program to allow veterans the option of seeking non-VA care when it could not be readily provided at VA. The VFW strongly supports the idea of veterans' choice, believing that a one-size-fits-all approach to providing health care is not the best option for every veteran. Likewise, we see the option to receive care from a family caregiver, as opposed to an institutional setting, as one that every severely disabled veteran should have. For this reason, we see the full expansion of the Caregiver Program as fully consistent with the spirit of VACAA, and urge Congress to approach this issue with the same urgency as it did the issue of access when it wisely created the Veterans Choice Program.

Mr. Chairman, this concludes my testimony. If you or the Subcommittee members have any questions, I would be happy to respond to them for the record.

Information Required by Rule XI2(g)(4) of the House of Representatives

Pursuant to Rule XI2(g)(4) of the House of Representatives, VFW has not received any federal grants in Fiscal Year 2013, nor has it received any federal grants in the two previous Fiscal Years.

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