

**IMPLEMENTATION OF CAREGIVER ASSISTANCE:  
MOVING FORWARD**

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**HEARING**  
BEFORE THE  
SUBCOMMITTEE ON HEALTH  
OF THE  
COMMITTEE ON VETERANS' AFFAIRS  
U.S. HOUSE OF REPRESENTATIVES  
ONE HUNDRED TWELFTH CONGRESS

FIRST SESSION

JULY 11, 2011

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## **IMPLEMENTATION OF CAREGIVER ASSISTANCE: MOVING FORWARD**

**MONDAY, JULY 11, 2011**

U.S. HOUSE OF REPRESENTATIVES,  
COMMITTEE ON VETERANS' AFFAIRS,  
SUBCOMMITTEE ON HEALTH,  
*Washington, DC.*

The Subcommittee met, pursuant to notice, at 4:00 p.m., in Room 334, Cannon House Office Building, Hon. Anne Marie Buerkle [Chairwoman of the Subcommittee] presiding.

Present: Representatives Buerkle, Roe, Benishek, Runyan, and Michaud.

### **OPENING STATEMENT OF CHAIRWOMAN BUERKLE**

Ms. BUERKLE. Good afternoon. The Subcommittee on Health will come to order.

Four months ago today, this Subcommittee held our first hearing of the year to discuss why the U.S. Department of Veterans Affairs (VA) had failed to implement the Caregivers Assistance component of Public Law 111-163. At that hearing, it was clear to me that VA must go back and address some serious deficiencies with the Department's initial implementation plan, particularly the strict eligibility requirements, in order to get this important program up and running.

I think we all agreed that day at that hearing, that time is of the essence, and our veterans and their caregivers need us now, not later.

Today we meet again to determine the progress the Department has made in those intervening months to adjust its implementation plan and to do right by our veterans and their caregivers who have already given so much to us all. In response to the concerns of Members, advocates and stakeholders, VA changed its eligibility requirements and expedited the implementation of caregivers' benefits by publishing an interim final rule (IFR) on May 5, 2011. The IFR allowed the Department to accelerate the Federal rulemaking process by immediately implementing the program prior to the consideration of public comments and the issuance of a final rule.

As the daughter of a full-time caregiver, I understand the profound impact injury can have, not only on the patient or the injured but also upon his or her family. Time is of the essence for these families, many of whom have sacrificed their personal, professional and financial security in order to take on full-time caregiving responsibilities for their veteran family member. We

owe it to these men and women to get it right, and we will not rest until we do.

Today we will hear from Debbie Schulz, a full-time caregiver for her son Steven who was injured in Iraq in 2005. She will speak to her experience applying for and obtaining services from VA.

We will assess the actions VA has taken to date to meet the intent of the law and the changes that still need to be considered prior to issuing the final rule.

I want to express our appreciation on behalf of the Health Subcommittee to all of you for being here today. I am very much looking forward to our discussion.

I now yield to the Ranking Member, Mr. Michaud, for any opening statements he might have.

[The prepared statement of Chairwoman Buerkle appears on p. 29.]

#### **OPENING STATEMENT OF HON. MICHAEL H. MICHAUD**

Mr. MICHAUD. Thank you very much, Madam Chair.

I would like to thank you for holding this very important hearing today on the Caregivers and Veterans Omnibus Health Care Service Act of 2010. Today's hearing is a follow-up to a March 11, 2011, Subcommittee on Health hearing on this very important issue where concerns were raised regarding delays in the roll-out of the implementation plan. The narrow criteria and the eligibility for the benefits was a major concern of this Committee.

At the beginning of July, the Department of Veterans Affairs issued its very first payment to family caregiver veterans. These family caregivers were the first to complete their caregiver training under this comprehensive assistance for family caregivers program, and VA will send out more than \$430,000 in stipend payments to nearly 200 recipients this month alone.

I am pleased that the veterans and caregivers are finally beginning to receive some of the services required under the law that we passed. I am pleased that the criteria for eligibility of these benefits have been expanded to be more in line with what Congress intended.

However, I would also like to hear more from the witnesses today about how the plan is being implemented in the field, what issues remain, and what oversight is being conducted by Central Office, and how can we ensure that this program successfully is implemented so that veterans and their caregivers receive the critical benefits without further delay.

The testimony we have received contains many concerns with the interim final rule, and I would like to hear from the VA on incorporating some of the suggestions in the final rule.

So, Madam Chair, once again, I want to thank you very much for having this hearing and look forward to continue to keep an eye on what's happening as we move forward with the caregivers legislation.

And I yield back the balance of my time.

[The prepared statement of Congressman Michaud appears on p. 29.]

Ms. BUERKLE. Thank you very much. I would like to now invite our first panel to the witness table. Joining us this afternoon is

Debbie Schulz. Debbie is a full-time caregiver for her son, Steven, who was wounded in Fallujah in 2005 when an improvised explosive device (IED) hit the Humvee in which he was traveling.

Ms. Schulz, I know that this has been a very personal crusade for you, and we thank you so much for taking the time to come here today to give us your testimony and to answer our questions. Please go ahead with your opening statement.

**STATEMENT OF DEBBIE SCHULZ, FRIENDSWOOD, TX  
(CAREGIVER)**

Ms. SCHULZ. Chairwoman Buerkle, Ranking Member Michaud and Members of the Subcommittee, thank you for allowing me to share with you the experience I have had with the Caregiver Assistance Program, and for your vital leadership in pressing to assure that the law is properly implemented.

Great progress has been made toward this, and my son Steven and I are already benefitting from the program. I am grateful for the assistance. And as Steven's caregiver, I cannot overemphasize the program's importance to his ongoing recovery and continued well-being.

But while the program has helped us, I can see where gaps in the VA regulation will and already have created problems for caregivers.

Our journey, as you have said, began 6 years ago when Steven suffered a severe traumatic brain injury (TBI) on April 19, 2005. He was in Fallujah when the IED exploded outside his Humvee. He was 20 years old. The injury left him with many physical and cognitive deficits. He has profound left-sided weakness with no functional use of his left arm. He walks slowly and only with assistance. Shrapnel blinded his right eye, and his brain does not perceive the left field of vision.

In certain situations, Steven may need a wheelchair or use it for convenience, but he can't push it on his own because of the profound weakness on his left side. And a power chair is not used because of his visual deficits.

Steven's thinking is somewhat slower, and due to the frontal lobe damage, he has some impaired impulse control. And he might blurt out things that are inappropriate. His affect is flat, and he has difficulty interpreting social cues. His speech is often difficult to understand. His attention span is short, and he has some memory problems. Without the ability to think, what do I do next, he does not feel comfortable being left alone for more than 30 minutes at a time.

Steven's life has changed since his injury, and of course, my life has too. I had been working as a special education teacher when he was injured. My husband and I, then 51 and 49, were preparing to become empty nesters. Instead, I became Steven's primary caregiver, advocate, life skills coach, chauffeur, secretary, bookkeeper, teacher, drill instructor, medical assistant, physical, occupational, speech therapist and on and on.

Leaving the workforce has created a financial hardship, and our world and that of our then 18-year-old daughter and 15-year-old son has changed profoundly.

I applied for the Caregiver Program on May 9, having been alerted by my VA social worker and others. Getting the application and completing it was easy. The one glitch I encountered was an alarming uncertainty regarding CHAMPVA health coverage, which was contingent on having no other insurance. With my health coverage about to be terminated, I felt trapped in an awkward limbo that went unresolved for several weeks. I was led to think I would not be eligible for CHAMPVA unless there was a total break in my coverage.

Within days of applying for the caregiver program, I was advised that the VA had received the application and the next step was to complete training and have a home visit. After I completed both of those, I received verbal confirmation that I had been approved.

On July 5, I received my first stipend check. I assume from the amount, that it represents a maximum payment. But unlike other caregivers, I have not received any written or verbal notice on how many hours were approved and have no specific way of knowing whether those determinations were appropriate.

We caregivers do stay in touch with one another, and I do have concerns about how the rules may affect many others. VA, to its credit, has implemented a streamlined system for processing applications. But it's important that the determinations and decisions are fair and appropriate, not simply fast.

In preparing my remarks, I spoke with many other caregivers, and already disparities in determinations are being found. The weak link, in my view, are flaws in the rules VA published in early May. The stipend is a good example of this. For the many families for whom finances are tight, the stipend is very important. But it is clear to me that the rules for determining the stipends need work. For example, I know a veteran who suffered the same injury as Steven but made a better recovery physically. Though he has far fewer physical limitations than Steven, he still has post-traumatic stress disorder (PTSD) and TBI cognitive issues. But his wife will get a stipend that only covers 10 hours of caregiving a week, amounting to about \$15 a day.

In our case, VA's methodology resulted in scoring Steven's needs at a relatively high level, and I believe this is probably because he needs assistance with both physical and cognitive issues. Since VA's scoring methodology calls for scoring each different impairment, his total score would be higher than say a veteran who has just cognitive issues. The fallacy in this methodology is that a veteran with TBI whose extreme lack of judgment, for example, makes him a safety risk, is not just a safety risk for 10 hours a week.

Caregiver friends of mine in this situation are almost always by their veterans' side providing oversight and assistance. There's something badly wrong with the methodology that results in a conclusion that a veteran who is a safety risk, whether it be for suicidality, impaired judgment or other circumstances, needs only 10 or 25 hours of caregiving a week. Clearly, these rules need close scrutiny, and some need some major change.

In closing, let me thank you, on behalf of my family and other caregivers across the country, for your sincere efforts to make this program a success. The problems I've highlighted in my remarks



and in my full statement can be solved. Doing so will strengthen the program and improve the well-being of our wounded warriors.

Thank you for the privilege of testifying, and I would be happy to answer any questions you may have.

[The prepared statement of Ms. Schulz appears on p. 30.]

Ms. BUERKLE. Thank you very much for your testimony here today. I know I speak for all of my Subcommittee Members as well, thank you for what you do for your son, and please extend our gratitude to him for his service and sacrifice on behalf of this Nation.

Ms. SCHULZ. I will. Thank you.

Ms. BUERKLE. I would like to just talk a little bit about the application process. You mentioned that you felt that it was streamlined and seemed pretty efficient.

Ms. SCHULZ. Yes.

Ms. BUERKLE. At what point after you applied, did you start to feel, if you felt any, some obstacles or some difficulties?

Ms. SCHULZ. Well, I think at this initial phase, it was really pretty easy. And I have to give the VA credit for getting it up and going. Where it broke down was in the communicating back to me. For instance, I still haven't received how many hours, I haven't received any sort of written or really verbal notification of—I just received a check.

And for other caregivers, it may be important if, say, they got approved for 10 hours, they need to know that, so if they don't agree, they can then have some recourse to come back and say, we need to rethink this or appeal it.

So, in my case, it was pretty efficient. The home visit wasn't exactly what I hoped for. But aside from that, I think the process was good.

Ms. BUERKLE. Do you know if the decision to participate in caregivers' assistance and for you to be able to get a stipend, was contingent upon the home visit or were there any other factors?

Ms. SCHULZ. My understanding, and of course, I am no expert, but my understanding was it was the home visit as well as his care team. And I am real lucky in that our VA care coordinator has been working with Steven since he was first injured. She was his social worker from the early days, so she knows our situation and knows the care team.

Ms. BUERKLE. Have you used any of the respite services that the Caregivers Assistance Program provides?

Ms. SCHULZ. Not since the Caregiver Act has been implemented. I have used in the past, and it has been cumbersome and less than ideal for my situation. I am hoping that with this Caregivers Act, that it will be age appropriate and it will be home based to the needs of what the veteran needs.

The program that I have used previously, you know, they can come out. They can work Monday through Friday. They can work 9 to 5. Well, when I am gone, that doesn't always fit my life. I mean, like I am here now, and my youngest son is actually doing the caregiving. But if we had to, you know, juggle schedules, and he may have to work—he works part time—I might need somebody to cover evenings. I might need, you know, other times besides be-

tween 9 to 5. So I am hoping that with this new program, that it will take into account the real needs of the veteran.

Ms. BUERKLE. Thank you.

Ms. Schulz, you mentioned that you noticed some disparities, from other caregivers that you talked to about the process and maybe some of them received an explanation for how much of a stipend they were receiving. What were the other disparities? My concern is that there is not a standardized effort here, and that the process needs standardizing.

Ms. SCHULZ. And that is exactly my concern. While the application process has been easy for most people to get in, there have been instances of, well, let's just say, within the State of Texas, within 200 miles of me, another caregiver, whose son has a TBI, as well as a spinal cord injury, is unable to transfer out of his wheelchair by himself, cannot dress himself, and she was awarded 25 hours of caregiving a week. She received written notice. She knew—that's how I found out the treatment team was supposed to do the determination because she told me her PACT team. I didn't know what that was. So I learn a lot from other caregivers. But she told me that her PACT team made the determination, and she got 25 hours a week. How can that be right? And that sort of disparity is really discouraging to caregivers and veterans.

Some of the other disparities in just how things are playing out. Another veteran applied, his wife applied, and they couldn't get a doctor, the VA social worker couldn't get a doctor to sign off on the initial application. His primary care doctor at the VA wouldn't sign off it. This is a veteran who has a TBI, as well as a spinal cord injury and hearing loss, and she is his caregiver and has been for several years. And I couldn't understand that. That's the type of disparity that really worries me and other caregivers.

Ms. BUERKLE. Thank you very much.

My time has expired. I now yield 5 minutes to the Ranking Member, Mr. Michaud.

Mr. MICHAUD. Thank you very much, Madam Chair.

You mentioned that the home visit wasn't what you expected it to be. What did you expect the home visit to be? And why, is there anything that stuck out that they did that they should not have done or—

Ms. SCHULZ. Well, my understanding of the home visit was to make sure that the home was appropriate and to also assess my needs as well as Steven's needs. And being a social worker in another life, I know, sort of how assessments should go, so that may have jaded me.

But he came in and didn't know who the veteran was. He thought I was the veteran at first. And I was, like, no Steven. So he had not read the chart, which was a sort of red flag to me.

The second thing was after he was doing, going through making sure I know about infection control, nutrition, all these things that I have been doing for 6 years now, and Steven has obviously been healthy and happy and at a good weight, not overweight or underweight, then he asked me if I know about catheter care. And Steven has never been at home with a catheter. Now for some veterans, that's an issue and I would need to know that. But I would like for the VA to realize that those home visits are a real chance

to come out and see what the needs of the veteran and the caregiver are. That's what I was expecting.

Mr. MICHAUD. As the VA starts to roll out its peer support mentoring program over the next year, do you have any suggestions on how this program should be implemented?

Ms. SCHULZ. I have to be honest. I don't know what the peer support monitoring program is. Is that other veterans that will be—

Mr. MICHAUD. Yes.

Ms. SCHULZ. I have not heard about it.

Mr. MICHAUD. Okay. Do you find that the VA hotline and caregiver Web site is user friendly? Have you used that?

Ms. SCHULZ. I used the hotline initially when it first was announced at the VA program, and they were not ready to be answering questions at that time. They maybe rolled it out a little prematurely because the questions were all about the Caregiver Act and when it was going to be implemented, and they did not know at the time.

And I find it easier, actually, and more effective to call directly to my son's social worker, who is now the care coordinator, or to my son's Federal recovery coordinator.

Mr. MICHAUD. Do you think that the outreach to spread the word about the caregiver program has been sufficient?

Ms. SCHULZ. I think that is an area where the VA has done excellent work because the day it was available, I had calls from my social worker and also an email, and there was also lots of information that was out in the public. It was on the social media sites, and so I think that that was an area they did very well in.

Mr. MICHAUD. You had mentioned that the timeliness of getting approved was pretty quick. The implementation was not as good as possible. The VA has been trying to get them completed within 30 days. Was your process completed within that time frame?

Ms. SCHULZ. It was close. It was very close. I have to say this is the fastest I have ever seen the VA move.

Mr. MICHAUD. And my last question, if you had to make one change within the system, what would be the change that you would suggest?

Ms. SCHULZ. One change? You are going to limit me? I think I would really tighten up those disparities so that that artificial cap of hours, because there are lots of veterans that need more than 40 hours. And what are we doing for them? And how can you—I mean, that disparity is so discouraging. And so really, working on that rule to get that right so that it is not just an artificial and so it is right across the country.

Mr. MICHAUD. Great. Well, thank you very much, and please thank your son for me for his service to this great Nation of ours. I want to thank you, as well, for all the efforts that you are putting in to taking care of your son, as well as being here today to let us know how we can improve the legislation that was enacted. I yield back the balance of my time.

Ms. BUERKLE. Thank you.

I now yield 5 minutes to the gentleman from Michigan, Dr. Benishek.

Mr. BENISHEK. Thank you, Madam Chairman.

Ms. SCHULZ, thank you so much for coming today. I just had a few questions to kind of clarify your situation. It seems like you must have had a relationship with the VA through your social worker that you know there and you have been taking care of. I mean, this is not the fellow that came out to review your situation for the home visit; this is somebody else then, right?

Ms. Schulz. He was an RN that worked with the spinal cord unit is all I know, and I don't know if it is a new position for him, but he had not read the chart and had no relationship with us.

Mr. BENISHEK. So did somebody come to your house to sort of evaluate? I mean, it would seem like your social worker that you have been working with would know what you are doing with your son on a daily basis, the care that he requires. So did somebody come out to just see how it's going at the house to observe you for a day or anything like that? No?

Ms. SCHULZ. Well, yes. I mean, he came out to the house, and I have heard instances where they went through the refrigerator. I heard one veteran who was told they didn't have enough food in the house. This particular RN did not look at our pantry, did not look in our refrigerator, but asked if we had smoke detectors, you know, basic safety things, which, you know, 6 years ago, would have made sense to me when he was very, very frail, and he was first sent home. At this point it was a little insulting, actually.

But I think that a home visit could be a real opportunity to find out what the veteran needs and what the caregiver needs.

Mr. BENISHEK. Right. Do you have an ongoing conversation with the VA about what is happening with your son? Is it through the social worker? I mean, do you speak to them on a weekly basis then?

Ms. SCHULZ. Not weekly. Probably, we talk to our Federal recovery coordinator once a month. I contact his social worker as needed. We see his doctors, depending on which doctor, probably every 3 to 6 months.

Mr. BENISHEK. All right. How far away are you from a veteran facility that your son could get care? Where does he have to go to get care?

Ms. SCHULZ. Our VA is about 30, 35 miles from us.

Mr. BENISHEK. Okay. Is there anybody coming in to help you do any of this care on a regular basis? Is there a physical therapy or anything involved?

Ms. SCHULZ. No. Not coming to the house, no.

Mr. BENISHEK. It just seems to me that there should be a little more teamwork involved in helping the care progress, or and then, you know, making sure that you can get the proper amount of hours, I mean, just observing what you do on a daily basis it seems like it would be fairly easy to figure out by just observing what you do for a day or even a half a day. And it is a little disappointing to me to hear that you didn't get a letter explaining what the benefit would be.

Ms. SCHULZ. And that has, I just have to share with you. That has always been my contention. If somebody from the VA came and spent 4 hours with me, especially early, early on, because I was requesting help back then and it wasn't available, they would know just how much and how needy he was.

So for future veterans, I think your point is exactly right. Somebody needs to really assess what the veteran needs are in a home setting, and that teamwork is crucial.

Mr. BENISHEK. Well, it just seems to me that there could be with the social worker that, you know, a mechanism for you to communicate what you need and maybe somebody could come to the house occasionally to help you or give you a morning off or something like that.

Ms. SCHULZ. Prior to this law, nothing was available that was appropriate for this young age veteran who is active and doing things but needs help in everything he does. But the home help assistance that was offered to me was not age appropriate. It was not reliable. It was just not right for him, and most young veterans. It is set up for a geriatric population.

Mr. BENISHEK. Right. How do you communicate with the other caregivers that you have been in contact with? Are these people that you have met at the hospital, during your going back—

Ms. SCHULZ. People we have met at the hospital, at different veterans functions, just along the road you meet other veterans, and we use social media and telephone and e-mail.

Mr. BENISHEK. Okay. Well, I really appreciate your coming and giving us a picture of what you are going through here. I think it can be helpful going forward to, not only for yourself, but other caregivers throughout the country. So I really do appreciate you coming.

And I yield back the remainder of my time.

Ms. BUERKLE. Thank you, Dr. Benishek.

I now yield 5 minutes to the gentleman from New Jersey, Mr. Runyan.

Mr. RUNYAN. Thank you, Madam Chair.

And Ms. Schulz, thank you for the time you spend taking care of your son and for his service to this great country. You said earlier you really don't know what you are entitled to, you have gotten no communication back from the VA. Do you even know if you have a correct rating? Have you reached out to them since this process, from them—not even, like you said, you don't have a written or a verbal commitment from them. Have you reached out to them to see if they just forgot about you?

Ms. SCHULZ. I have not, because I received the check on July 5 and so I was doing holiday stuff and so I have not emailed them.

Mr. RUNYAN. Okay. Because, you know, going into some of your further testimony, and even some of the questions you have asked, it has been kind of—in the VA Committee, we always talk about the stakeholders being involved. And I think you have brought it up with the home inspection, it is a premier opportunity for that to happen, to really see what is going on there. And you know, it is not about—well, it seems like the VA approach is, well, you are not going to be entitled to this because you don't have this need, that need, this need. It is more of yourself, seeing the relationship between you and your son, not as mother and son, as caretaker and patient. And I think that is a unique opportunity that we really need to look at.

Off the top of your head, do you have a round about number of how many hours you put in a week to actually take care of your son?

Ms. SCHULZ. That is a tough question because if we are in the home environment, he may be sitting at his computer, working on stuff, and I am not really having to do anything. But say we are out somewhere, like if he would have come with me up here, somebody needs to be right there by him all the time because he can get lost and confused. But I would say anywhere from 50 to 60 hours a week is realistic. And mind you that Steven is not someone who needs hour-to-hour medical care. His is just safety, supervision and redirection.

Mr. RUNYAN. Well, I think that raises the point where you say, you know, they want to cap hours. You know, depending on how active and how, whether they are out of the home, whether they are physically able to be out of the home. You can have the mental challenges with the TBI, the PTSD, that kind of stuff but physically be able to interact in society, but you need help with that.

So I think going more towards a stakeholder approach, and having stories like yours is only going to help this process. And I think the VA really needs to be open to that and take a better approach on it. So I thank you for that.

And Madam Chair, I yield back.

Ms. BUERKLE. Thank you again, Ms. Schulz.

Unless anyone else has any further questions of our witness, thank you again for taking the time to come here today and answer our questions and testify before us.

Ms. SCHULZ. Thank you so much.

Ms. BUERKLE. Thank you.

And with that, I will ask Ms. Frese to begin her testimony.

I would ask at this time that our second panel join us at the witness table. Also, with us this afternoon is Anna Frese, the Director of the Family Support Program for the Wounded Warrior Program (WWP); Ms. Cheryl Cox, the Caregiver Support Coordinator for the Syracuse VA Medical Center; and Ms. Mary Fullerton, the Caregiver Support Coordinator for the North Florida/South Georgia VA Healthcare System. Thank you all very much for joining us this afternoon.

**STATEMENTS OF ANNA FRESE, DIRECTOR, WARRIOR SUPPORT PROGRAM, WOUNDED WARRIOR PROJECT; CHERYL COX, LCSW, CAREGIVER SUPPORT COORDINATOR, SYRACUSE DEPARTMENT OF VETERANS AFFAIRS MEDICAL CENTER, U.S. DEPARTMENT OF VETERANS AFFAIRS; AND MARY FULLERTON, LCSW, CAREGIVER SUPPORT COORDINATOR, NORTH FLORIDA/SOUTH GEORGIA VETERANS HEALTHCARE SYSTEM, U.S. DEPARTMENT OF VETERANS AFFAIRS**

**STATEMENT OF ANNA FRESE**

Ms. FRESE. Chairwoman Buerkle, Ranking Member Michaud and Members of the Subcommittee, thank you for inviting Wounded Warrior Project to testify today regarding the implementation of the Caregiver Assistance Program. The program's success is important to me, not only as WWP's Director of Family Support and liai-

son to family caregivers, but also as a long time advocate for my brother, Eric, whose injuries in Iraq led to his need for round-the-clock care due to severe brain injury.

Let me thank this Committee for all it has done in shaping the caregiver law and jumpstarting and accelerating a process that now is directly helping members of families and insisting on full implementation of the law.

Overall, I know VA has 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. Some have encountered problems, and other are waiting for applications to be processed.

But I am really most concerned about VA's implementing regulation published on May 5 because it still fails to get some issues right. As a result, some deserving families will likely be denied help. Others will probably not get the extensive help they should, and many others were discouraged from even applying.

VA's rule is a big improvement over the initial implementation plan. WWP has submitted extensive comments on VA's rule. But let me highlight just a few of the problems, many of which relate to warriors with TBI and mental health conditions.

As currently written, eligibility criteria do not adequately address the need for caregiving as it applies to warriors with severe mental health conditions. Typically, where such a condition is really severe, a family feels that that they can't leave a warrior alone. But each case differs. But often, the warrior lacks full cognition or judgment to be fully aware of danger. In other cases, behavior may be marked by a lack of impulse control or might otherwise leave a family fearful of possible suicide risk or violence. 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 TBI, VA's eligibility rule seems workable.

But where the same safety risk is due to PTSD, depression or anxiety, it seems much less likely that VA will provide caregiver assistance under the new rules.

A second area of concern is how VA's eligibility criteria are being applied around the country. WWP recently conducted a survey to understand families' experiences under the new program. Among the findings, the survey suggests there is a wide variability from facility to facility as to who makes eligibility determinations and how they are made.

Let me share an example. One caregiver has provided almost constant care and supervision for her husband, who suffers from PTSD and traumatic brain injury; 11 days after applying for caregiver assistance, a VA nurse practitioner contacted her to advise her that the application had been denied. Without either reviewing the veteran's medical records or consulting his longstanding care team, the nurse concluded on the basis of the veteran's compensation and pension exam records that he did not need assistance in performing activities of daily living and, thus, wasn't eligible.

Among her many errors was to overlook the fact that eligibility could solely be based on the need for supervision or protection. Luckily, this situation ended favorably, but only because a VA employee took—another VA employee—took the initiative to inter-

vene. The case illustrates the inherent problem of the rule which is altogether vague as to how clinical eligibility determinations should be made and who is to make them.

This and other cases also raise the question, how can a veteran or caregiver appeal an adverse medical or legal decision? The implementing regulation is completely silent on this issue. We believe it is essential that VA establish systematic recourse for those caregivers who may be denied benefits in error. But feedback from caregivers indicates they are unaware of where to turn in the event that they disagree with VA determination.

Since caregivers generally can no longer work outside of the home and often care for loved ones on a full-time basis, the stipend was to provide some financial support. Let me offer an example to highlight what we see as flaws in the way the rule works regarding the amount of the stipend. Take the case of a veteran who sustained a severe TBI but, after a lengthy rehabilitation, is able to perform all activities of daily living. But the TBI manifests itself in severe mood swings, sometimes aggressive violent outbursts. Because he can't control these behaviors, even with medication, his wife must be with him full time.

Applying VA's current rating skill, which measures need for assistance on a scale of zero to four, this veteran might get a score of four in three different areas, inability to self-regulate, safety risk, and inability to plan or organize. But because the veteran doesn't need assistance in any other areas, he or she would get a total score of 12, which under the VA rule means the veteran is deemed to need only 10 hours a week of caregiver assistance. Yet, the veteran actually needs full-time support.

In closing, we do commend the VA for the substantial improvements they have made and for the speed in which they launched the program. We also believe flaws in the interim rule must be corrected to ensure that the programs fulfill the intent of the Congress and promise of the law.

WWP looks forward to working with the VA and this Committee on that shared goal. Thank you.

[The prepared statement of Ms. Frese appears on p. 33.]

Ms. BUERKLE. Thank you very much, Ms. Frese.

Ms. Cox.

#### **STATEMENT OF CHERYL COX, LCSW**

Ms. COX. Good afternoon, Chairwoman Buerkle and Members of the Committee. Thank you for the invitation to discuss the Caregiver Support Program, established in title 1 of Public Law 111-163, as implemented at the Syracuse VA Medical Center.

My name is Cheryl Cox, and I am the Caregiver Support Coordinator at the Syracuse VA. I have been a clinical social worker at the VA for 4 years and was the ambulatory care social worker prior to becoming the caregiver support coordinator. I received my Master of Social Work from the State University of New York at Buffalo in 1993, and have over 18 years of experience working in mental health and medical settings.

The care provided by family caregivers is essential in allowing our veterans to maintain as much independence as possible, remaining at home in their community, surrounded by their loved



ones. I am truly honored to be a part of the groundbreaking Caregiver Support Program.

Throughout my career, I have been fortunate to work with caregivers and am truly impressed with their tireless dedication and the level of care they provide. To date, the Syracuse VA Medical Center has received seven applications for the Family Caregiver Program. I am working with these veterans and their family caregivers as well as their medical team to complete the application process. Our first caregivers who have completed the caregiver training are expected to have their home visits and complete the process within the next week or 2.

Throughout the initial implementation, I cannot say enough about Syracuse's Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF) team and the support we have received from leadership, both at the local and national levels. In advance of accepting applications, our local OEF/OIF team identified potential eligible veterans and caregivers. Our team worked together to contact these veterans and caregivers to ensure that they were receiving all possible benefits and services, and to assist them with the application for this new program. Throughout April, the National Caregivers Support Office provided several key training sessions for the caregiver support coordinators on the program and application process.

Since I began working at the VA, I have had the privilege of meeting and working with caregivers of veterans from all eras. In my role as an ambulatory care social worker, I have assisted numerous caregivers with information on VA and community programs and services, assisted with transitions to varying levels of care, and provided other forms of support. I am continually impressed with their dedication to their loved ones, and I am honored to be able to provide support to them.

Through the Caregiver Support Program, I have had the opportunity to do intensive case management with those applying for the enhanced benefits. Again, these caregivers and the sacrifices they make never cease to amaze me. One young wife of a veteran comes to mind. This veteran suffered a gunshot wound to the head by sniper fire while serving in Iraq. He continues to have seizures, memory impairment and vision loss. Following his initial hospitalization and treatment, he spent 6 months in a traumatic brain injury center in Richmond, Virginia. His wife shared how she did not leave his side the entire time, juggling care for their two small children, who were 11 and 5 at that time. She has remained by his side as his wife, advocate and devoted caregiver. She has not been able to work outside the home due to her commitment to her husband and providing the care he needs. She has been very appreciative of the support and recognition this program provides.

The Caregiver Support Line in Canandaigua has been operational since February of this year. It is an important part of this program, as it gives caregivers a place to turn for information and support. I have received several referrals from the support line to assist caregivers and families of veterans from all eras with questions regarding VA services and programs. In my role as the Caregiver Support coordinator, I have been able to provide assistance

in leading them to appropriate VA and community resources while providing much needed support.

Facilitywide, I have been actively providing education to staff on the Caregiver Support Program and exploring ways in which to reach out to as many caregivers as possible. Over the next few months, Syracuse will establish a Caregiver Support Advisory Board, and I will be implementing a support group for caregivers. I look forward to providing ongoing support to these unsung heroes.

Thank you again for the opportunity to discuss Syracuse's implementation of the Caregiver Support Program.

Ms. BUERKLE. Thank you very much.

Ms. Fullerton.

#### **STATEMENT OF MARY FULLERTON, LCSW**

Ms. FULLERTON. Good afternoon, Chairwoman Buerkle, and Members of the Committee. Thank you for inviting me here to share how North Florida/South Georgia Veterans Health System has been implementing the family Caregiver Support Program.

I have focused much of my career as a social worker working with veterans and their family caregivers, and it has been a wonderful opportunity to have been selected and serve as the full-time Caregiver Support Coordinator.

VA Central Office has provided comprehensive training to the caregiver support coordinators, the teams and the services who are involved in this process.

Additionally, Veterans Integrated Services Network (VISN) 8 has regularly scheduled teleconferences where the caregiver support coordinators are informed about the program implementation, as well as offering a forum to ask questions. Experts have been brought in to help the caregiver support coordinators identify and better understand specific diagnoses, such as post-traumatic stress disorder.

North Florida/South Georgia Veterans Health System leadership is very supportive of the Caregiver Support Program. I meet regularly with the patient aligned care teams to streamline the implementation processes for this program by discussing the role of the home-based primary care, traumatic brain injury mental health concerns, among others. I also meet regularly with our Medical Administration Services regarding benefit criteria, and I am working with volunteer services to identify additional ways we can support our veterans and their caregivers.

Through July 1st of this year, North Florida/South Georgia Veterans Health System has received 23 applications for the primary family Caregiver Support Program. Nine of these applications are in process; 14 did not meet the program eligibility criteria. Of those that did not meet the eligibility criteria, six were injured before 9/11; one is on active duty without a date of discharge; five did not require the continuous and approved caregiver support services; and two experienced injuries that were not incurred or aggravated in the line of duty.

My first application was with a veteran and his wife who live in South Georgia. He and his wife have been married for a number of years and have two wonderful children. This veteran experienced four blast injuries and lost consciousness during mortar blasts. As a result, he developed severe migraines and seizures. He has con-

stant headaches. And when the migraines are severe, the pain is debilitating.

He also experiences post-traumatic stress disorder, traumatic brain injury, visual impairment, tinnitus, loss of taste and smell, and multiple other problems. His wife was working full time as a teacher but has quit her job to take care of her husband full time at home. She openly states that what she does for her husband is inspired by the love that they share. She accepts the loss of her career with no regrets about her caregiving role. Currently their only income is from Social Security Disability and his VA benefits. She and I have discussed that no amount of money could purchase the type of care that she personally provides for her husband. Their VA OEF/OIF/Operation New Dawn case managers have been very active in this veteran's care, identifying supportive services for the whole family.

The wife has shared how thankful she is for the current services being provided to the family. She has already participated in the Easter Seals training and felt that it was very beneficial. She is also very appreciative of the financial support, which will be paid directly to her.

The application process for the Family Caregiver Program is only a part of the Caregiver Support Coordinator's role. I receive and respond to referrals from the VA Caregiver Support Line, and as of June 30 of this year, I had received over 100 referrals. The majority of these referrals were Vietnam and World War II veterans and their caregivers. I follow up with these callers within 30 days and again at 60 days to see if I can provide additional assistance and offer supportive counseling and referrals for VA and community services.

I also am involved in community outreach and coordinate care with agencies that provide additional services and support to the veterans and their caregivers. In May, I coordinated the eighth annual resource fair held at the VA. These were community agencies as well as VA services.

Again, I appreciate the opportunity to talk with you today and would like to thank you for your ongoing support to our veterans and their families.

Ms. BUERKLE. Thank you very much. At this time, I will yield myself 5 minutes for questions.

Ms. Frese, I would like to start with you, if you would. If you could change one thing with this program, where do you see a deficiency or something that needs to be changed?

Ms. FRESE. I think one of the issues is one that Debbie, Ms. Schulz, mentioned previously in dealing with the determination of the stipend and the range of hours. So I won't be redundant on that, but I think that is something that definitely attention needs to be brought to.

I think the second thing is the eligibility, the mental health eligibility criteria. The IFR sets a much higher standard for eligibility with the current Global Assessment of Functioning (GAF) score in cases involving psychological trauma or other mental health conditions than for any other condition. And there seems to be a disparity in the needs for the mental health compared to the different physical disabilities that others may be having.

The amount of hours the family caregivers are providing, I think, regardless of either the mental health condition or a physical disability remain the same. There is the need there. And I also hear from others that because seeing that GAF score and the eligibility criteria, it has dissuaded many from applying, just not understanding that they still may be eligible. And it also can create a misunderstanding with some of the professionals that they work with. The education with that eligibility criteria would be greatly helpful for the family members applying but also for some of the VA personnel that come into contact with the families, where there is a need and they would benefit from this program.

Ms. BUERKLE. Thank you.

Ms. Cox, and Ms. Fullerton, what is the biggest complaint that you hear from both the veterans and the caregivers themselves? And, how would you suggest remedying them?

Ms. COX. I can tell you, in Syracuse, one of the biggest challenges has been the question about illness versus injury, and right now in the interim rule, it is specific to an injury that was incurred or aggravated on or after 9/11. And we do have caregivers that are providing significant amounts of care to veterans based on an illness that they may be service-connected for, and under the regulation, they are not eligible, so that is what I am hearing the most about.

Ms. BUERKLE. Thank you. Ms. Fullerton.

Ms. FULLERTON. Quite honestly, ours has been going fairly well. I haven't heard any complaints. We focus on the veterans and working with the caregivers trying to meet their needs. We are lucky that we have open communication with all the team members that we can discuss if there were any issues coming up. I know that finances is probably the number one concern with these families, and it is really rewarding to be able to get them help that way.

Ms. BUERKLE. Thank you.

This is maybe for Ms. Cox and Ms. Fullerton. If a veteran is denied access to the program, is there an appeal process? Do you know of anyone who has been denied and appealed and was successful?

Ms. COX. I can speak for Syracuse. We have had one that was denied. I did send a letter to the veteran and the caregiver explaining the appeals process and encouraged them to appeal if they feel like that is in their best interest. To date, they have not actually appealed the process.

But I can say that I have worked closely with that family to let them know about the other services that they may be eligible for. And at this point, they may not be eligible for the stipend and some of the enhanced benefits, but we do have other services, like home-based primary care and home health aides that they could utilize.

Ms. BUERKLE. Thank you.

Ms. Fullerton.

Ms. FULLERTON. We have had a few denials. I have talked with the caregivers and the veterans regarding what the denials were based on. They understand that it is a team decision; that we take into consideration their primary care, their OEF/OIF case man-

agers, any mental health providers that are involved in that process. When I explain the criteria and the severity of illness and the need for the essential caregiver, they understand that. I do explain when they are denied that there is an appeals process, and they are more than welcome to go through that, and I would help to walk them through that.

Ms. BUERKLE. Thank you very much.

At this time, I yield to the Ranking Member, Mr. Michaud.

Mr. MICHAUD. Thank you very much, Madam Chair.

When the caregiver is going through the process, do they participate in the clinical assessment at the start of the process?

Ms. FULLERTON. Actually, my experience I have had one wife that asked to be part of the clinical evaluation with her primary care provider, and he welcomed that. You know, they said, by all means, for them to be there. Most of the providers actually know the wives and, I say wives—that is who are our caregivers, the majority of them—know both of them. So they have been very open to have them part of that.

Ms. COX. And in Syracuse, we have used a team approach, so most, actually all, of the veterans that have applied have been closely case managed by our OEF OIF team. They know them very well, so we have worked with them and their primary care doctor, and then if they have other components, like mental health, so we have done it really as a team to make sure that we are being as inclusive as possible.

Mr. MICHAUD. But it is not required that you be inclusive?

Ms. COX. It is not required, but once we receive the initial application, the caregiver support coordinator is expected to contact the caregiver to do an initial assessment within 2 days. So when I do that, I do elicit from the caregiver the kinds of things that they are assisting the veterans with so that I can bring that back to the team and assist with the clinical eligibility.

Mr. MICHAUD. Ms. Frese, have you found it, among the individuals that you talked to, that it is a problem that the caregiver is not part of the clinical assessment process?

Ms. FRESE. I think it makes the most sense, as you heard again from Ms. Schulz herself, that the majority of these families, many of the families have been doing this for an extended period of time and have a very established treatment team, and so it seems to make most sense that with the receipt of an application from that caregiver, that that treatment team would be questioned or involved from the beginning and the caregiver would be part of that.

The surveys that we had sent out and received back, it is not—that is an inconsistency that we did receive back, that the majority, there is not an active involvement in working with a team and understanding where the decision process is coming, how it has been made, who is involved and coming down to the endpoint of determining the number of hours of where that came from.

Mr. MICHAUD. Thank you.

Ms. Fullerton, you mentioned that you received a lot of training from the VA for case workers. However, we heard Ms. Schulz mention in her testimony that the case worker came there and thought that she was the veteran, so evidently, they did not read the case,

so I have to question the training, or is it just this one individual that did not do his or her work?

Ms. FULLERTON. At North Florida/South Georgia, the home-based primary care team is the one that is going to be doing that initial assessment and the monitoring. They are very well trained to work with the veterans and the caregivers in the home. I have talked to them personally about every veteran that is coming through the training system that would be coming up, and they have been able to access the records, and we have talked about what the needs are. And that is considered a very supportive visit. They have a template that they would be filling out to make sure the home is safe and that the veteran and the caregiver understands the training that they have and if they have any supports with that, but it is going to be a person that is very familiar with coming into the home and will know that veteran, if not face to face, will know their record. We have had two veterans that actually are followed by home-based primary care, so they are very familiar, which is nice.

Mr. MICHAUD. I guess I would be concerned hearing Ms. Schulz' testimony when she did not have a very good home visit and, in fact, that they didn't know who the veteran was. I guess that is a little concerning about the training. Maybe it is just this one individual.

My next question actually for Ms. Cox and Ms. Fullerton, as the VA rolls out its peer support monitoring program over the next year, whether it is veteran to veteran or caregiver to caregiver, do you have any suggestions to how the program should be implemented?

Ms. COX. I guess I would have to think about that a little bit. But I know that, you know, as social workers and as caregiver support programs, we are generally involved in support groups, and so if we could assist with facilitating or giving input into how those groups work and what works best that might be helpful. And I would imagine we would have a piece of assisting in the implementation.

Mr. MICHAUD. Thank you very much, Madam Chair.

Ms. BUERKLE. Thank you.

I now yield 5 minutes to the gentleman from Michigan, Dr. Benishek.

Mr. BENISHEK. Thank you, Madam Chairman.

Well, it seems that Ms. Cox and Ms. Fullerton have a little different experience than Ms. Schulz related to us here. I mean, it sounds as if you are relating to me a much better evaluation than Ms. Schulz related to us.

Do you have an ongoing communication then, like, more often than once a month, with the patients? I mean, I just think, from the testimony, there is a lot of variability here in the care. I just wanted to know, is there someone here that we could find out more about that variability in care?

Ms. COX. I believe Ms. Amdur will talk to the clinical eligibility and the assessment.

But I can say, in Syracuse, we have had seven applications. So it is on the—I don't want to say the lower end, but I really have

time to be in contact with the caregivers that are applying for the program in Syracuse.

And I did hear Ms. Schulz's concerns about the home visit. And I agree, it really shouldn't happen like that. But I think we are working together with the teams and trying to do the best that we can for the veterans and the caregivers to get them the services they need.

We also have weekly calls across the Nation, national calls, where we receive ongoing support and training. And, at the local level, we have biweekly calls in our network. So we are communicating with the other caregiver support coordinators, trying to make sure that we are on the same page.

Mr. BENISHEK. Ms. Frese, do you have any support with a caregiver support coordinator? I mean, have you worked with people like Ms. Cox and Ms. Fullerton, in your experience?

Ms. FRESE. I have not had direct contact with the caregiver support coordinators. In my family's experience, my mother has completed the application and has had contact with them. And in visiting with the families, you know, I think—

Mr. BENISHEK. You are not very far along in the process, is that what I am getting from you?

Ms. FRESE. Our family is not, but I think, you know, in hearing from Debbie as well, VA launched this program quickly. And WWP has heard from caregivers that there have been many positive actions with the caregiver support coordinators. And that has maybe been one of the first positive contacts with the VA at that beginning stage. They were informative in the beginning with the 800-number. Maybe not—

Mr. BENISHEK. Well, yeah—

Ms. FRESE [continuing]. The best prepared, but at least the coordinators were informed.

But I think we are looking at—you know, the success of this program depends on the framework that has been established. And the framework has serious holes in it, such as we addressed with the mental health eligibility and the determination for the stipend.

Mr. BENISHEK. So, then, does every medical center end up having a caregiver support coordinator then?

Ms. COX. We do, yes.

Ms. FULLERTON. We have an alternate, as well. So if we are here, we have an alternate that has gone through the same training and is involved in the phone calls, so they can kind of step in and be us for a while.

Mr. BENISHEK. All right. Well, I understand this is all still pretty new, but I think it is going to involve a little continued monitoring, as far as I can see, to make sure that the results that you two are seeing reflect what is going on throughout the system. So I look forward to continuing oversight of this process.

I will give back the rest of my time. Thank you.

Ms. BUERKLE. Thank you, Dr. Benishek.

I now yield 5 minutes to gentleman from New Jersey, Mr. Runyan.

Mr. RUNYAN. Thank you, Madam Chair.

And, ladies, thank you for your testimony.

Ms. Cox, you might have more of a background on this, but I was curious: As we are trying to find the proper number of hours to care to disability, is there anything in the private sector, whether it is county statistics, maybe Alzheimer's Association, are there organizations like that that have formulas?

Ms. COX. Not that I am aware of, to date. And I think that this program is pretty groundbreaking. I don't know of other community agencies that actually pay a stipend to caregivers to provide that care. So I am not really aware of a specific formula that would help identify the—

Mr. RUNYAN. But not so much to—not so tied to a dollar amount, but just the needs of hours.

Ms. COX. Uh-huh.

Mr. RUNYAN. Not aware of any?

Ms. COX. Yeah, not that I am aware of.

Mr. RUNYAN. Because I know, dealing with that—I, frankly, have had two family members have Alzheimer's disease and pass from it—I know how difficult that can be. And I currently have one with dementia that is going through the same deal and also going through the process, which raises another question.

When you do have a brain injury early on, you may not need medical treatment for it, but, obviously, as we move down the road and we age, it is a precursor to early-onset dementia or Alzheimer's, which is going to require things like this. I think having the ability to—I don't know if the VA is going to be able to pull out these numbers and be able to do that type of stuff early on.

But I was just asking, with your background of—they were out there, and obviously not. And I think that obviously one of the questions we have, is: How do we get this, and how do, you know, we make it across the board? Because there are exceptions to every rule—

Ms. COX. Right.

Mr. RUNYAN [continuing]. And everybody needs to be treated fairly. I guess we don't.

And that is really all I had. I yield back the remainder of my time.

Ms. BUERKLE. Thank you, Mr. Runyan.

I now yield to the gentleman from Tennessee, Dr. Roe.

Mr. ROE. Thank you.

And thank you all for being here.

And, Ms. Schulz, I read your testimony here, and it is very compelling. But back to what Congressman Runyan is saying, there probably are some private-sector models if you look, for-profit and non-for-profit health care organizations that are caregivers. They don't provide a technician or a nurse or an LPN, but they go and they wash clothes and help. So there are probably some models out there. And I don't know that that would be helpful, but I would look.

And, certainly, it is 24/7. I will give you just one brief example of someone I know who was shot through the neck in 1968, and his wife was told that he would probably live 7 years. He is still alive. And he is alive because of his caregiver. She was 19 years old with an 11-month-old child when that happened. And she is still taking care of him today.



And I think, Ms. Frese, your point about including these people—they are experts. When the professionals like me and the medical system, told her that her husband would live 7 years and he has lived over 40, I think I would listen to those folks. So I think that is a great point you make, that they should be brought in and questioned about what they have been doing. You obviously have been doing something right. So I would definitely do that.

What are the biggest hurdles that you have found so far in doing this? I know, as Dr. Benishek said, this is new territory. So what is the biggest frustration hurdle you have had so far?

Ms. COX. So, just to reiterate, the biggest challenge for me as a clinician, because I want to support these caregivers and I want them to have what they need to continue to provide this care, has been the illness versus injury and that it excludes some caregivers that provide significant amounts of physical care to our veterans.

Mr. ROE. Okay.

Ms. FULLERTON. I have worked in geriatrics quite a long time, and I have heard a number of things from the vets that are not within this 9/11 era and that they are doing the same type caregiving. And it is a little bit frustrating that this program is not open to them. I have encouraged them that they will hopefully be considered at some time.

I make sure that I refer them to as many as services as there are. They are eligible for the respite program regardless of what era they are, you know, for in-home respite. So, make sure they have the supports they can. But to not be recognized financially has been difficult.

Mr. ROE. I agree with you. I mean, this caregiver that I am speaking of, she is a hero to me. I mean, she has saved the taxpayers millions of dollars with the care. She gave up a career. What is so frustrating for me for her is that, not only is she not included in this bill, she also couldn't be in the workforce and gather time with Social Security.

And you know that her husband's life expectancy—he is about 69 years old now—is not going to be as long as hers will be. And I don't know how we make that right, but we need to make that right. That is something that, when I first heard that situation, I thought, that is a wrong that needs to be corrected. And I don't know how we do that.

But I agree with you, that is one that I have seen personally. And there probably are many, many others. And that is not taking care of a veteran who is a senior who has diabetes and so forth. It had nothing to do with service-connection through an injury that occurred in—whether it was World War II, Korea, Vietnam, wherever, Desert Storm, it doesn't matter. So I agree with you.

I thank you all for being here.

And I yield back the balance of my time.

Ms. BUERKLE. Thank you very much.

Unless any of my colleagues have additional questions, thank you all very much for your testimony here today. You are now excused.

And, at this point, we will ask our third and final panel to come to the witness table.

Representing the Department is Ms. Deborah Amdur, the Chief Consultant for Care Management and Social Work for the Veterans Health Administration. Accompanying Ms. Amdur is Mr. Keith A. Welsh, the Director of the National Caregiver Support Program.

I welcome both of you today, and we look forward to hearing your testimony.

Ms. Amdur, you may proceed.

**STATEMENT OF DEBORAH AMDUR, LCSW, ACSW, CHIEF CONSULTANT, CARE MANAGEMENT AND SOCIAL WORK SERVICE, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS; ACCOMPANIED BY KEITH A. WELSH, LCSW, DIRECTOR, NATIONAL CAREGIVER SUPPORT PROGRAM, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS**

Ms. AMDUR. Thank you.

Chairwoman Buerkle, Ranking Member Michaud, and distinguished Members of the Committee, thank you for the opportunity to discuss the progress VA has made in implementing the provisions of title I of the Caregivers and Veterans Omnibus Health Services Act of 2010.

I would like to acknowledge our family caregivers, Ms. Frese and Ms. Schulz, who came to share their experiences today, and acknowledge the veterans that they provide care for.

With me is Keith Welsh, our National Caregiver Program Director.

When we appeared before you in March, you asked us if we would be providing services and support to families by July. I am happy to report that we are delivering the benefits and services created under the Caregivers Act. We are providing family members who have taken on the responsibility to be the primary family caregiver with stipends, and we are training hundreds of family caregivers to deliver the support our veterans need.

Many VA staff members have worked very hard to get this program up and running because we understand the key role that family members fill in supporting a veteran's independence and wellbeing.

Earlier this year, we heard your concerns and the concerns of the veterans service organizations and revised our plans for implementing the program in response. We made a special effort to be explicit that eligible veterans with traumatic brain injuries and significant mental health challenges would qualify for these benefits. And we developed a broader set of eligibility criteria consistent with the law that will allow several thousand veterans to qualify. We estimate approximately 3,600 veterans and servicemembers will meet the criteria that we have adopted in the interim final rule published on May 5th.

Today, we are processing more than 1,400 applications and have over 300 primary family caregivers who have completed the approval process, which includes comprehensive training and a follow-up home visit. Once approved, we are providing them with stipends and health care benefits if they are eligible, retroactive to the date of their initial application.

VA has trained several hundred family caregivers already, and we continue to train more every day. Training is available in person at VA medical centers and community locations, through self-study by book and DVD, and an online option will be available starting next week.

In implementing this program, we have developed a hybrid model that has centralized many of the administrative functions while decentralizing clinical decision-making. This approach ensures that our experts in the field are able to focus on addressing the specific needs of each veteran while delivering consistent health care and stipend benefits to designated and eligible primary family caregivers. This approach allows us to monitor the status of applications across the system. It will also make it easier to identify any variations that occur in delivery of the benefit.

We have provided comprehensive training to VA caregiver support coordinators and clinicians who are responsible for determining a veteran's eligibility for the program. However, recognizing that this is a new benefit and effort, VA is monitoring these decisions to ensure that we are consistent in how we apply the program criteria.

We are continuing to reach out to eligible veterans and encourage them to apply. We have contacted Post-9/11 veterans currently receiving aid and attendance benefits from VA to recommend that they submit an application for the Family Caregiver Assistance Program. We appreciate the Committee's efforts to help us spread the word about this program as well.

Looking forward, we will continue to review the public comments we received concerning the interim final rule. The window for submitting comments closed on July 5th, and our final rule will either continue the program as implemented or revise it based upon our considerations of these comments.

VA will also continue to provide the array of services already available to eligible and enrolled veterans and their caregivers, including such programs and services as home-based primary care, our caregiver support line, home telehealth, respite care, and our new caregiver Web site, which provides a wealth of information and resources for caregivers, veterans, families, and the public.

Evidence-based support programs and a peer-support mentoring program are in development and will be rolled out over the next 12 months to provide further assistance to our family caregivers.

Although we have only recently initiated this program, we have received a great deal of positive feedback from veterans and their caregivers on the services that we are delivering and the support that VA professionals in the field are providing. We appreciate the Committee's support as we continue to work to deliver the benefits that veterans and their caregivers have earned.

Thank you for inviting me here today to share the progress that we have made. I am prepared to answer your questions at this time.

[The prepared statement of Ms. Amdur appears on p. 37.]

Ms. BUERKLE. Thank you very much.

At this time, I will yield myself 5 minutes for questions.

You were here during Ms. Schulz's testimony. She talked to us about just receiving the stipend payment with no explanation of

the benefit or the stipend. And I am interested to hear why that isn't explained to the caregiver, how you don't rationalize or justify what it is they are being paid and how you are allocating that stipend?

Ms. AMDUR. As our caregiver support coordinators indicated, we did provide and continue to provide extensive training to those in the field who are implementing the actual program and benefits. And we have heard the concerns, and take them very seriously, that we need to have more transparency in terms of how decisions are made.

And so we are first reminding our caregiver support coordinators that they need to make sure that they are sharing very openly with the family caregivers and the veterans the basis on which decisions are made. We are also in the process of developing a letter, which will be included with the letter that is currently sent that notifies the family caregiver and veteran of their eligibility for the program. And that will include an explanation of how the determination was made.

Ms. BUERKLE. When will that be implemented so we can be assured that all the caregiver assistants are receiving this information?

Ms. AMDUR. We are really working to implement that immediately. We feel it is extremely important.

The other thing that I think is really essential here is that we are sure that everybody is well-informed about the appeals process and the fact that, you know, we are very open to that. Certainly, we know our clinicians are very interested in hearing if there are concerns about the eligibility assessment process and are very supportive of individuals appealing the decisions and reconsidering them.

I do want to let you know that we, as I said, have concerns about inter-rater reliability: 152 medical centers; we want to ensure that these criteria are being implemented across the board in an appropriate manner. So we do have a quality assessment measure underway. We have asked alternate clinicians to review not just the eligibility assessment forms that have been completed but also the medical records in order to compare whether they would reach the same conclusion as the team that has done the initial assessment.

I can share with you the results of our initial assessment of 50 records. Eighty-four percent were consistent with the eligibility and had no difference in the tier level.

Sixteen percent of them had a difference in the tier level that was determined, but, actually, it was in the veteran's favor. And this is what we expected. I mean, we know that our clinicians want to do the best possible for all of these veterans and their caregivers, so it wasn't surprising to us that they may have ranked something higher than a second review.

There were three that were scored lower. We have looked into those cases. One of them we felt, you know, there were serious concerns and have asked for a reconsideration of that particular case.

Ms. BUERKLE. Thank you.

In the instance where the veteran is denied and then they appeal, I understand there is an appeals process. Is it the same re-

viewing body that goes through the criteria? Or does it go to a higher level, as it would in a court?

Ms. AMDUR. It does. VA has a clinical appeals process that has been in existence for a long time, and it is that process that we are using. The case is reviewed by the chief of staff at the medical center and clinicians that he or she will determine should be involved in that. But they are not the clinicians who made the original determination.

Ms. BUERKLE. Thank you.

Ms. AMDUR. If the family is still uncomfortable with that decision, we then will bump it up to the VISN level and eventually to Central Office, where we would convene a board to re-review.

Ms. BUERKLE. Thank you.

There are a lot of concerns that have been raised regarding the fact that this stipend and this reimbursement to the caregiver should be made retroactive because the VA failed to enact this in a timely manner pursuant to the statute. And, I just would like to have you speak to that issue.

Ms. AMDUR. We have had that issue reviewed. It has been discussed and under consideration. You know, my understanding at this point was that the determination was that we would backdate to the time of the initial applications.

But, certainly, we will, along with other things, look at that as well, because it is one of the comments that we received in the commentary on the IFR. We are taking those very seriously. They are under review at this point, and we will certainly respond to them in our response with the final rule.

Ms. BUERKLE. I see my time has expired. Just one quick question.

If you are talking about—is that a case-by-case, making it retroactive? Or is that just—that would be something, you look at all the comments and you make the decision that, no, everyone should be reimbursed retroactively because it wasn't their fault that this was delayed?

Ms. AMDUR. I think we would absolutely make a decision like that consistent across the board.

Ms. BUERKLE. Thank you very much.

I yield now to the Ranking Member, Mr. Michaud.

Mr. MICHAUD. Thank you very much, Madam Chair.

In reading the Paralyzed Veterans of America's written testimony, they question the commitment the VA has to this particular program, citing lack of funding in 2012. Trying figure out exactly what the money is, it is hard to figure out. Can you tell us what the budget request is and how you arrived at that number?

Ms. AMDUR. Certainly.

In our 2012 budget, our projected need was for \$158 million. It was based upon our calculations of the potential number of individuals that would be eligible and the services and benefits that would be provided to them, as well as inclusion of services and benefits that would be provided under the provision of the law for general caregivers.

We are looking on a regular basis in terms of our rate of new applications that we are receiving. We will be in a better position to make a firm determination once we get closer to the end of this

fiscal year. But we have been assured that we will have that amount of funding and what is needed in order to be in full implementation in 2012.

Mr. MICHAUD. And would you be able to provide the Committee the number of requests that you receive for services when you have the final number?

Ms. AMDUR. Absolutely. I would also be very happy, sir, to come on a regular basis and brief all of you, if that would be helpful to the Committee.

Mr. MICHAUD. I asked the other panel—and there is no policy, or it is not in the rules, but are family caregivers able to participate in the in-person clinical assessment? It appears that they have been, but, here again, this might not be consistent throughout the VA system. Do you see a problem with making that a part of the process?

Ms. AMDUR. Not at all. I think that our clinicians do recognize that the family caregivers have extremely valuable information in terms of what the care needs of that individual veteran are and that we really need to be getting their input.

As our caregiver support coordinators shared, I mean, many of these families are very well known to our clinical teams. They have been working with them for many years, in some cases. And so I think that they really do know and understand and are regularly communicating with the family caregivers.

But we will absolutely make sure that that message is sent out loud and clear, that their input needs to be considered and they need to participate in that evaluation process, yes.

Mr. MICHAUD. You had mentioned, as did the previous panel, about the comprehensive training that VA employees receive. What is really astonishing, though—and I heard Ms. Schulz's testimony about her home visit; it wasn't what she thought it would be. I mean, just one of the basic things I still can't get over is where someone mistook her for the veteran. That seems to be very basic. Evidently, he didn't even read what he was supposed to, and so I would question the training, or is it this just one employee that—

Ms. AMDUR. I, too, found that extremely concerning, believe me. As a clinician, you know, who has done home care, I know the importance of certainly making sure you are well-read in terms of the case and the individual that you are visiting and know and understand as much as you can about the situation before you go into that home.

And, you know, one of the things that we have relied on our colleagues in the veterans service organizations is, when they do hear about cases like this—and we greatly appreciate her sharing this—it gives us an opportunity to go back to that particular facility and really look at what their internal systems are.

In general, I think that we certainly have received some very positive input in terms of the home visits, descriptions that they felt that the team that came in or the individual that came in was a true ally to them, that they felt a great sense of understanding; it was very validating to have somebody in the home really recognize what their experiences have been.

So, you know, important, again, to go back to those individual situations where the experience is not what it should be and an opportunity to retrain and revisit how they are implementing.

Mr. MICHAUD. Thank you very much. I think that is extremely important, because I have also heard a lot of positive comments from caregivers as far as the program. But you always are going to get individuals out there who are not doing what they should have been doing, and those are the ones that will tend to be highlighted over and over again. So I am very glad to see that you are taking it seriously in trying to solve the problem before it gets worse.

Ms. AMDUR. Absolutely. Thank you.

Mr. MICHAUD. Thank you.

I yield back, Madam Chair.

Ms. BUERKLE. Thank you very much.

I now yield to the gentleman from New Jersey, Mr. Runyan.

Mr. RUNYAN. Thank you, Madam Chair.

And thank you for your testimony.

I just wanted to revisit, really, two questions. One previously I think had been asked, but the other one dealing with home inspections and it being an opportunity for a caretaker, in the comfort of their own home, to really have a lot of our stakeholder input in it.

Ms. AMDUR. Yes.

Mr. RUNYAN. I don't know if it was you or one of the other panelists mentioned a checklist. You know, that is all great, but it is the interaction, the ability to take these ideas back to the VA and really know the needs. Obviously, the VA has the needs; that is the checklist. But we need to expand that.

Is there a process there to have that implemented?

Ms. AMDUR. Oh, absolutely. And I think that the majority of our folks who are out there doing these home visits are well-seasoned clinicians who are, on a regular basis, in veterans' homes and do understand the importance, that this is not a policing activity; they are there to really sit down with that veteran and family caregiver, talk about where they are, what they need, are there other services that we need to bring in that home, other equipment.

And, you know, again, I am alarmed at what was shared, but we also have folks who are really sharing with us, on blogs and emails and so forth, that they have found an experience that was quite different, which is what we certainly would promote.

Mr. RUNYAN. Thank you.

And going back to the same question I asked Ms. Cox, about finding, you know, everybody has their own needs, whether it is hours or something else—in your testimony, you brought up your partnership with Easter Seals. And are there statistics out there from non-profits, you know, publicly available statistics that say, this is how many hours a day we spend with a person in this condition?

Ms. AMDUR. Actually, the National Alliance for Caregiving completed a study of caregivers of veterans, which was published in January of this past year. And that has been extremely helpful for us, because it did provide us with some data, not just about caregivers in general, but about veteran caregivers. I believe, in that study, the average amount of time that a family caregiver was pro-

viding care, direct care, was about 20, 21 hours a week, if I recall. But, you know, there are studies out there, and we certainly are looking at them and also getting input from our family caregivers.

One of the things, though, that is important to us is that we don't want our family caregivers to feel that they have to report hours to us. That is not what is intended here. There is a process, an assignment of a stipend amount, the idea being that they don't need to be reporting those hours on a regular basis. That doesn't mean we don't want to take into account the amount of hours that they are providing. But, again, you know, this is something in recognition of the overall sacrifices that they are making.

Mr. RUNYAN. Very well. And mostly because they are usually on call 24 hours a day because they happen to be in the home, which, frankly, saves us millions, billions of dollars a year.

Ms. AMDUR. Without question.

Mr. RUNYAN. Thank you very much.

I yield back the balance of my time.

Ms. BUERKLE. Thank you very much.

If there are no further questions, I move that Members have 5 legislative days to revise and extend their remarks and include extraneous materials.

Without objection, so ordered.

Once again, on behalf of the Health Subcommittee, I would like to thank all of you for being here today and for your testimony.

We will continue to monitor the progress of the VA regarding the Caregivers Assistance Program. As we have consistently said, time is of the essence, because our men and women deserve this. They deserve us to act responsibly and to provide for the folks who are willing to give them care in their home and maintain that high level of care that Dr. Roe spoke of, we need to be there for them quickly—yesterday, pretty much.

So we will continue to monitor this. We will have another hearing probably within the next 3 months, and we will stay on top of this so we can assure our veterans and the people who need our services that they will get them.

Thank you all very much. This hearing is now adjourned.

Ms. AMDUR. Thank you.

[Whereupon, at 5:29 p.m., the Subcommittee was adjourned.]



## A P P E N D I X

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### **Prepared Statement of Hon. Ann Marie Buerkle, Chairwoman, Subcommittee on Health**

Good morning. The Subcommittee will come to order.

Four months ago today, this Subcommittee held our first hearing of the year to discuss why the Department of Veterans Affairs (VA) had failed to implement the caregiver assistance program as required by Public Law 111-163.

At that hearing, it was clear to me that VA must go back and address serious deficiencies with the Department's initial implementation plan, particularly the strict eligibility requirements, and get this important program up and running.

Today, we meet again to determine the progress the Department has made in the intervening months to adjust its implementation plan and do right by our veterans and their caregivers who have already given so much.

In response to the concerns of Members, advocates and stakeholders, VA changed its eligibility requirements and expedited the implementation of caregiver benefits by publishing an Interim Final Rule (IFR) on May 5, 2011. The IFR allowed the Department to accelerate the Federal rulemaking process by immediately implementing the program prior to the consideration of public comments and issuing a final rule.

As the daughter of a full-time caregiver, I understand the profound impact injury can have not only on the injured, but also on his or her loved ones.

Time is of the essence for these families—many of whom have sacrificed their personal, professional, and financial security in order to take on full-time caregiving responsibilities for their veteran family member. We owe it to these men and women to get it right and we will not rest until we do.

Today, we will hear from Debbie Schulz, a full-time caregiver for her son Steven who was injured in Iraq in 2005. She will speak to her experience applying for and obtaining services from the VA.

We will assess the actions VA has taken to date to meet the intent of the law and the changes that need to be considered prior to issuing the final rule.

Thank you all for being with us this morning. I am very much looking forward to our discussion.

I now yield to the Ranking Member, Mr. Michaud, for any opening statement he may have.

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### **Prepared Statement of Hon. Michael H. Michaud, Ranking Democratic Member, Subcommittee on Health**

Thank you, Madam Chair.

I would like to thank you for holding today's hearing on Public Law 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010. Today's hearing follows up on a March 11, 2011, Subcommittee on Health hearing on this very same issue where concerns were raised regarding the delays in the rollout of the implementation plan, the narrowing of criteria for eligibility of these benefits, and next steps.

At the beginning of July, the Department of Veterans Affairs issued its very first payments to family caregivers of veterans. These family caregivers were the first to complete their caregiver training under the program of Comprehensive Assistance for Family Caregivers, and VA will send out more than \$430,000 in stipend payments to nearly 200 recipients this month alone.

I am pleased that veterans and caregivers are finally beginning to receive some of the services required by P.L. 111-163, and I am pleased that the criteria for eligibility for these benefits have been expanded to be more in line with the original intent of Congress. However, I would like to hear more from our witnesses today about:

- How the plan is being implemented in the field;
- What issues remain;
- What oversight is being conducted from Central Office; and
- How we can ensure that this program is successfully implemented so that veterans and their caregivers receive these critical benefits without further delay.

The testimony we received contained many concerns with the interim final rule and I would like to hear more from VA on incorporating some of these suggestions in the final rule.

Madam Chair, thank you again for holding this hearing, the second in a series of hearings to assist in our oversight of the implementation of P.L. 111–164. As we continue to monitor this issue, we will work to actively engage VA as we move forward.

I yield back.

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### **Prepared Statement of Debbie Schulz, Friendswood, TX**

Chairman Buerkle, Ranking Member Michaud, and Members of the Subcommittee,

Thank you for allowing me to share with you my experience with VA's implementation of the comprehensive caregivers assistance program. Thank you too for your leadership in pressing VA to implement this important law so that congressional intent is fully realized. Much progress has at last been made, though—based on my experience and what I have heard from other caregivers whom I've met over the years since my son's injury—I believe VA will need to go further.

As a caregiver for my son, Steven K. Schulz, USMC ret., I cannot adequately express how important this program will be to his ongoing recovery and continued well-being. If fully and properly implemented, the law will assure that he will be able to stay in his home with age-appropriate supports and his family will be able to continue to provide the care that Steven needs on a daily basis. Because of Steven's severe brain injury, incurred in 2005 while serving in Iraq, I have not returned to my employment as a high school teacher. While this has allowed Steven the benefits of being cared for at home rather than in a long-term care facility, it has been a financial hardship to our family, and has diminished my retirement benefits. The implementation of the caregiver assistance program has brought both joys and concerns. The joys are that the program is up and running, the application process was easy and well advertised, and each VA has a point of contact for caregivers. As one mom of a veteran 8 years post injury said, "Out of all the applications, assessments, programs we have been involved with in the past 8 years, this was the easiest, least stressful for us to date." I have several concerns, though. Given that many caregivers have left the workforce, I'm particularly concerned about VA's implementation of the stipend. VA's methodology to determine the number of hours of caregiver assistance required for purposes of a monthly stipend payment is very flawed. VA has also set an artificial cap that limits a stipend to a maximum of 40 hours per week. This is concerning for the many caregivers who provide nearly round-the-clock care. I also see evidence of disparity between VA facilities and how provisions for CHAMPVA services are administered. Like many other caregivers, I've also been concerned about the limited access to information on how clinical decisions regarding the program are made as well as a dearth of information on how to appeal any determination under the program—whether it is a question of basic eligibility or a VA determination that a veteran only needs a very limited number of hours of caregiving per week.

#### **Life Before and After Injury**

But first I want to share with you some background information about my son and his injuries. My son, Steven K. Schulz, was injured April 19, 2005 in Fallujah, Iraq, when an improvised explosive device went off outside the Humvee in which he was riding. He was 20 years old, unmarried, and my oldest son. The resulting traumatic brain injury was severe and life-altering. We have been on a bumpy road of recovery for the last 6-plus years. I say "we," because it has been a family effort to assure that Steven has gotten the supports and treatment he needed. I hope that explaining the gravity of his injuries will illustrate how critical the proper implementation of this important law is, not just for Steven Schulz but for many, many other veterans and their families whose lives have been turned upside down after sustaining severe injuries.

Steven's brain injury has left him with many physical and cognitive deficits. He has profound weakness on his left side, with no functional use of his left arm. He walks slowly and with assistance of a service dog, cane, or person. He cannot sus-

tain walking longer than three blocks, over lawns or uneven terrain, if multiple flights of stairs are encountered, or in very busy environments. He is blind in his right eye due to shrapnel, and his brain does not perceive the left field of vision (hemionopsia). This leaves him with a very narrow visual field and monovision. Steven uses a wheelchair for long distances and when he is not wearing his adaptive equipment at home, but because of the profound weakness of his left side, moving in a wheelchair is very slow and inefficient, and assistance is required. Because of his vision deficits, he is not a candidate for a motorized wheelchair.

Steven's thinking is slower, his thought process takes longer and initiating and sustaining conversation or ideas is difficult. Due to his frontal lobe damage, his impulse control, although much improved since immediately after injury, often causes him to say aloud any thoughts or ideas prior to filtering, even if the thought is mean, insensitive, or vulgar. His affect is often very flat and without expression, and he has difficulty interpreting social cues. His speech is difficult to understand as he talks rapidly and does not enunciate very well. Steven's attention span is very short. Although it has improved over the years, he still cannot attend to a 30-minute television show. Steven can read, but no longer enjoys it. He has some memory problems. The ability to initiate activities was severely altered. Because of this initiation problem, Steven has to be guided through most all activities of daily life. Without the ability to think, "what do I do next," being left alone is very problematic. Steven does not feel comfortable being left alone more than 30 minutes.

What about the future? Since very early in his rehabilitation, Steven has told his therapist that he wants the normal things, "a wife, children, and to drive a car." He now accepts that he will likely never drive a car because of his visual deficits, but he is still looking for that wife. We have seen marked improvements from the early injury, but we are realistic about the dream of returning to his pre-injury self.

How has my life changed? Prior to his injury on April 19, 2005, I worked as a special education teacher at Friendswood High School. Before I started teaching, I had worked as a psychiatric social worker for 9 years for the State of Texas. Both of these careers prepared me for some of the realities of traumatic brain injury, but not the realities of becoming a caregiver. My husband, 51 and I, 49, were preparing to become "empty nesters," were sprucing up our house, and generally doing well when the blast occurred. TBI affects the whole family for a very long time, most likely a lifetime. My daughter, Elaine, was 18 years old, in her first year of college, and my youngest son, Clay, was 15 years old, a sophomore in high school when that bomb blasted. This type of injury changes a family. They went from typical teens to mature beyond-their-years young adults. I became Steven's primary caregiver, advocate, life skills coach, chauffer, secretary, bookkeeper, teacher, drill instructor, medical assistant, physical/occupational/speech therapist and his mom. That blast changed the fabric of our family.

### **My Experience with the Caregiver Assistance Implementation**

I applied for the Caregiver Program on May 9th, the first day it was available. I was called by Steven's social worker at the Houston VA and reminded that the program was accepting applications, and had seen reminders on many social network sites, and in some veteran related media. Getting the application online was easy and equally easy to complete. I faxed the application to make sure it arrived promptly. As I was filling out the application I knew that my health insurance was being terminated, but I didn't have a firm date. When I asked the social worker if I should indicate that I have insurance or instead explain that it was being terminated. I was instructed that I could not apply for CHAMPVA unless I was without insurance. The CHAMPVA document I received clearly stated that you are not eligible for CHAMPVA if you have access to insurance through COBRA. That alarmed me since I could theoretically obtain COBRA coverage, but the astronomical cost would make eating unaffordable.

Within several days of applying for the caregiver program, I received a phone call saying the application had been received and the next step was to complete a training program, and then a home visit. The only training available to me at that time was a home-based workbook, which was fine with me, because frankly, after care giving for 6 years the thought of sitting for 2 days hearing things I had already been taught was not appealing. The workbook was fine, but again a redundancy and somewhat insulting to have to complete. I would strongly suggest that future applicants be "grandfathered" as trained if they have been caregivers for several years. Let me acknowledge, though, that one of my fellow caregivers (7 years post-injury) went to the classroom training and very much enjoyed meeting fellow caregivers.

On May 15, I received notice that my health insurance had been terminated effective April 30, 2011. I notified the social worker and she had me fax the termination letter to her and she forwarded it to the application center. The disturbing implica-

tion here is that I was led to believe that I was not eligible for CHAMPVA until I had a lapse in coverage.

The most disturbing aspect of the whole process was the home visit. The RN sent to assess our home did not even know who the veteran was. When I introduced myself to the RN and told him Steven was not yet home as he had gone out with his brother and would be back shortly, the RN asked, "Steven is your caregiver?" The RN clearly had not read any medical records pertaining to this home visit. Later in the interview, he went on to lecture me about how I must take care of myself, but offered no solutions aside from asking my family to "relieve me of my burden." The home assessment made sure we had smoke detectors, that I knew about infection control, that I knew about nutrition and meal preparation, and that I had been instructed in the proper care of a catheter. Steven had not had a catheter since his earliest hospitalization, and never as an outpatient. This kind of inept assessing did not inspire confidence. My understanding was that the home visit was to assess both veteran and caregiver for needs. That was certainly not accomplished during that visit.

About a week later, I received verbal confirmation that I was approved for the program with no other details available at that time. This lack of detail was upsetting, because I had no way of knowing how the determination had been made, if it was accurate, or if I had recourse to appeal the decision if it was adverse in any way. I certainly did not know who had made the decision. I was hopeful that the evaluation and determinations had been made by Steven's treatment team who has worked with him over the last 6 years, as they have a fairly clear idea of his needs. July 1st I received my CHAMPVA card and booklet. July 5th I received my first stipend check. As of this writing I have not received written notice of how many hours were deemed appropriate. Guessing by the stipend amount, Steven was in the upper tier, but the fact that I have to guess, when others have been provided that information, illustrates the lack of consistent information provided from one VA medical center to another.

### Concerns

When Steven first came home from the hospital, he needed 24/7 care. Not because he was on a ventilator, had a feeding tube, or was unable to move or speak, but because his thinking was so confused that he forgot his leg was not working, or he could not figure out what to do. He needed assistance to use the bathroom every 2 hours around the clock for the first year. I share this with you because setting an artificial cap of 40 hours per week assumes that the caregiver actually stops providing needed care because 40 hours has been reached. Luckily for us, we trained Steven's bladder and brain to "sleep through the night" again. But that is just one example of why, the VA must address that often times 40 hours is not enough for the veteran. For veterans who do have ventilators, feeding tubes, or cannot move or speak, they still must be attended to throughout the night. Their issues will not learn to sleep through the night. For those caregivers, I ask that their struggle be properly quantified by the VA and the caregiver assistance program.

Social media has been a wonderful avenue for veterans and caregivers to connect with others and alleviate their social isolation and share information about benefits, programs, and ways to navigate the systems of DoD/VA/TRICARE. Because of all this sharing, the disparities between how programs are administered often become very apparent. VA programs have been rife with regional disparities of how services are delivered. I would like to say that this new program is free of such disparities but that is not the case. Already, within our VISN I can report one caregiver received a full documentation as to the stipend she would receive; her secondary caregivers were interviewed and given ID cards. I have not gotten such documentation and the secondary caregiver I put on the application has not had any VA notification at all. These are small items, but within a 200-mile radius, vastly different experiences. The biggest disparities seem to be in how veterans are rated to quantify how many hours will be assigned to a caregiver. One example, a veteran with the same injury as Steven, a severe TBI, but he made a better physical recovery, can walk further with a cane, has better balance, can drive locally, but has PTSD issues on top of TBI cognitive issues. He was allowed 10 hours of caregiving a week. How can 2 hours a day Monday thru Friday be enough time for this veteran? Never mind the weekend when oversight and care is still needed. For veterans with "safety and supervision needs" 10 hours cannot be appropriate.

With finances an ongoing struggle, I'm of course very happy and relieved to be receiving a stipend. It will make an enormous difference. But I am concerned about other caregivers. The VA's methodology for determining roughly how much care a veteran needs is crude at best. In our case, it resulted in "scoring" Steven's needs at a relatively high level. But, I believe, that this is because he needs assistance

with respect to *both* physical limitations as well as cognitive and behavioral challenges. Since VA's scoring methodology calls for aggregating each different impairment, his "score" would generally be higher than for another veteran with TBI who is limited "only" in a few cognitive and behavioral domains. The fallacy in this methodology is that a veteran with TBI whose extreme lack of judgment, for example, makes him a safety-risk is not simply a safety-risk for 10 hours a week. Caregiver-friends of mine in this situation must be almost constantly at the veteran's side. Yet the way in which the VA regulation calls for determining the extent of needed-caregiving, for purposes of determining the amount of the caregiver stipend, fails to recognize that the potentially overwhelming nature of a traumatic brain injury, for example, may require full-time caregiving whether or not it manifests itself in many different kinds of limitation or impairment.

One dear friend, Cheryl Lynch, founder of American Veteran's with Brain Injuries, and a mother of a veteran with TBI proposes a simple, yet brilliant way of solving the issues of stipend calculations: differentiate between "some of the time," "most of the time" and "all of the time." Apply these terms to the veteran, do they need help/oversight some of the time, most of the time, or all of the time? Develop a check list around the ADL's (activities of daily living) and IADL's (independent activities of daily living), and answer the question, "does the veteran need assistance in this area some of the time, most of the times, or all of the time." "Some of the time" would be someone who can get dressed and do many of his tasks on his own, yet needs to have 'someone' available for oversight and in case things go wrong. "Most of the time" would be someone like Steven who without oversight cannot function day to day. "All of the time" would be someone who without the help of others cannot function hour to hour. I also think that there is room to have spaces in between so the veteran would be moved to the higher rating because of specifics, like seizures, suicide risks, safety, etc. A rating like this would also eliminate the artificial setting of an hourly rate. The need for flexibility in ratings is crucial, because veterans with TBI, PTSD, or mental health issues may have flare-ups in their conditions resulting in decreased abilities. Right now there does not seem to be consistent application as to why VA considers any particular veteran to need 10 vs. 25 vs. 40 hours of caregiving, and that is a BIG problem.

In closing, let me thank you on behalf of my family and other caregivers across the country for your sincere efforts to make this program a success. The problems I've highlighted can be solved. Doing so will not only strengthen this important program, but improve the well-being of our wounded warriors.

Thank you for the privilege of testifying. I would be happy to answer any questions you might have.

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**Prepared Statement of Anna Frese, Director, Warrior Support Program,  
Wounded Warrior Project**

Chairman Buerkle, Ranking Member Michaud, and Members of the Subcommittee,

Thank you for inviting Wounded Warrior Project to testify today regarding the implementation of the caregiver assistance program. The program's success is important to me not only as the Director of Wounded Warrior Project's (WWP) Family Support Program and liaison to our family caregivers, but also as a long time advocate for my brother Eric whose injuries in Iraq led to his need for round-the-clock care due to severe brain injury.

While caring for severely wounded 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.

Let me acknowledge the critically important role this Committee has played—not only in shaping the caregiver law—but in jump-starting and accelerating a process that in the last weeks began providing long-awaited help to numbers of families. We are equally grateful for your insistence that VA's plan complies fully with the law.

I was honored to appear before this Committee at a hearing in June 2009 on "Meeting the Needs of Family Caregivers of Veterans" and explain how drastically our family's life was changed by my brother's injuries and his total-care needs. My parents are one of the many families who have hoped for years for the establishment of a caregiver-support program. As the program has been implemented, however, they experienced some real ambivalence.

My family's experience is telling. They did not apply immediately as others had, but delayed because of concerns about one rigid aspect of the VA program. VA requires home visits every 3 months to monitor the veteran's well-being. In my family's case, however, a VA-provided speech therapist works with Eric twice weekly in the home. With those visits and Eric's seeing his VA primary care physician and three other VA-provided physicians routinely every 2 to 3 months, VA is certainly able to confirm his well-being. My family questioned the need under the circumstances for additional home visits by new staff who don't know Eric or the family. Ultimately, they did finally apply but the home-visit issue frankly still rankles. Their application is still in process.

Overall, I know 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. I have worked with many others who are still in limbo, waiting for applications to be processed and unsure of what comes next.

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

#### *Eligibility Criteria and Mental Health*

As you know, traumatic brain injury and PTSD are the signature wounds of this war. Many of the problems I hear about regarding VA's implementation are from wives and moms 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. Each case differs. But often, the warrior lacks full cognition or judgment to be fully aware of danger. In other instances, a warrior's behavior may be erratic, may be marked by lack of impulse-control, or might 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. But in instances where that same safety risk or other similar problem is due to PTSD, depression or anxiety, 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 I've 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, for example.

#### *Clinical Determinations*

A second area of concern is how VA's eligibility criteria are being applied at medical centers around the country. WWP recently conducted a survey to understand the experience of families who have applied for assistance under the new 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 is not only occurring between VA and veterans and their caregivers, but also between VA Central Office and the field.

Let me share one example. For the past several years, a caregiver has provided almost constant care and supervision for her husband who suffers from PTSD, traumatic brain injury, and persistent short-term memory stemming from injuries. The caregiver submitted an application for caregiver assistance when it became available on May 9th and was contacted for the first time by a nurse practitioner on May 20th 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 VAMC 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. Let me quote:

*"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 implementing regulation is completely silent on this important issue. Yet it is essential that VA establish systematic recourse for those caregivers and wounded warriors who may be unduly denied benefits. Initial 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.

#### *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 of illustrations may be helpful. Take the case of a veteran who sustained a severe traumatic brain injury 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 buddies 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 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 me 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 revises 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 traumatic brain injury, 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 traumatic brain injury 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 wounded warriors' needs rarely conform to a 9-5 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.

#### *Program strengths and weaknesses*

While WWP believes that VA must make changes to its final regulation (and submitted extensive recommendations on July 5th in response to VA's *Federal Register*



notice regarding its VA's interim final rule), we also recognize the progress VA has made over the past several months 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. VA did make training accessible to caregivers by providing the option of using a self-guided workbook. This tool offered an easy approach to clearing a requirement. But the workbook was simplistic, and for those seeking more specialized instruction it was disappointing. It would be helpful in the future for VA to ascertain early-on what individual training needs a caregiver-applicant has, and tailor training to meet those needs.

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 since releasing the initial implementation plan, 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.

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**Prepared Statement of Deborah Amdur, LCSW, ACSW, Chief Consultant,  
Care Management and Social Work Service  
Veterans Health Administration, U.S. Department of Veterans Affairs**

Chairwoman Buerkle, Ranking Member Michaud, and distinguished Members of the Committee, thank you for the opportunity to discuss the progress the Department of Veterans Affairs (VA) has made in implementing the provisions of title I of Public Law 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010 (the Act).

When we appeared before you in March, we provided an update on VA's Implementation Plan for this program and our expected way ahead. We heard the concerns you and the Veterans Service Organizations raised about the eligibility criteria we were considering, and we worked to revise the criteria to include a broader population of veterans.

We are pleased to report that the Family Caregiver program is fully operational and that primary family caregivers have begun receiving stipend payments for the support they are providing to veterans. On May 5, 2011, VA published an Interim Final Rule (IFR), which implemented the Family Caregiver Program of the Caregivers and Veterans Omnibus Health Services Act of 2010. The public comment period for the IFR closed on July 5, 2011, and we are reviewing the comments we received to determine if any changes to the IFR are necessary. Our final rule will either continue the program as implemented in the IFR or revise it based upon our consideration of the comments.

My testimony today will discuss the eligibility criteria VA is using for this program under the IFR; the training and application process, as well as an update on our progress in these areas to date; and other benefits and programs VA is offering and will be offering to caregivers of veterans.

***Eligibility Criteria***

Under the statutory and regulatory program now in effect, to be eligible for benefits under the Family Caregiver program, Veterans must have incurred or aggravated a serious injury (including traumatic brain injury, psychological trauma, or other mental disorder) in the line of duty on or after September 11, 2001. These veterans must also be in need of personal care services because of an inability to perform one or more activities of daily living (i.e., bathing, eating, dressing, toileting), or require supervision or protection based on symptoms or residuals of neurological impairment or injury. Servicemembers who are undergoing medical discharge with an identified date of discharge are also eligible for support under this program. Servicemembers and veterans must require the assistance of a caregiver

for a period of at least 6 months to qualify. Veterans cannot receive simultaneous personal care services from another party; for example, a veteran could not receive home-health-aide services 24 hours a day, 7 days a week and receive support through the Family Caregiver program. Veterans must agree to receive care from a VA-designated primary care team so that the VA can appropriately support these veterans and family caregivers. After conducting a thorough analysis of VA's records and assessing the current veteran population, VA estimates that approximately 3,600 veterans and servicemembers may be eligible for benefits under the Family Caregiver program.

VA also included specific criteria in the IFR to ensure veterans with a traumatic brain injury or neurological impairment would be eligible to receive benefits. These criteria include a need of supervision or assistance because of seizures, difficulty planning or organizing information, deficits in sleep regulation, delusions or hallucinations, memory deficits, or problems with mood regulation, such as agitation or aggression.

### ***Processing Applications and Training Caregivers***

VA began accepting applications for the new Family Caregiver program on May 9, 2011. During the first week, we assisted more than 625 veterans, servicemembers and family members in applying for new benefits under the program. Through June 29, 2011, VA has 1,259 applications in process and had approved stipends for 182 veterans. As of July 8, VA had processed 176 stipend payments totaling over \$430,000 for primary family caregivers; this includes stipend payments for the support these caregivers have provided since May 9, 2011. The tracking device VA developed to monitor pending applications allows us to pinpoint where any application is in the process and to identify geographic or demographic trends. Based on the limited data available, Family caregivers are overwhelmingly women (92 percent), spouses (67 percent), and between 26 and 64 years old (45 percent between 26–40, and 43 percent between 41–64). The 10 facilities with the highest number of applications in process are Fayetteville, NC; Dallas, TX; Jackson, MS; Durham, NC; Puget Sound, WA; Augusta, GA; Orlando, FL; Houston, TX; San Antonio, TX; and Washington, DC.

We have been working through the local Caregiver Support Coordinators to reach out to eligible veterans and servicemembers in the community to encourage them to apply. Post 9–11 veterans currently receiving VA's Aid and Attendance benefit due to injury in the line of duty have been contacted and encouraged to apply for the new caregiver program. Veterans and family members must submit a joint application, which can be accomplished in person, by mail, by phone (1–877–222–VETS [8387]) or online ([www.caregiver.va.gov](http://www.caregiver.va.gov)). Additional support and information is also available through the National Caregiver Support Line (1–855–260–3274). Within three business days of having received an initial application, the Caregiver Support Coordinator, at the veteran's preferred VA medical center, will contact the veteran and the primary family caregiver to assist with completing the application process and schedule required training. This training is necessary before any additional benefits can be provided to the primary family caregiver. VA has partnered with Easter Seals to provide comprehensive Caregiver Training to family caregivers of eligible post-9/11 veterans as authorized by the law. Easter Seals brings more than 90 years of experience in helping people with disabilities and special needs, and we are very pleased to partner with such a renowned organization.

Training may be completed in any of three ways: by attending a family caregiver training session conducted at a local VA medical center or community location; by self-study using a workbook and DVD that is mailed to the family caregiver(s); or by completing the training online; the online training will be available by July 15, 2011.

More than 450 family caregivers have completed their training since the beginning of June, and we continue to train more caregivers every day so they can better support their loved one and begin receiving the benefits included in the law.

Once the family caregiver training is complete, a VA clinician will visit the veteran's home. This visit is designed to ensure that the primary family caregiver and veteran have everything they need to be successful in the home setting. Our clinicians are trained to do this in a supportive and encouraging manner. One family caregiver described this home visit as follows: "All in all, the home visit was as painless as the rest of the process, and in fact it was comforting to have someone in my home to see what else I could do to help my husband . . ."

Once the home visit is complete, the primary family caregiver will begin receiving a monthly stipend based on the veteran's level of need. The primary family caregiver may also be eligible for health insurance through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA), provided that

the primary family caregiver is not already entitled to care or services under a health plan contract. VA is making the stipend and health insurance benefits retroactive to the date of initial application. Our expectation is that the entire process, from initial application to the delivery of benefits, will be complete within 30 days.

We will continue to conduct well-being visits every 90 days or as clinically indicated. These visits, like the initial home visit, will be performed in a supportive manner. The visits are designed to evaluate the veteran's and the primary family caregiver's physical and emotional state. VA clinicians conducting these visits may make recommendations for additional training, support, equipment or other services in the best interest of the veteran.

#### ***Other Benefits and Programs***

In addition to the benefits specific to the primary family caregiver of veterans (the stipend, health care coverage through CHAMPVA, mental health services, and at least 30 days of respite care), VA offers a number of benefits and services to all caregivers of veterans. VA's National Caregiver Support Line, mentioned briefly above, has responded to more than 9,000 calls from veterans and family members since it was activated in February 2011. This Support Line, staffed by clinical social workers, provides immediate and highly responsive access to information for caregivers, and can help coordinate local support through the Caregiver Support Coordinator at each VA medical center. These Coordinators are able to offer additional assistance by connecting veterans and family members with both VA and non-VA resources. Since April 1, 2011, every VA medical center has had a full time dedicated Caregiver Support Coordinator in place.

VA's home-based care programs are well-established and have been supporting veterans in the community for many years. Home-based primary care is a unique program that provides comprehensive long-term primary care through an interdisciplinary team that visits the homes of veterans with complex, chronic disabling diseases or injuries for which routine clinic-based care is ineffective. Another recent initiative is the Veteran-Directed Home and Community-Based Care program, which provides veterans of all eras the opportunity to receive services in a veteran-centered manner that allows them to avoid institutional placement while continuing to live in their homes and communities. VA operates this program in collaboration with the Administration on Aging under the Department of Health and Human Services.

Veterans and their caregivers who are in need of close monitoring of vital signs or frequent communication with a health care team can benefit from home telehealth services. Telehealth offers the possibility of treating chronic conditions cost effectively while contributing to patient satisfaction.

General education and training are also available to all caregivers. VA routinely offers in-person educational support for caregivers of veterans undergoing discharge from an inpatient stay at a VA facility and teaches techniques, strategies, and skills for caring for a disabled veteran. We offer instruction and specialized training in several specialty areas, such as traumatic brain injury, spinal cord injuries or disorders, and blind rehabilitation. The Caregiver Support Program has provided multiple national education and training to VA staff throughout the country and to a wide range of Federal, State and local organizations.

Our respite care programs are available to any caregiver of a veteran. All veterans are eligible for 30 days of respite care per year, and this respite care can be provided at home or in an institution. Respite care provides the caregivers of veterans with a needed break to relieve the demands of caring for a chronically ill, injured, or disabled family member, and to prevent caregiver burnout. In fiscal year 2010, more than 12,000 veterans and caregivers received respite care through VA. More than 7,500 of these veterans received respite care in home, and more than 4,700 received care in a nursing home at VA expense. Adult Day Health Care Centers also provide respite care in a safe environment with constant supervision.

VA launched a new Web site on May 31, 2011, [www.caregiver.va.gov](http://www.caregiver.va.gov), which provides a wealth of information and resources for veterans, families and the general public. The Web site has had over 63,000 hits, totaling over 400,000 pages viewed since its launch. This site provides information on local and national resources, common veteran conditions, caregiver self-care, and other topics identified as important by caregivers.

Evidence-based support programs and a peer-support mentoring program are in development and will be rolled out over the next 12 months to provide further assistance to the family caregivers of veterans.

### **Conclusion**

Although we have only recently initiated this program, we have received a great deal of positive feedback from veterans and their caregivers on the services we are delivering and the support VA professionals in the field are providing. For example, one caregiver described the application and evaluation part of the program by saying, "The process has been incredibly painless and very quick, which has been a huge breath of fresh air . . ." We know there is room for continued improvement, and we appreciate the opportunity to hear from you and the other witnesses at today's hearing to determine how we can make this program even better. Thank you for inviting me here to testify today to do that. I am prepared to answer your questions at this time.

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### **Prepared Statement of Adrian Atizado, Assistant National Legislative Director, Disabled American Veterans**

Madame Chairwoman and Members of the Subcommittee:

On behalf of the more than 1.2 million members of the Disabled American Veterans (DAV) and its Auxiliary, thank you for inviting our organization to submit testimony for this important oversight hearing on the Department of Veterans Affairs (VA) proposed interim final rule (IFR) to implement title I of the Caregivers and Veterans Omnibus Health Services Act of 2010, Public Law (P.L.) 111–163.

As you may be aware, DAV submitted comments to the IFR and it is with sincere appreciation that we have this opportunity to share our comments, concerns, and recommendations. We believe VA's effort in proposing rules to implement a national caregiver support program is commendable. Nonetheless, we believe the program as proposed will fall short of its Congressional mandate without a number of significant changes.

Based on VA's advances in medicine, health technology, expansion of home care and the Department's push to provide the highest quality of care to veterans in the least restrictive setting to achieve rehabilitation, recovery, and community reintegration, today's VA health care and the delivery of such care have shifted the burden, cost, and responsibility for some levels and types of care onto sick and disabled veterans, their families and other loved ones.

Without proper training and support, family caregivers and veterans receiving care from family caregivers can incur greater emotional, physical, and financial strain. Families have been brought to the verge of bankruptcy and ruin. Such adverse impacts would affect the quality of care and quality of life of caregivers and care recipients, as well as other family members and loved ones. We believe a strong and flexible VA family caregiver program can provide caregivers the support they need and allow veterans to remain in their own homes—a much healthier outcome for the victims of war, their families, and for VA as well.

We urge this Subcommittee to continue its strong oversight of this critical program and to ensure VA meets two required reports to be submitted to the House and Senate Veterans' Affairs Committees not later than 2 years after the effective date (January 30, 2013) on a comprehensive annual evaluation on implementation and on the feasibility and advisability of expanding caregiver assistance under title 38, United States Code (U.S.C.), §1720G(a) to caregivers of veterans seriously injured in the line of duty prior to September 11, 2001. In addition, we urge Congress to provide sufficient program funding to help make this program a success.

#### **Effective date of benefits provided under 38 U.S.C. § 1720G**

We note that public comments have been submitted to VA on the issue of effective date for benefits provided under 38 U.S.C. §1720G. We believe Section 101(a)(3) of P.L. 111–163 is pertinent and provides that the amendments made by this subsection shall take effect on the date that is 270 days after the date of the enactment of this Act (January 30, 2011).

VA proposes the effective date of its rule is May 5, 2011. (76 Fed. Reg. at 26148). The Department provides further clarification under 38 CFR 17.40(d), "[C]aregiver benefits are effective as of the date that the signed joint application is received by VA or the date on which the eligible veteran begins receiving care at home, whichever is later. However, benefits will not be provided until the individual is designated as a family caregiver." Additionally, "[T]he stipend . . . due prior to such designation, based on the date of application, will be paid retroactive to the date that the joint application is received by VA or the date on which the eligible veteran begins receiving care at home, whichever is later."

In statutory interpretation, if "the plain meaning of a statute is discernable, that 'plain meaning must be given effect.'" *Johnson v. Brown*, 9 Vet.App. 369, 371 (1996)

(quoting *Tallman v. Brown*, 7 Vet.App. 453, 460 (1995)); see also *Brown v. Gardner*, 513 U.S. 115, 119 (1994). “Determining a statute’s plain meaning requires examining the specific language at issue and the overall structure of the statute.” *Gardner v. Derwinski*, 1 Vet.App. 584, 586 (1991) (citing *Bethesda Hosp. Ass’n v. Bowen*, 485 U.S. 399, 403–05 (1988)), *aff’d sub nom. Gardner v. Brown*, 5 F.3d 1456 (Fed.Cir. 1993), *aff’d*, 513 U.S. 115 (1994). Because the plain reading of the P.L. 111–163 is unambiguous, we believe the effective date of benefits provided under 38 U.S.C. § 1720G should be January 30, 2011.

#### **Eligibility requirements for the family caregiver program**

VA proposes a veteran or servicemember be eligible for benefits and services provided under 38 U.S.C. § 1720G(a) if the individual meets requirements under 38 U.S.C. § 1720G(a)(2)(A) and (B), and *all three* elements under (C). However, the law clearly defines an eligible individual as one that meets requirements under 38 U.S.C. § 1720G(a)(2)(A) and (B), and *only one of the three* elements under (C).

Under 38 U.S.C. § 1720G(a)(2), to be eligible for a program of comprehensive assistance for their family caregivers, an individual must: (A) Be a veteran or member of the Armed Forces undergoing medical discharge from the Armed Forces, and; (B) have a serious injury (including traumatic brain injury, psychological trauma, or other mental disorder) incurred or aggravated in the line of duty in the active military, naval, or air service on or after September 11, 2001. In addition, the individual must be in need of personal care services because of *one of the following*: (i) An inability to perform one or more activities of daily living; (ii) A need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury; or (iii) Such other matters as the Secretary considers appropriate.

VA on the other hand, proposes to define an eligible veteran for the family caregiver program under 38 U.S.C. § 1720G(a)(1), to mean a veteran or servicemember who is determined to be eligible for a Primary and Secondary family caregiver. VA provides further clarification that to be eligible for a Primary and Secondary family caregiver under this rule, VA proposes the veteran or servicemember meet all requirements under 38 CFR § 71.20 (a) through (g).

DAV disagrees strongly with this proposal. In requiring a veteran or servicemember to meet all of the conditions under 38 CFR § 71.20, VA’s proposal goes beyond the plain reading of the law and imposes a more restrictive criteria that will result in fewer veterans in urgent need being deemed eligible for the benefits of the law. This proposed stricture will serve to deny benefits to deserving veterans.

We strongly recommend VA revise its proposed definition of an “eligible veteran” for the purposes of this benefit, and accordingly to revise its proposed eligibility criteria.

In addition, we voiced our concern that VA’s interpretation of the proposed definition in individual cases may mean a veteran with a *serious illness* other than those specifically listed may be excluded from eligibility for family caregiver benefits, even if he or she meets all other requirements as proposed in the IFR. Such an outcome would be inequitable and not in keeping with the intent of Congress in enacting this benefit for those who nearly gave the ultimate sacrifice in combat deployments, training accidents and in contracting serious diseases in the line of duty or while performing military duty.

Veterans and servicemembers this program was intended to benefit have been and continue to be described as those who are, “wounded, ill, and injured.” From the recently established programs within the Department of Defense (DoD), such as the Recovery Coordination Program (RCP), established by Section 1611 of the fiscal year 2008 National Defense Authorization Act, to the VA Federal Recovery Coordination Program (FRCP), wounded, *ill* or injured servicemembers, and their families have been the target population to provide comprehensive assistance.

We also believe Congress intended this program for those veterans and servicemembers who are “seriously ill.” The Joint Explanatory Statement of P.L. 111–163 states, “[T]he Compromise Agreement also includes an authorization for appropriations that is below the estimate furnished by the Congressional Budget Office. The lower authorization level is based on information contained in a publication (*Economic Impact on Caregivers of the Seriously Wounded, Ill, and Injured*, April 2009) of the Center for Naval Analyses (CNA).” This report was written “[t]o estimate the economic impact on caregivers of the seriously wounded, ill, and injured (WII),” at the request of the Principal Deputy Assistant Secretary of the Air Force for Manpower and Reserve Affairs who was tasked by the Joint DoD/VA Wounded, Ill, and Injured Senior Oversight Committee.

Subsequent to the passing of P.L. 111–163, VA’s press release dated February 9, 2011, (New and Enhanced VA Benefits Provided to Caregivers of Veterans), which quotes Secretary of Veterans Affairs Eric K. Shinseki declaring, “[c]aregivers make

tremendous sacrifices every day to help veterans of all eras who served this Nation ... They are critical partners with VA in the recovery and comfort of *ill* and injured veterans, and they deserve our continued training, support and gratitude.” (Emphasis added.)

Furthermore, VA’s June 4, 2009, testimony before the House Veterans’ Affairs Subcommittee on Health, discussing the Department’s programs and support of family caregivers states, “[c]aregivers deliver essential services to seriously injured veterans and servicemembers and VA continues to support these compassionate providers as they help our wounded, *ill* and injured heroes regain and maintain health.”

Accordingly, we recommend VA adding the term “seriously ill” as considered under 38 U.S.C. § 1720G(a)(2)(B) and accordingly to revise its proposed eligibility criteria.

**Definition of “in the best interest” of the veteran or servicemember**

In citing 38 U.S.C. § 7120G(a)(1)(B), (“[T]he Secretary shall only provide support under the program required by subparagraph (A) to a family caregiver of an eligible veteran if the Secretary determines it is in the best interest of the eligible veteran to do so.”), VA proposes the following:

[I]n the best interest means, for the purpose of determining whether it is in the best interest of the eligible veteran to participate in the Family Caregiver program under 38 U.S.C. 1720G(a), a clinical determination that participation in such program is likely to be beneficial to the eligible veteran. Such determination will include consideration, by a clinician, of whether participation in the program significantly enhances the eligible veteran’s ability to live safely in a home setting, supports the eligible veteran’s potential progress in rehabilitation, if such potential exists, and creates an environment that supports the health and well-being of the eligible veteran.

38 CFR § 71.15. We read this proposal to mean the “in the best interest” test includes that the following criteria must be met: (1) Participation in the program *significantly enhances* the eligible veteran’s ability to live safely in a home setting; (2) Participation in the program supports the eligible veteran’s potential progress in rehabilitation, if such potential exists; and (3) Participation in the program creates an environment that supports the health and well-being of the eligible veteran.” (Emphasis added.) (38 CFR § 71.15)

DAV takes no issue with the proposed criteria 2 and 3. However, we take issue with the proposed criteria. 1. First, the “significantly enhances” criterion is ill-defined. The discussion on this criterion in the IFR and the proposed regulation does not provide for, or define, a measurement system or scale to express the degree to which the “significantly enhances” standard is or is not met.

Second, the goal of this program is, “[t]o ensure the veteran is able to live in a residential setting without unnecessary deterioration of his or her disability, and safe from potential abuse or neglect.” 76 Fed. Reg. at 26148. (See also the Joint Explanatory Statement of P.L. 111–163, “[T]he overall caregiver support program for caregivers of eligible [Operation Enduring Freedom] or [Operation Iraqi Freedom] veterans would authorize VA to provide training and supportive services to family members and certain others who wish to care for a disabled veteran in the home and to allow veterans to receive the most appropriate level of care.”)

We believe criteria 2 and 3 subscribe to the aforementioned goal as described in the IFR based on certain terms such as “[s]upports the eligible veteran’s potential progress ... if such potential exists,” and “creates an environment that supports ...”

However, we believe criterion 1 proposes an unreasonable standard beyond the goal of the program. For example, comparing criterion 1, “[p]articipation in the program significantly enhances the eligible veteran’s ability to live safely in a home setting,” to the program’s goal “[t]o ensure that the situation [occurs in which a] veteran is able to live in a residential setting without unnecessary deterioration of his or her disability, and safe from potential abuse or neglect.” Criterion 1 is clearly a higher standard.

In addition, when determining whether benefits and services from VA’s medical benefits package will be provided to an eligible veteran, 38 CFR § 17.38(b) states:

“[C]are referred to in the ‘medical benefits package’ will be provided to individuals only if it is determined by appropriate health care professionals that the care is needed to promote, preserve, or restore the health of the individual and is in accord with generally accepted standards of medical practice.

- (1) *Promote health.* Care is deemed to promote health if the care will enhance the quality of life or daily functional level of the veteran, identify a predisposition for development of a condition or early onset of disease which can be partly or totally ameliorated by monitoring or early diagnosis and treatment, and prevent future disease.
- (2) *Preserve health.* Care is deemed to preserve health if the care will maintain the current quality of life or daily functional level of the veteran, prevent the progression of disease, cure disease, or extend life span.
- (3) *Restoring health.* Care is deemed to restore health if the care will restore the quality of life or daily functional level that has been lost due to illness or injury.”

We note VA does not impose any form of the “significantly enhances” criterion to provide care, yet it is a requisite consideration veterans and their family caregivers must meet in order to participate in these benefits. DAV believes this imposes an unnecessarily high standard and undue burden on the veteran, servicemember, and family caregivers of these individuals.

We recommend VA revise its proposed regulation to include a measurement system or scale to express the degree to which the “significantly enhances” standard is or is not met, or else remove the pertinent phrase entirely.

**“In the best interest” as a requirement for eligibility of a veteran or servicemember**

As previously mentioned, VA proposes that to be eligible for benefits under 38 U.S.C. § 1720G(a), a veteran or servicemember must meet all requirements under 38 CFR § 71.20, including subsection (d). (“[A] clinical determination has been made that it is *in the best interest* of the individual to participate in the program”) (Emphasis added). VA further clarifies and designates the “in the best interest” determination as a medical determination in citing 38 U.S.C. 1720G(a)(1)(B). (76 Fed. Reg. at 26149). (“[V]A concludes that determinations of ‘in the best interest’ must be clinical determinations.”).

DAV is concerned with VA’s proposed use of the “in the best interest” determination as an eligibility requirement and its designation as a clinical determination.

According to the language of the law, we believe the “in the best interest” determination is to be performed on an eligible veteran. (“[I]f the Secretary determines it is in the best interest of the *eligible* veteran...”.) (Emphasis added). Furthermore, the purpose of using the “in the best interest” determination is to satisfy a condition that would require VA to provide support under 38 U.S.C. § 1720G(a) to a family caregiver of a veteran or servicemember, and not for the purposes of determining eligibility of the veteran himself or herself for the benefit.

Regarding the designation of “in the best interest” determinations as clinical determinations, DAV notes the proposed regulation does not explicitly characterize the “in the best interest” determination to be a “medical determination.” However, we believe VA is at least strongly implying the phrase “clinical determination” as analogous to “medical determination,” according to 38 CFR § 20.101(b), which in turn may import implications for a veteran’s procedural and appellate rights in the case of an adverse decision.

Current regulations stipulate the Board of Veterans’ Appeals (BVA) jurisdiction over eligibility issues outlined under 38 CFR § 20.101(b):

[T]he Board’s appellate jurisdiction extends to questions of eligibility for hospitalization, outpatient treatment, and nursing home and domiciliary care; for devices such as prostheses, canes, wheelchairs, back braces, orthopedic shoes, and similar appliances; and for other benefits administered by the Veterans Health Administration.

However, because VA’s proposal makes eligibility determinations contingent upon a medical determination (presumably to be made by a Veterans Health Administration clinician), it is in conflict with 38 CFR § 20.101(b), which also states:

[M]edical determinations, such as determinations of the need for and appropriateness of specific types of medical care and treatment for an individual, are not adjudicative matters and are beyond the Board’s jurisdiction. Typical examples of these issues are whether a particular drug should be prescribed, whether a specific type of physiotherapy should be ordered, and similar judgmental treatment decisions with which an attending physician may be faced.

Congress broadly divested all Federal courts but the United States Court of Appeals for Veterans Claims (CAVC) and the United States Court of Appeals for the Federal Circuit of jurisdiction to review any “questions of law and fact necessary

to a decision by the Secretary under a law that affects the provision of benefits by the Secretary to veterans.” 38 U.S.C. 511(a).

The question of a veteran’s eligibility for benefits administered by the VA is subject to a question of law and fact necessary to a decision by the Secretary and is therefore subject to one review on appeal to the Secretary, where final decisions on such appeals shall be made by the BVA. (38 U.S.C. §§ 7104, 7105, 7108)

Based on VA’s proposed regulation, however, should an appeal be perfected based on a denial of eligibility due to a “medical determination,” it may preclude review by the BVA and thus obviate appellate review by CAVC. (38 CFR 20.101(b)). We believe such an outcome would be antithetical to the purposes of the act, and indeed, would not be in the best interest of the severely disabled veterans this law aims to serve.

**Proposed definition of “personal care services” and their use in calculating the amount of monthly stipend**

The law defines “personal care services” to mean, “[s]ervices that provide the veteran the . . . [a]ssistance with one or more independent activities of daily living [and] [a]ny other non-institutional extended care (as such term is used in section 1701(6)(E) of this title). 38 U.S.C. § 1720G(d)(4). 38 U.S.C. § 1701(6)(E) further provides, “[N]oninstitutional extended care services, *including* alternatives to institutional extended care that the Secretary may furnish directly, by contract, or through provision of case management by another provider or payer.” (Emphasis added).

VA proposes to define personal care services as, “[C]are or assistance of another person necessary in order to support the eligible veteran’s health and well-being, and perform personal functions required in everyday living ensuring the eligible veteran remains safe from hazards or dangers incident to his or her daily environment.” (38 CFR § 71.15).

DAV believes VA’s proposed definition is inadequate. In its discussion, VA limited the scope used to define the term “personal care services,” thus limiting its definition and other elements of the family caregiver program that are contingent upon its definition. These elements include identifying the personal care services required by the eligible veteran, education and training of family caregivers to meet those needs, and calculation of the monthly stipend.

VA indicates the statutory term “independent activity of daily living,” [d]oes not have a commonly understood usage or meaning,” and interprets the phrase to mean, “[p]ersonal functions required in everyday living to sustain health and well-being and keep oneself safe from hazards or dangers incident to one’s daily environment. (76 Fed. Reg. at 26149).

DAV agrees that “independent activity of daily living” is not a commonly used phrase; however, based on the context of the statute, the goal of this program, and VA health care programs and services that allow disabled veterans to remain in the community, we believe it is reasonable for VA to include in its proposed definition, services that provide the veteran assistance with Activities of Daily Living and Instrumental Activities of Daily Living.

“Activities of daily living” are defined as, “[e]veryday routines generally involving functional mobility and personal care, such as bathing, dressing, toileting, and meal preparation.” Stedman’s Medical Dictionary 30, 22 (28th ed. 2006). Instrumental Activities of Daily Living are defined as: “more complex and demanding activities of daily living required for more independent living[.] . . . includ[ing] using the telephone, traveling, shopping, preparing meals, doing housework, taking medications properly, and managing money.” Stedman’s Medical Dictionary 942, 1724 (28th ed. 2006).

Furthermore, to define “other non-institutional extended care (as such term is used in section 1701(6)(E) of this title),” VA cites 38 U.S.C. § 1701(6)(E) as the statutory authority for the Department to provide non-institutional extended care and states that it provides non-institutional care services to enrolled veterans (and as provided in 38 CFR 17.36(a)) through VA’s medical benefits package, which include but are not limited to “noninstitutional geriatric evaluation, noninstitutional adult day health care, and noninstitutional respite care.” 38 CFR § 17.38(a)(1)(xi)(B).

By using the phrase “[a]s such term is used in section . . . ,” DAV believes that the law is merely citing 38 U.S.C. § 1701(6)(E) to help define the term “non-institutional extended care” and that it does not preclude other statutory authority that allows the Department to provide non-institutional extended care and alternatives to institutional extended care.

Consider for example, 38 U.S.C. § 1710B(a)(5), which discusses other, “[n]oninstitutional alternatives to nursing home care as the Secretary may furnish as medical services under section 1701(10) of this title.” In addition, 38 U.S.C. § 1720C provides VA authority to provide “[N]oninstitutional alternatives to nursing



home care.” (“[T]he Secretary may furnish medical, rehabilitative, and health-related services in noninstitutional settings for veterans who are eligible under this chapter for, and are in need of, nursing home care.”).

Other statutory authorities that allow VA to provide home-based health care services include 38 U.S.C. § 1717. This section provides the authority for VA to provide home health services to an eligible veteran in any residential setting. (“[A]s part of medical services furnished to a veteran under section 1710(a) of this title, the Secretary may furnish such home health services as the Secretary finds to be necessary or appropriate for the effective and economical treatment of the veteran . . . The Secretary may furnish home health services to a veteran in any setting in which the veteran is residing”).

While section 1717 does not specifically state the authority provided is for non-institutional or alternatives to institutional extended care, VA has used this authority to provide home health services under HBPC (See VHA Handbook 1141.01, Home-Based Primary Care, at 1). HBPC is an interdisciplinary home health care program delivering primary care provided by an interdisciplinary health care team in the homes of veterans. The goals of this program include “[P]romoting the veteran’s maximum level of health and independence by providing comprehensive care and optimizing physical, cognitive, and psychosocial function,” and “[R]educing the need for, and providing an acceptable *alternative* to, hospitalization, *nursing home care*, emergency department and outpatient clinic visits, through longitudinal care that provides close monitoring, early intervention, and a therapeutic safe home environment.” (Emphasis added.)

Based on these laws and regulations, we look finally at VA’s fiscal year 2012 budget request, for which Congress has provided appropriations and which lists those extended care programs it has categorized as “non-institutional.” These services include VA, State, and Contract Adult Day Health Care, Home-Based Primary Care, Homemaker/Home Health Aide Programs, Spinal Cord Injury Home Care, Telehome Health, and “Other Home Based Programs.”

In its proposed definition for “personal care services,” VA does not mention consideration of services beyond those under 38 CFR §§ 17.36(a) and 17.38(a)(1)(xi)(B). Instead, VA proposes to “[c]linically rate the eligible veteran’s inability to perform each of the seven [Activities of Daily Living] . . . [and] . . . the eligible veteran’s need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury using the seven impairments listed in the definition of that term in [38 CFR] § 71.15.”

While we understand the assessment of need is required clinically and by law (to provide caregiver training and ongoing support in providing personal care services to the eligible veteran under 38 U.S.C. 1720G(a)(3)(A)(i)(I) and (II)), we believe it reasonable to infer Congress intended the personal care services reflect skilled and unskilled home care services VA currently provides. Neither VA’s proposed definition of personal care services nor the 14 categories of its assessment instrument reflect the plain reading of the law, which specifically “[m]eans *services provide[d] [to] the veteran.*” (Emphasis added).

In addition, DAV’s concern with VA’s proposal is four-fold. One, VA proposes to use a new 14-item instrument based on “[t]hree widely accepted clinical tools for measuring Activities of Daily Living and functional dependence . . . The Katz Basic Activities of Daily Living Scale (Katz ADL); the UK Functional Independence Measure and Functional Assessment Measure (FIM + FAM); and the Neuropsychiatric Inventory (NPI).” However, unlike VA’s 14-item assessment instrument, the Katz ADL, UK FIM + FAM, and the NPI have proven reliability (internal consistency/reproducibility), validity (construct and criterion validity), responsiveness as an outcome measure, *interpretability (provides clinically relevant event)*, and burden (cost and time to administer).

Two, VA proposes to evaluate the level of dependency with “[T]he sum of the zero-to-four scores assigned to each of the 14 categories . . . is then applied to a presumptive level of need: Eligible veterans who score 21 or higher . . . are presumed to need . . . 40 hours of care per week . . . an eligible veteran who scores 13 to 20 total . . . will be presumed to require 25 hours per week of caregiver assistance . . . [and] . . . an eligible veteran who scores 1 to 12 will be presumed to require 10 hours per week.” (76 Fed. Reg. at 26155). We note the validity and reliability of the Katz ADL instrument has been proven using a 2-, 3-, or 4-level scale, the UK FIM + FAM with a 7-level scale and the NPI uses a 6-level scale to measure “frequency” and a 3-point scale to measure “severity.” However, VA provides no discussion that using the Department’s proposed 5-level scale (0–4) for its new instrument will provide equivalent inter-rater reliability and validity as the three assessment instruments on which it is based.

Three, VA proposes to give equal weight to all scores and/or items when clinically evaluating the level of a veteran's dependency based on its 14-item instrument. It is particularly conspicuous that VA provided no discussion or evidence this particular proposal is clinically or scientifically valid especially when all 14 items are derived from three distinct assessment instruments that measure different domains.

Four, VA proposes to use, "[t]he sum of the zero-to-four scores assigned to each of the 14 categories ... to assign a presumed number of hours required of the caregiver," ostensibly, to meet the law's requirement that VA determine, "[t]he amount and degree of personal care services," the family caregiver provides the veteran. DAV is concerned that VA's proposed presumptions eliminate the flexibility afforded to the clinical team assigned to perform these assessments to determine how long and how often any one type of assistance or personal care service a patient would require, which can vary from one patient to another, to remain in their community of choice. This variability can be of such value as to change the level of benefits the caregiver may receive.

With the time burden of performing the Katz ADL instrument consisting of a short six-item rating scale, the time required to administer the FIM+FAM is approximately 35 minutes, and the NPI interview can be completed in 7 to 10 minutes. However, according to a 1994 article in *Neurology* titled, "The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia," a caregiver of a patient with more psychopathology will require longer interviews than the presumed 7 to 10 minutes.

Because it is not only the level of caregiver benefit affected by the final definition of personal care services as well as the determination of the amount and degree of such services, but also the family caregiver's responsibility to the veteran, we recommend VA use these three instruments and determine the actual personal care services the eligible veteran needs and those personal care services the family caregiver will be required to provide (VA proposes in 38 CFR § 17.25(c), an assessment of specific personal care services and a "[t]reatment plan listing the specific care needs of the eligible veteran"). We also recommend VA determine the frequency and hours required to perform such personal care services. Such assessments are currently performed outside VA as well as the determination of frequency and hours of home care services a patient needs to remain in their community. We believe this is a more reasonable and accurate approach to meet the law's requirement for VA to determine the amount and degree of personal care services each eligible veteran needs.

#### **Beneficiary travel limitations**

VA's family caregiver beneficiary travel proposal, based on 38 U.S.C. § 1720G(a)(6)(C), would be subject to any limitations or exclusions under Part 70 or title 38. VA indicated there is no reason to believe that section 1720G extends beneficiary travel benefits to family caregivers but does not also require the equal application of the limitations that apply to all individuals eligible for benefits under part 70.

DAV recommended VA take the opportunity to revise its regulations to meet the travel and transportation policies contained in its own 2009 Geriatric and Extended Care Strategic Plan.

This strategic plan, which has been submitted to Congress, notes, "[t]he major goal of community-based extended care is to reduce or eliminate the need for veterans to travel to access care. Nonetheless, assistance in transportation options is a consistently cited top need for informal caregivers. VA does allow caregivers to travel with veterans who themselves have a travel benefit, if their presence is necessary to the well-being of the veteran. But this does nothing for veterans lacking the benefit, or for assisting caregivers to participate in support groups."

Significant barriers identified by VA in the strategic plan include, "[A]vailability of transportation services for disabled individuals is variable, insufficient, requires effort to access, and is often costly. Likewise, transportation is often provided only for care recipients and not for caregivers. Eligibility requirements are strict and round-trip duration times are excessive for many patients." Moreover, "[f]indings from a 2006 survey of VA health care staff (primarily social work, nursing, and physicians working in CLCs and HBPC programs) rating the perceived importance and availability of a range of caregiver support services. Inadequate transportation was cited most frequently by VA staff as a barrier to accessing [Adult Day Health Care] and caregiver support groups."

Notably, issues with the eligibility requirements were specifically discussed in the strategic plan. ADHC has strong appeal for veterans whose family caregivers may be absent (e.g., for work or other commitments) during workdays. ADHC may be provided for a specific number of days outside the number of routinely scheduled

visits. These days would be counted as respite care under 38 U.S.C. 1720B since these ADHC visits are temporary additions to the routine services the veteran already receives.

"[V]eterans with an indication for medical transport and meeting eligibility criteria, (outlined in *Beneficiary Travel Handbook 1601B.05 July 29, 2008*), may be eligible for special mode transportation to and from medical appointments. Caregivers may ride with the veteran if there is a determined need for an attendant. Although this benefit is available at all VA medical centers, the extent of its use can vary considerably based on the definition of "medically indicated." In general, this refers to veterans requiring air or ground ambulance, wheel chair transportation, or transportation specially designed to transport disabled persons."

The Beneficiary Travel Handbook 1601B.05 was recently revised but such revisions did not address the issues surrounding the eligibility criteria. The strategic plan recommendations regarding beneficiary travel include (#26) a, "[n]eeds based (not eligibility based) beneficiary travel for frail/disabled veterans."

We urge VA to reconsider its proposal to provide to family caregivers beneficiary travel benefits, "[s]ubject to any limitations or exclusions under part 70 as well." (76 Fed. Reg. at 26153). Doing so would include family caregivers of those veterans who already face barriers to use this critical and needed benefit to access support and services.

Madam Chairwoman, DAV believes VA has a unique opportunity to address within its health care system, a national health care challenge with regard to informal caregivers. This new VA program could be a blessing to caregivers of severely disabled veterans and a benevolent response to those grievously injured in war and in military duties. We believe the comments, concerns, and recommendations we submitted will make the caregiver support program more effective, more humane, and one that will reach more veterans as intended by Congress and the American people.

Again, we thank you for the opportunity to present our views on VA's IFR for title I of P.L. 111-163. The DAV is committed to working constructively with Congress, VA, and the Administration to ensure family caregivers do not remain undertrained, underpaid, underappreciated, undervalued, and exhausted by their duties.

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**Statement of Tom Tarantino, Senior Legislative Associate,  
Iraq and Afghanistan Veterans of America**

Madam Chairwoman, Ranking Member, and Members of the Committee, on behalf of Iraq and Afghanistan Veterans of America's 200,000 member veterans and supporters, I thank you for inviting me to testify at this hearing to share our members' views on this important issue.

My name is Tom Tarantino and I am the Senior Legislative Associate with IAVA. I proudly served 10 years in the Army beginning my career as an enlisted Reservist and leaving service as an Active Duty Cavalry Officer. Throughout those 10 years, my single most important duty was to take care of other soldiers. In the military, they teach us to have each other's backs. Although my uniform is now a suit and tie, I am proud to work with this Congress to ensure the entire country has the backs of America's servicemembers and veterans.

The fight is not over when our warriors leave the combat zone. They have made a commitment: we have asked them to sacrifice their time and families, to risk their lives and limbs, to protect us. It is only right that we as a people, as a Nation, make good on our commitment to take care of our warriors, especially when they leave pieces of themselves on the battlefield. Taking care of our veterans often means taking care of their families.

IAVA strongly supports the Caregivers Assistance Program. We recognize that wounded warriors deserve the chance to live the fullest life possible. Whether their wounds are physical, mental, or some combination of the two, veterans heal better and faster when they are comfortable and happy with access to the support of family and friends. If the choice is between being warehoused in a VA or DoD facility or recovering at home surrounded by family and friends, IAVA believes that the compassionate choice and the logical choice are one and the same. As one spouse of a wounded warrior put it, "[W]e just want to be included in our society rather than being segregated."

It is our duty to ensure that the any assistance program fully meets the needs of those it is designed to help. To that end, IAVA would like to make some suggestions about modifications to the Interim Final Rule for the Caregivers Assistance Program.

**1. The GAF score required to enter the program is too restrictive. In addition, the requirement to have a continuously low GAF score is restrictive and self-defeating.**

The Interim Final Rule sets several criteria for entry into the program; one of these is evaluation using the General Assessment of Functioning (GAF). To be eligible for the program, a veteran must have a GAF score of 30 or below at the beginning and end of a 90 day period and the score cannot rise above 30 in the interim. In other words, 3 continuous months of a 30 or below GAF score.

The first problem we see is that a GAF score of 30 corresponds to such severe impairment that a veteran would need treatment that is beyond the scope of a family caregiver. Higher GAF scores still present serious problems: a GAF score of 31–40 denotes “some impairment in reality testing and communication or major impairment in several areas” including being unable to work. A GAF score of 41–50 denotes “Serious symptoms (e.g., suicidal ideation, severe obsessional rituals, frequent shoplifting) OR any serious impairment in social, occupational, or school functioning” including the inability to keep a job or maintain friendships.

The point of any rehabilitation is to help veterans get better. Under the VA rule, however, if a veteran shows improvement by receiving a single GAF score above 30, he or she becomes ineligible to receive Caregivers Assistance. The VA rule appears to force a choice: get treated, get better and be ineligible or remain non-functional with a poor quality of life and be eligible.

IAVA believes that relaxing the GAF criteria would be in the best interests of veterans. Raising the GAF score required to participate in the program to as high as 50 would still mean that veterans with profound mental health issues would be eligible for the program and not be penalized for improving.

**2. Stronger coordination with DoD programs and third-party providers is necessary.**

The VA definition of primary care team on 26149 of Vol. 76 No. 87 of the *Federal Register* does not make it clear who composes that team. Because a significant population eligible for this program are retired medically from service or covered by insurers outside the VA, many receive treatment outside the VA system, for example from TRICARE providers and third-party providers under fee-for-service programs. Veterans who are diagnosed with mental or physical disabilities that make them eligible for the Caregivers Assistance Program after separation from service may also have been treated by physicians and clinicians outside the VA system, i.e. through private insurance. With pending legislation that is likely to expand fee-for-service programs and third-party providers, situations where a veteran is under the care of a doctor outside the VA system will only increase. It is imperative that VA primary care teams consult these doctors and utilize their assessments and that this requirement is explicitly stated.

IAVA has spoken with veterans or family members being treated outside of the VA system whose treating physicians have never been consulted by VA clinicians making eligibility determinations or treatment recommendations. In one case, a clinical psychiatrist who for over 5½ years has treated a veteran with traumatic brain injury (TBI) and mental health issues stemming from his war injuries has never spoken to or been contacted by VA personnel in any capacity. If such a long-standing relationship does not qualify for the “primary care team” then what will?

IAVA does not support the contention that clinicians outside the VA should make the call on who is eligible for the program. It is a VA program and the VA should administer it. However, IAVA believes that review of existing patient records and consultations with non-VA clinicians who are treating a particular veteran should form at least part of the basis for decisions. Clinicians who determine entry into the program and progress in the program must consult with clinicians who are actually treating the veteran. There is no need to reinvent the wheel and delay veterans and their families’ entry into the Caregivers Assistance Program.

**3. Differentiation between Primary Family Caregivers (PFC) and Secondary Family Caregivers (SFC) needs to be lessened. Qualifications for SFC, particularly the requirements reside with the veteran, need to be relaxed.**

IAVA understands the levels of caregiver differentiation and agrees that different levels of commitment should receive different levels of benefits. The structure that the VA has proposed for the levels of responsibility and the number of Family Caregivers (FC), however, will negatively impact family caregivers, particularly during periods of respite care. Accommodation in the VA’s interpretation of 38 CFR 71 should be made for exceptional circumstances and the authority to accommodate should be made clear as well.

VA has established that there can only be one PFC, although there does not need to be one at all. VA has also established that there can be a maximum of only two SFC, even if there is no PFC. A veteran, therefore, could have between 1 and 3 family caregivers. A veteran may have an unlimited number of General Caregivers (GC). VA describes GC as "Good Samaritans" [Federal Register Vol 76 No 87 26152] and that corresponds to the level of benefits they receive: just enough to make them helpful with "less critical personal care." This means that the bulk of care rests on the shoulders of PFC and SFC. The difference between PFC and SFC are that PFC receive all the benefits of SFC and a monthly stipend, respite care for at least 30 days per year and health care coverage through CHAMPVA. Any FC must be "(i) The eligible veteran's spouse, son, daughter, parent, step-family member, or extended family member; or (ii) Someone who lives with the eligible veteran full-time or will do so if designated as a family caregiver."

Keeping in mind the above restrictions and benefits, let us consider the following scenario: a wounded veteran without a large family who has no PFC. Essentially, with the requirements for entry into the Caregivers Assistance Program, that veteran will rely on 1 to 3 SFC for assistance with the vast majority of their specialized needs. The veteran may not have a PFC for a variety of reasons: inability of family or friends to commit as the primary source of care, desire of the veteran not to be a burden on family, or a small family or no family, i.e. an orphan. Whatever the reason, if there is no PFC then the SFC should be pro-rated a monthly stipend based upon their level of care. This will help defray the costs of care for the SFC, who receive the same training and are expected by the VA to perform the same tasks at the same level of competency as the PFC. One can easily imagine a scenario with a rotation of SFC who share the responsibilities of care on a rotating basis and they should be eligible for benefits commensurate with their level of responsibility.

In addition, the restriction on FC to live with the veteran should be relaxed. For example, if a spouse of a wounded veteran is the PFC then a sibling or parent might be willing to be a SFC. However, under the current interpretation, a best friend or a cousin would not be eligible to be a SFC unless that person lives with the veteran "full-time." This distinction does not recognize that in some cases immediate family members may not have as close a relationship with a veteran as the veteran's best friend, for example. If the SFC "generally serves as a back up to the Primary Family Caregiver" [Federal Register Vol. 76 No. 87 26148] then anyone with (1) a close relationship that mirrors that of a family member and (2) who is willing to accept the responsibility of an SFC should be classified as an "extended family member" and allowed to function as an SFC if the veteran and/or PFC approve regardless of whether or not they are domiciled with the veteran. In addition, the definition of "Someone who lives with the designated veteran full-time" should be interpreted to recognize that "full-time" living might occur on a part-time basis as in the next suggestion.

#### **4. The provision of "respite care" needs to be clearly defined**

What respite care consists of or entails is not clearly defined but in practice has been either placing a veteran into a VA hospital or placing a home health care aide in the veteran's home. While these are acceptable alternatives, with the availability of SFC and GC creating an unfamiliar environment should be the last resort rather than the first option. The practice of the provision of respite care is too rigid and, as one caregiver put it, "People won't use it because it doesn't meet their needs" nor does it meet the intent of the Caregivers Assistance Program.

Another scenario similar to the ones given above might entail the respite of a PFC. During this period, VA will provide "respite care." In conjunction with the suggestion above, relaxing the definition of extended family would allow the option of a SFC to move in with a veteran full-time for a short period of time, enough to allow respite for a FC while still giving the veteran the continuity of care and home life the program is intended to provide.

In addition, pro-rating a stipend for SFC would allow them to defray part of the costs associated with providing respite for another FC. Covering travel for the respite caregiver would also be beneficial. The current interpretation appears to assume that all who take on the role of a FC reside in geographic proximity. This is often not the case and accommodation should be made. Provision should be made for covering the actual costs of travel, as is done under TRICARE.

While some might contend that these measures will add costs to the program, the associated benefits of meeting the intent of the program (allowing a veteran to remain in a home environment while recovering) and the cost of removing a veteran to a VA hospital or providing in-home care through an unfamiliar home health care aide are likely greater.

IAVA understands the need establish solid criteria to receive caregivers assistance. With budgets coming under tremendous scrutiny, government agencies must do their utmost to make certain that there is not even the perception of fraud, waste or abuse. However, the Caregivers Assistance Program is not a boondoggle or a giveaway. It is not a program designed to make anyone wealthy. It is not even designed to make anyone, veteran or family member, whole again. The Caregivers Assistance Program merely provides the ability to exist at an extremely modest level while helping a loved one.

The story of Sarah Wade, who has been instrumental in getting this program instituted, is a great example. When her husband, Ted, was injured, she was enrolled in college with the hope of becoming a Foreign Service officer; Ted was going to become a commissioned officer through the Army's Green to Gold program. Our country lost the future contributions of a fantastic couple dedicated to public service; the Wade's lost their plans for the future. Now, Sarah cares for Ted and his very modest benefits from medical retirement and SSI, as well as her part-time work, sustains them. Had life continued for them as planned, they would have made very comfortable salaries. Now though, as Sarah succinctly puts it "Ted was capped at an E-5 for the rest of his life. Our standard of living was frozen."

While the "VA does not intend that the stipend replace career earnings" [p. 26155, *Federal Register* Vol. 76, No. 87], caring for a veteran who qualifies for the Caregivers Assistance Program is a full-time job in itself. The income from the Caregivers Assistance Program will not make anyone rich nor will it place veterans and their families remotely close to where they would have been financially before their injuries. But it will give them, and thousands of other veterans and their families, a small cushion and a little peace of mind while their (and our) heroes recover.

IAVA believes that the Congress, the VA and the American people have recognized how important this issue is. We support the efforts of all those who are dedicated to taking care of our warriors when they return home, especially those wounded warriors who need our help the most. We hope that our comments help make that goal a reality.

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**Statement of Barbara Cohoon, Ph.D., R.N., Government Relations  
Deputy Director, National Military Family Association**

Chairwoman Buerkle and Distinguished Members of this Subcommittee, the National Military Family Association would like to thank you for the opportunity to present testimony on *"Implementation of Caregiver Assistance: Moving Forward."* The National Military Family Association will take the opportunity to discuss our concerns regarding the Department of Veterans Affairs' Caregiver Implementation Plan and several issues of importance to family caregivers of the wounded, ill, and injured servicemembers, veterans, their families, and caregivers in the following subject areas:

- I. VA Caregiver Implementation Plan
- II. Additional Caregiver Compensation
- III. Senior Oversight Committee

**VA Caregiver Implementation Plan**

While our Association is extremely appreciative of Members of Congress for the passage of this landmark legislation, we have some concerns regarding the Department of Veterans Affairs' (VA's) implementation plan. These concerns include the need for these important caregiver benefits to start earlier in the servicemember's recovery process, retroactive stipend to the implementation of the law on January 31, 2011, and the establishment of a Department of Defense (DoD) and VA seamless transition of caregiver benefit.

**Illness**

Illness was one condition that was intended to be included in the caregiver provision in *Caregivers and Veterans Omnibus Health Services Act of 2010*—Public Law 111-163. Congressman Michael Michaud (D-2nd/ME) introduced the *Caregiver Assistance and Resource Enhancement Act* (CARE Act, H.R. 3155). According to his press release on July 29, 2009, "[t]he bill would establish a caregiver program to help family and non-family members who provide care for disabled, ill, or injured veterans." This bill passed the full House of Representatives. As the new caregiver program was launched, Secretary of Veterans Affairs Eric K. Shinseki commented on February 12, 2011, "They [caregivers] are critical partners with VA in the recovery and comfort of ill and injured veterans. The law states, "[n]eed for supervision or protection based on symptoms or residuals of neurological or other impairment

or injury.” The inclusion of the words “or other impairment” could include illness related conditions. However, illness was not included in the VA’s interpretation of the law. This creates the potential for DoD’s caregiver compensation benefit and the VA’s caregiver benefit to apply to different sets of servicemembers and veterans. DoD’s includes illness and the VA’s would not. This could potentially create a disparity in benefits and a lack of a seamless transition regarding compensation. Maintaining financial compensation will be key in ensuring these families’ financial situations stay stable during transition from active duty to veteran status. The frequent mention of our Armed Forces members’ exposure to toxic chemicals from burn pits may have a long-lasting effect. Therefore, service-connected illnesses need to be included as a qualifying condition. Our Association recommends that illness be included as an eligibility requirement by the VA.

#### **Starting Time of the Benefit**

The time to acknowledge the caregiver’s important role and to implement the caregiver benefit is while the wounded, ill, and injured servicemember is still on active duty status. The self-selection process of a caregiver occurs during the early phase of the recovery process. All Service branches are holding onto their wounded, ill, and injured servicemembers much longer than previous wars. Years may have passed before the caregiver and the wounded, ill, and injured servicemember reach eligibility and can benefit from the VA’s important programs and services. Therefore, we recommend that the designation of caregiver benefits be established while they are still upstream on active-duty beginning with the start of the Medical Evaluation Board (MEB) process, rather than wait until they have transitioned to veteran status.

Waiting until after the receipt of a medical separation date to start the caregiver benefit application process will prevent caregivers from being able to receive training and obtain benefits early enough in the recovery phase to make a difference in their quality of life and in the quality of care they provide. Servicemembers often receive care in a military hospital and/or VA Polytrauma Center, recover at home, and then return to the hospital for follow-on care and subsequent surgeries. The VA’s training requirement will prevent eligible caregivers from receiving any advance training for in-home care until the servicemember is being medically discharged from the military. Our Association finds this troubling because a recent survey by the National Alliance for Caregiving, “*Caregivers of Veterans—Serving on the Homefront*,” found a top challenge faced by veteran caregivers was not knowing what to expect medically with the veteran’s condition and not knowing how to address Post-Traumatic Stress Disorder (PTSD) or mental illness. Caregivers have frequently stated they did not know how to care for a servicemember or veteran when they were discharged from the hospital and went home during their recovery phase. This can cause increased stress on an already anxious caregiver. Our Association believes the sooner you provide caregivers with the skills they need to perform their duties, the sooner they will be able to provide a higher quality of care to the wounded, ill, and injured servicemember and veteran. The VA’s decision to wait until the servicemember is medically discharged from the military before beginning the training program will certainly prevent this valuable training opportunity from occurring at the appropriate time to make a difference in the quality of care of the wounded, ill, and injured servicemember.

The delay in eligibility also impacts the ability to obtain time sensitive needed benefits, such as access to mental health counseling, health care benefits, and financial compensation. This especially impacts non-spouse caregivers who would greatly benefit from these services. A recent VA press release stated 17 percent of caregiver applicants were from mothers. According to the “*Caregivers of Veterans—Serving on the Homefront*” survey, one in four respondents were parents caring for Operation Enduring Freedom and Operation Iraqi Freedom veterans.

Our Association is hearing that caregivers are reaching the stage of burnout and many are deciding to walk away from their roles as caregivers. According to “*Caregivers of Veterans—Serving on the Homefront*” survey, there are widespread impacts on the caregiver’s health, such as increased levels of stress and anxiety (77 percent), and not sleeping (77 percent), and a decrease in the utilization of healthy behaviors, such as seeing their medical provider. The caregiver survey highlighted the increased stress our veteran caregivers are under compared to their National counterparts. The law and Congressional intent were to allow the VA to provide assistance through value-added benefits to the caregiver early enough in the process to make a difference and prevent the development of physical health, mental health, and/or financial problems. The longer the VA waits to begin benefits, the more opportunity there is for the caregiver’s quality of life to worsen and for the caregiver to reach

the stage of burnout. Caregivers of our wounded, ill, and injured need these services sooner in the recovery process than later.

The interim final rule states, “we do not believe that Congress intended to authorize prolonged caregiver benefits for active duty servicemembers, particularly because they have authorized Department of Defense to provide similar benefits to active duty servicemembers.” Our Association would disagree with this statement. They are two separate benefits with significant differences. The DoD’s benefit does NOT include training, health care, counseling, or respite care, which are only included in the VA’s caregiver benefit. Reliance on the DoD program only further delays caregivers from receiving health care, counseling, respite, and training benefits as it was intended to have been received. Also, DoD’s benefit only provides compensation in the form of a payment to the servicemember who meets certain eligibility criteria and has a caregiver. The benefit is geared more towards the VA’s aid and attendance benefit in regards to establishing the level of compensation received by the servicemember rather than the VA’s new caregiver benefit. It would be better if these two benefits married up with a seamless transition of the aid and attendance benefit. The DoD benefit should not be considered a “caregiver benefit.”

#### **Starting all Programs at the Same Time**

The VA has decided to begin all of the benefits at the same time. They could very easily make training information and access to valuable VA and DoD resources available much earlier in the process than their proposed timeline. Again, the earlier access to pertinent resources and information related to VA and DoD benefits for the servicemember, veteran, and caregivers, will only be a win-win for everyone involved. Allowing early access to information validates the important role caregivers provide. Plus, an educated caregiver will only provide better care in the long run. Our Association recommends the VA begin caregiver benefits as early as possible while the servicemember is still on active duty status and not wait until they have received a final determination.

#### **Stipend**

Our Association, along with other Veteran and Military Service Organizations, frequently state how important this piece of legislation is for our Nation’s caregivers. Every day the VA delays its implementation only places additional stress on an already strained population. We really cannot afford to put this off even one more day. The least the VA could do in order to compensate for its delay is to provide retroactive stipend payments to caregivers from the original date of implementation required by law.

Our Association appreciates the VA acknowledging the need to compensate caregivers for providing direct hands-on medical care. However, we notice that the VA did not include a provision to pay caregivers for performing non-medical care services. Our Association has always proposed that financial compensation should recognize the types of medical and non-medical care services provided by the caregiver. The law states “the amount of the monthly personal caregiver stipend provided under subparagraph (A)(ii)(V) shall be determined in accordance with a schedule established by the Secretary that specifies stipends based upon the amount and degree of personal care services provided.” The law allows the Secretary of the VA the flexibility to include non-medical care services to be captured. The law also states “stipends,” not stipend, can be provided.

The reason for wanting to include a non-medical compensation benefit is because there are many hours in a day spent performing these activities that play an integral part in maintaining the servicemember and veteran’s quality of life yet are not captured by the VA’s U.S. Department of Labor’s Bureau of Labor Statistics (BLS) stipend matrix. Plus, Section 1115 of title 38 of the United States Code provides compensation to the veteran only when the spouse cannot perform the duties of a caregiver. This same level of stipend should be applied to non-medical care services provided by caregivers to servicemembers and veterans.

#### **CHAMPVA**

Our Association is pleased caregivers will have the opportunity to benefit from the Civilian Health and Medical Program of the Department of Veterans Affairs, known as CHAMPVA. The population most likely to use this benefit will be the veteran’s parent. However, there may be spouses who will qualify for this benefit. If the veterans were medically separated and were not medically retired, their spouses and children do not qualify for TRICARE (Department of Defense’s health care benefit) following separation from the Service. Under this circumstance, veteran spouses and their children qualify for CHAMPVA once the veteran obtains a 100 percent disability rating from the VA. The veteran spouse, who qualified under the “Caregiver” benefit, should retain CHAMPVA coverage following revocation of the caregiver ben-



efit because the veteran had received a 100 percent disability rating by the VA. We want to ensure spouses of 100 percent disabled veterans, no matter how they initially qualified for the CHAMPVA health care benefit, retain this benefit.

CHAMPVA coverage should be a retroactive benefit. Caregivers that are currently submitting applications should be told to keep all of their health care receipts from the time the caregiver law should have been implemented, January 31, 2011. The eligible caregiver would submit their receipts once they meet the VA caregiver requirement. The VA should then provide CHAMPVA coverage for eligible caregivers back to this date. Future caregivers should be told to keep all of their health care receipts from the time the application was submitted. The VA should then cover all future eligible caregivers for CHAMPVA back to when the application process was submitted. They should be encouraged to seek care from CHAMPVA providers in the interim period. The Department of Defense did this exact same procedure for the new TRICARE Young Adult benefit. Eligible young adults were told to keep all of their medical receipts and submit them once the law was implemented.

#### **Mental Health Services**

The interim final rule states, “[t]he counseling provided to family caregivers is intended to treat those family caregivers, independent of whether that treatment is likely to support the clinical objectives of the eligible veteran’s treatment plan.” The interim final rule further states the VA will provide these same mental health services to Secondary family caregivers as well as Primary family caregivers. The interim final rule discusses this information under the “Supplementary Information” section. However, when the counseling benefit is discussed in § 71.40 Caregiver benefits, it states all counseling services are described under § 71.50. This section states “VA will provide . . . in connection with the treatment of a disability for which the veteran is receiving treatment through VA.” It appears to contradict what was stated earlier. Our Association would like to make sure that this is clearly stated in both Sections that Primary and Secondary family caregivers will receive counseling services independent of whether that treatment is likely to support the clinical objective of the eligible veteran’s treatment plan as intended by the VA’s interim final rule.

#### **Aggravated While in the Line of Duty**

According to the interim final rule, the words “incurred or aggravated a serious injury” must have occurred while in the line of duty. It is unclear if a veteran’s caregiver would qualify for this benefit if the injury, obtained while on active duty but was now aggravated to the point of needing caregiver assistance, occurred on veteran status. An example would be a veteran who has an embedded piece of IED shrapnel in the brain that began to leak toxins or needed to be surgically removed resulting in a worsening medical condition and the requirement of a caregiver. The veteran would still benefit from other VA programs, such as aid and attendance, but his/her caregiver could no longer qualify for this important benefit. Our Association would like to ensure caregivers are still eligible for the VA’s caregiver benefit even if the serious injury was aggravated after the servicemember became a veteran.

#### **Report on Expansion of Family Caregiver Assistance**

Our Association is concerned that the VA did not reference a report on the feasibility and advisability of expanding the caregiver benefit to family caregivers of veterans who have a serious injury incurred or aggravated in the line of duty while on active duty before September 11, 2001. We want to make sure the VA fulfills this reporting responsibility because it is an integral part of the implementation of the caregiver program.

#### **Additional Compensation for the Caregiver**

Our Association is appreciative of the generous benefits included in the *Caregivers and Veterans Omnibus Health Service Act of 2010*. However, there were some areas not addressed. Our Association would like to take the opportunity to present recommendations.

A report by the Center for Naval Analysis determined 85 percent of caregivers left employment or took a leave of absence from work or school while performing their caregiver duties. They found that the average loss of earnings per caregiver was approximately \$3,200 per month. The financial strain placed on the family of our wounded, ill, and injured servicemember and veteran by the caregiver leaving outside employment has a trickle down affect. Caregivers who have been saving for retirement now find they are ineligible for their employers’ 401(k)s. We believe a mechanism should be established to assist caregivers to save for their retirements, for example, through the Federal Thrift Savings Plan.

Once the recovery process is finished and the veteran's care has stabilized, the caregiver may decide to work outside the home in order to help make financial ends meet. These caregivers may need the ability to learn new skills in order to compete in today's workforce. We recommend VA offer these caregivers the opportunity to participate in VA's vocational rehabilitation programs and help retool the caregiver's resume. We must also find innovative ways to encourage civilian and government employers to hire these caregivers, especially when the veteran is unable to work.

According to the Center of Naval Analysis, wounded, ill, and injured servicemembers and veterans, their families, and caregivers are assisted by many non-governmental organizations (NGOs) and charities. This assistance is important with the overall financial stability of these families during the recovery phase. Our Association's concern, as we continue into another year of economic downturn, is that we may find many of these NGOs and charities no longer able to assist in the manner they have previously. We believe the availability of outside assistance by others will need to be monitored closely by both the VA and DoD to make sure these families are still being helped. If they are no longer being assisted, we believe the VA and DoD may need to begin providing assistance in those areas previously covered by NGOs and charities.

#### **Relocation Allowance for Caregivers**

Active duty servicemembers and their spouses qualify through the DoD for military orders to move their household goods (known as a Permanent Change of Station (PCS)) when they leave the military service. Medically retired servicemembers are given a final PCS move. Medically retired married servicemembers are allowed to move their family; however, medically retired single servicemembers only qualify for moving their own personal goods.

The National Military Family Association suggests the VA should pay for the caregivers move as part of the VA caregiver law. We recommend that impending medically retired single servicemembers who are eligible for the VA's caregiver benefit be allowed the opportunity to have their caregiver's household goods moved, too. This should be allowed for the eligible primary caregiver and their family. The reason for the move is to allow the impending medically retired single servicemember the opportunity to relocate with their caregiver to an area offering the best medical care, rather than the current option that only allows for the impending medically retired single servicemember to move their belongings to where the caregiver currently resides. The current option may not be ideal because the area in which the caregiver lives may not have all the health care services required for treating and caring for the impending medically retired servicemember. Instead of trying to create the services in the area, a better solution may be to allow the impending medically retired servicemember, their caregiver, and the caregiver's family to relocate to an area where services already exist, such as a VA Polytrauma Center.

The decision on where to relocate for optimum care should be made with the help of the VA caregiver team: Federal Recovery Coordinator (case manager); the servicemember's physician; the servicemember, and the caregiver. All aspects of care for the impending medically retired servicemember and their caregiver shall be considered. These include a holistic examination of the impending medically retired servicemember, the caregiver, and the caregiver's family for, but not limited to, their needs and opportunities for health care, employment, transportation, and education. The priority for the relocation should be where the best quality of services is readily available for the impending medically retired servicemember and eligible for the VA's caregiver benefit along with his/her caregiver.

#### **Veteran Housing**

Many of our wounded, ill, and injured servicemembers and veterans from this current conflict are being cared for by their parents. Also, many adult children of our senior veterans are experiencing first-hand the challenge of trying to juggle the needs of the parents along with the needs of their children, and are referred to as the "sandwich" generation. Parent caregivers worry about who will care for their wounded son or daughter as they age and are unable to fulfill the role of caregiver. Caregivers may reach burnout and will need alternative solutions for providing care. The VA needs to be cognizant of the ever changing landscape and needs of their veteran population and those who care for them. The VA needs to offer alternative housing arrangements, such as assisted living facilities and family/retirement villages, which allow a diversified population to live together in harmony. This will go a long way in allowing for family units to stay together, foster independent living, and maintain dignity for the veteran.

Brooke Army Medical Center (BAMC) has recognized a need to support our wounded, ill, and injured families by expanding the number of guesthouses co-lo-

cated within the hospital grounds and providing a family reintegration program for their Warrior Transition Unit. The on-base school system is also sensitive to issues surrounding these children. A warm, welcoming family support center located in guest housing serves as a sanctuary for family members. VA medical facilities could benefit from looking at successful programs like BAMC's that embrace the family unit and commit to building family friendly environments of care for our wounded, ill, and injured servicemembers, veterans, and their families. We recommend the development of alternative housing and living arrangements for veterans, their families, and those who care for them.

### **Mental Health**

The need for mental health services will remain high for some time even after military operations scale down and servicemembers and their families transition to veteran status. Veterans' families and caregiver requirements for a full spectrum of mental health services—from preventative care and stress reduction techniques, to individual or family counseling, to medical mental health services—will continue to grow. It is also important to note if DoD has not been effective in the prevention and treatment of mental health issues, the residual will spill over into the VA health care system. The VA must be ready. They must partner with DoD and State agencies in order to address mental health issues early on in the process and provide transitional mental health programs. They must maintain robust rehabilitation and reintegration programs for veterans, their families, and caregivers that will require VA's attention over the long-term.

The National Military Family Association is especially concerned with the scarcity of services available to the veterans' families and caregivers as they leave the military following the end of their activation or enlistment. Military families will no longer qualify for many of the Services' family support programs and DoD's Military OneSource. Our Association recommends the VA increase outreach to veterans, their families and caregivers, and the communities they live in about available mental health resources to help them deal with the residual effects of long frequent deployments.

### **Children of the Veteran and Caregiver**

The impact of the wounded, ill, and injured veteran on their children is often overlooked and underestimated. These children experience a metaphorical death of the parent they once knew and must make many adjustments as their parent recovers. Many families relocate to be near the treating Military Treatment Facility (MTF) or the VA Polytrauma Center in order to make the rehabilitation process more successful. As the spouse focuses on the rehabilitation and recovery, older children take on new roles. They may become the caregivers for other siblings, as well as for the wounded parent. Many spouses send their children to stay with neighbors or extended family members, as they tend to their wounded, ill, and injured spouse. Children get shuffled from place to place until they can be reunited with their parents. Once reunited, they must adapt to the parent's new injury and living with the "new normal." We must remember the caregiver may not be the veteran's spouse. They may be the wounded veteran's parent, sibling, or friend. These children are also affected and Congress and the VA must be cognizant of their potential psychological needs as well.

We encourage partnerships between government agencies, VA, DoD, and State agencies and recommend they reach out to those private and non-governmental organizations who are experts on children and adolescents. They could identify and incorporate best practices in the prevention and treatment of mental health issues affecting these children. We must remember to focus on preventative care upstream, while still in the active duty phase, in order to have a solid family unit as they head into the veteran phase of their lives. VA, DoD, State, and our local communities must become more involved in establishing and providing supportive services for our Nation's children.

### **Expansion of Caregiver Pilot Programs**

The VA currently has eight caregiver assistance pilot programs to expand and improve health care education and provide needed training and resources for caregivers who assist disabled and aging veterans in their homes. These pilot programs are important; however, there is a strong need for 24-hour in-home respite care, 24-hour supervision, emotional support for caregivers living in rural areas, and coping skills to manage both the veteran's and caregiver's stress. We are appreciative that P.L. 111-163 will provide for increased respite care hours, along with counseling and mental health services for caregivers, but neither addresses the 24-hour supervision. We recommend if these pilot programs are found successful, they should be implemented by the VA as soon as possible and fully funded by Congress. Another

program not addressed is the need for adequate child care. The caregiver may have non-school aged children of their own or the wounded, ill, and injured veteran may be a single parent. The availability of child care is needed in order to attend their medical appointments, especially mental health appointments. Our Association encourages the VA to create a drop-in child care program for medical appointments on their premises or partner with other organizations to provide this valuable service.

#### **Senior Oversight Committee**

The National Military Family Association is appreciative of the provision in the National Defense Authorization Act for Fiscal Year 2009 (NDAA FY09) continuing the DoD and VA Senior Oversight Committee (SOC) until December 2010. The DoD established the Office of Wounded Warrior Care and Transition Policy to take over the SOC responsibilities. The office has seen frequent leadership and staff changes and a narrowing of their mission. We urge Congress to put a mechanism in place to continue to monitor this Office for its responsibilities in maintaining VA and DoD's partnership and making sure joint initiatives create a seamless transition of services and benefits for wounded, ill, and injured servicemembers, veterans, their families, and caregivers.

#### **Recommendations**

- *Broaden eligibility criteria to meet Congressional intent;*
- *Establish a DoD and VA seamless transitional caregiver benefit;*
- *Provide retroactive stipend payments to the original date of implementation required by law;*
- *Begin caregiver benefits as early as possible while the servicemember is still on active duty status and not wait until they have received a final determination;*
- *Coordinate and collaborate health care and behavioral health care services between the VA, DoD, and State and governmental agencies in sharing of resources;*
- *Approve relocation allowances and provide alternative housing and living arrangements;*
- *Increase outreach to veterans, their families, and the communities they live in about available benefits;*
- *Provide opportunities for the entire family to reconnect and bond as a family again;*
- *Provide a holistic approach to care that incorporates the impact of the wound, illness, or injury on the family unit;*
- *Expand all of the VA's caregiver pilot programs; and*
- *Continue oversight of the SOC/Office of Wounded Warrior Care and Transition Policy by Members of Congress.*

The National Military Family Association would like to thank you again for the opportunity to provide testimony on the VA's caregiver implementation plan for P.L. 111-163. Military families support the Nation's military missions. The least their country can do is make sure servicemembers, veterans, their families, and caregivers have consistent access to high quality health and behavioral care. Wounded servicemembers and veterans have wounded families. The system should provide coordination of care, and VA and DoD need to work together to create a seamless transition. We ask this Subcommittee to assist in meeting that responsibility. We look forward to working with you to improve the quality of life for servicemembers, veterans, their families and caregivers, and survivors.

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#### **Statement of Paralyzed Veterans of America**

Chairwoman Buerkle, Ranking Member Michaud, and Members of the Subcommittee, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to submit our views on the ongoing implementation of the caregiver provisions of P.L. 111-163, the "Caregivers and Veterans Omnibus Health Services Act." Additionally, we appreciate the opportunity to outline the concerns that we raised in our comments on the Interim Final Rule that the Department of Veterans Affairs (VA) published on May 5, 2011, on the final implementation of the caregiver program. We urge Congress to continue to conduct oversight of the VA's implementation plan to ensure that its full intent is being met. Moreover, we encourage the Subcommittee to continue to follow-up with the VA on the reporting requirements for the next 2 years.

PVA has 65 years of experience understanding the complex needs of spouses, family members, friends, and personal care attendants that love and care for veterans

with life-long medical conditions. As a result of today's technological and medical advances, veterans are withstanding combat injuries and returning home in need of medical care on a consistent basis. Such advances are also prolonging and enhancing the lives and physical capabilities of injured veterans from previous conflicts. No matter the progress of modern science, these veterans need the health-care expertise and care from a health team comprised of medical professionals, mental health professionals, and caregivers. As a part of the health care team, caregivers must receive ongoing support to provide quality care to the veteran.

PVA and its partners worked extremely hard to get comprehensive caregiver legislation enacted during the 111th Congress. Fortunately, on May 5, 2010, the President signed into law P.L. 111-163, the "Caregivers and Veterans Omnibus Health Services Act." This legislation created an innovative new caregiver program to be administered by the Department of Veterans Affairs (VA). The law called for the VA to begin implementation of this important new program within 270 days of enactment of the bill. This placed the deadline for implementation of this legislation in February of this year. Unfortunately, the VA was very slow to accomplish that task.

As you know, the VA republished its Interim Final Rule on May 5, 2011, regarding the implementation of the caregiver provisions of P.L. 111-163. PVA expressed concerns with four areas of the caregiver program as outlined by the VA's rules. They include: veterans' with severe illnesses excluded from eligibility; the caregiver stipend; the revocation of primary family caregiver status; and, the report on expansion of family caregiver assistance. Additionally, we have expressed concern in previous comments for the record with the projected funding needs to implement the caregiver program and continue to maintain it through at least FY 2015, as originally envisioned by the legislation. We will explain each of these issues individually.

#### ***Veterans' With Severe Illnesses Not Considered Eligible***

PVA has serious concerns that veterans who have incurred a severe illness as a result of their service are excluded from consideration as eligible for this program. This is the number one complaint that we have received from our members who are eligible under the Post-9/11 criteria for this program. PVA's membership includes veterans with spinal cord injury or dysfunction (disease). A spinal cord disease is no less catastrophic than a spinal cord injury. It is a fact that veterans who have been diagnosed with Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS) will eventually experience a catastrophic impact on their activities of daily living. And yet, these individuals who may be in greater need of caregiver services than any other population of injured veterans have no avenue for support through the new caregiver program.

Unfortunately, the VA's interpretation of the law excludes consideration of veterans with severe illness. However, the legislation was clearly intended to support populations of veterans that have experienced a catastrophic injury or illness. In fact, Congressman Michael Michaud (D-ME), then Chairman of the House Veterans' Affairs Subcommittee on Health, commented when introducing similar caregiver legislation, "the bill would establish a caregiver program to help family and non-family members who provide care for disabled, ill, or injured veterans." Additionally, the Secretary of Veterans Affairs, Eric Shinseki, emphasized during the roll-out of the new caregiver program that "caregivers are critical partners with VA in the recovery and comfort of ill and injured veterans." Meanwhile, the VA has interpreted the language of the law very narrowly ensuring that veterans dealing with catastrophic illnesses will be unable to participate in the program. This is simply unacceptable.

We have been told that the VA believes it needs clarifying legislation in order to make this change to the program. If this is in fact true, then the Subcommittee must move immediately to consider legislation to correct this inconsistency in the implementation of the program in order to ensure that caregiver assistance is available for veterans who have experienced either injury or illness.

#### ***Caregiver Stipend***

With regards to the caregiver stipend, the interim final rule states that the caregiver stipend amount will be determined by the eligible veteran's level of dependency based on the degree to which the eligible veteran is unable to perform one or more activities of daily living (ADL), or the degree to which the veteran is in need of supervision or protection based on symptoms of residuals of neurological or other impairment or injury.

The rule also states that the 14 ADLs and needs that are listed in the *Eligible Veterans and Servicemembers* section will each be given a clinical rating from zero to four, with zero representing no caregiver assistance needed in that area by the

veteran, and four meaning the veteran is in need of total assistance with regard to that specific ADL or need.

PVA is concerned that in the current calculation for caregiver stipends, personal care services are not taken into consideration. It is often the case that the very injuries that necessitate a caregiver also result in the veteran not being able to perform personal functions that are also necessary to ensure his or her health and safety, but are not direct medical activities. As a result, the caregiver provides “personal care services” such as financial management or weekly shopping that occupies a significant amount of his or her time and energy.

In the rule, VA defines personal care services as “care or assistance of another person necessary in order to support the eligible veterans health and well-being, and perform personal functions required in everyday living ensuring the eligible veteran remains safe from hazards or dangers incident to his or her daily environment.” While this definition may capture some of the caregiver services outlined in the definition for ADLs, there are many daily responsibilities involving personal care that are not included, and will therefore not be included in the Primary family caregiver stipend. If the stipend is to be an accurate reflection of the eligible veteran’s level of dependency and an acknowledgement of the sacrifices that Primary family caregiver make to care for seriously injured veterans, personal care services must be taken into consideration in the stipend calculation.

#### ***Revocation of Primary Family Caregiver Status***

The interim final rule allows for up to 30 days of continuing caregiver benefits after a veteran revokes the status of a Primary family caregiver. PVA understands that the purpose of this safeguard is to determine if remediation is possible, and to allow time for the revoked caregiver to find additional health care coverage if necessary. It is for similar reasons that PVA believes that guidelines should also be put in place that requires the caregiver to provide the veteran with notice should he or she choose to revoke their caregiver status. By designating a specific amount of time that is required for caregivers to continue their responsibilities after notice of revocation, with the exception of caregiver abuse or negligence, the VA gives the veteran time to arrange for replacement care as the veteran will need time to identify a new primary caregiver, make arrangements with the secondary caregiver if necessary, and complete a new VA caregiver application.

#### ***Report on Expansion of Family Caregiver Assistance***

Perhaps the most important provision in P.L. 111-163 for PVA is the reporting requirements outlined in § 1720G(d). PVA cannot overemphasize the importance of this provision. Specifically, the law states,

“Not later than 2 years after the date described in subsection (a)(3)(A), the Secretary shall submit to the Committee on Veterans’ Affairs of the Senate and the Committee on Veterans’ Affairs of the House of Representatives a report on the feasibility and advisability of expanding the provision of assistance under section 1720G(a) of title 38, United States Code, as added by subsection (a)(1), to family caregivers of veterans who have a serious injury incurred or aggravated in the line of duty in the active military, naval, or air service before September 11, 2001.”

PVA was disappointed that veterans who became injured or ill prior to September 11, 2001, were excluded from the comprehensive caregiver support programs. The fact is, PVA’s members—veterans with spinal cord injury or dysfunction—would benefit from this program more than any other population of veterans. And yet, the majority of those veterans are excluded by the arbitrary date of September 11, 2001, from the comprehensive caregiver program. No reasonable justification (other than cost considerations) can be provided for why pre-9/11 veterans with a service-connected injury or illness should be excluded from the comprehensive caregiver program. Catastrophically disabled veterans needs are not different simply because they may have been injured prior to the selected date.

With regards to the interim final rule, PVA is particularly concerned that the VA offered no reference to this reporting requirement in its proposed rules. We believe that given the opportunity, the VA may simply choose to ignore this requirement so as not to draw attention to an obvious deficiency in the caregiver program that it cannot or will not be able to implement. The VA must ensure that it fulfills this reporting requirement as it is an integral part of the implementation of the caregiver program. This critical report will pave the way to access to much-needed caregiver assistance for many more catastrophically disabled veterans who are currently being denied eligibility simply because of the arbitrary date assigned to this benefit by Congress.

Lastly, PVA remains concerned about the VA's lack of commitment in its FY 2012 budget request and FY 2013 advance appropriation estimate for the funding necessary to fully implement this program. While the Administration claims to have provided an additional \$208 million for implementation of P.L. 111-163, it is not clear where that additional funding is included in the FY 2012 Medical Care budget request. Our analysis suggests that for FY 2012, the VA actually requested approximately \$65.9 million for the implementation of the caregiver provisions of P.L. 111-163 and an additional \$70.6 million for FY 2013. While we appreciate the fact that the Military Construction and Veterans' Affairs appropriations bills approved by the full House and currently being considered in the Senate purportedly address this funding need, we believe insufficient funding has been provided to fully implement this program. With this in mind, PVA, along with the co-authors of *The Independent Budget*—AMVETS, Disabled American Veterans, and Veterans of Foreign Wars—recommended approximately \$385 million to fund the provisions of P.L. 111-163 in FY 2012.

PVA would like to thank this Subcommittee for the opportunity to express our views relating to the implementation of the VA's new caregiver program. We hope that the Subcommittee and Congress will take an active role to ensure that the VA is actually implementing the provisions of P.L. 111-163 as intended. Failure to comply with the intent of Congress is simply not an option in this case. The most severely disabled veterans and their families are depending on the VA to get it right. We look forward to working with the Subcommittee as it continues addressing these issues. We will gladly respond to any questions. Thank you.

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### Statement for Wounded Warrior Project

Chairman Buerkle, Ranking Member Michaud, and Members of the Subcommittee,

Wounded Warrior Project (WWP) applauds this Committee's ongoing oversight of the Department of Veterans Affairs' (VA) implementation of the comprehensive caregiver assistance program. This Committee's vigilance and leadership have been critical to the important progress made in moving the program from what was, initially, a flawed implementation plan to a reality that is already making a difference in the lives of families who have endured so much.

We trust this hearing will underscore that—even as VA has made significant improvement to the implementation plan and great strides in rolling out the program—more work must be done, particularly in refining the Interim Final Regulation (IFR) published on May 5, 2011. VA's adoption of WWP recommendations, submitted as comments on that regulation, would help bridge remaining gaps between the law's promise and regulatory-barriers many families still face.

In our view, the following comments offer the Department a road map for achieving in full the goal Congress set in enacting a historic caregiver-assistance law. WWP is pleased to provide this Committee with these comments as part of our statement for the record:

#### 1. Eligibility issues:

- a. ***Under the IFR, warriors with certain serious mental health conditions would likely be deemed "ineligible" for caregiver-assistance. Accordingly, new Section 71.15, which identifies reasons that might create a need for supervision or protection, should be expanded to include pertinent symptoms of PTSD, anxiety and depression.***

The caregiver law provides that an eligible veteran is one who has a serious injury, and it specifies that that term includes "psychological trauma, or other mental disorder." The IFR identifies possible bases for establishing a need for caregiver assistance. Among those is that a wounded warrior requires supervision and protection based on symptoms or residuals of neurological or other impairment or injury. The IFR identifies seven different circumstances that might require supervision or protection, but the Department specifically welcomes additional suggestions on these circumstances. WWP agrees that additional criteria are needed. The seven factors identified in the IFR do address very relevant considerations. Nevertheless, we do not believe the factors are sufficiently comprehensive, particularly with respect to widely prevalent mental health conditions that in some circumstances dictate a need for caregiving assistance.

For example, in the case of a veteran with PTSD, "need for supervision or protection" could conceivably be established under the IFR based on its inclusion of such symptoms as difficulty with sleep regulation and inability to moderate agitation.

However, a veteran with PTSD marked by other severe symptoms (such as significant avoidant behaviors) may need a caregiver's supervision and protection, but would likely not qualify under these IFR criteria. In addition, a veteran with significant anxiety and related fearfulness (such as fear of leaving the home) could also require some degree of caregiver assistance. As currently drafted, there is no single criterion or group of criteria under Section 71.15 related to supervision or protection that would address such anxiety symptoms. Similarly, it is not clear that symptoms of depression are necessarily covered under that Section. (The reference to "self regulation" is at best ambiguous because it is described in terms that suggest it applies only to being able to regulate an agitated or aggressive state. And while very severe depression could involve suicidality and thus be covered under the "safety risk" criterion, an individual with depression may pose no safety risk and still need considerable assistance. PTSD, anxiety and depression are not only widely prevalent among OEF/OIF veterans, but can certainly dictate a need for caregiving assistance in the nature of supervision and protection. Given that PTSD and other mental disorders are signature wounds of this war, and specifically included in the statute, it would be unreasonable to fail to take account of common, severe symptoms of those conditions. Accordingly, the criteria in Section 71.15 should be revised and expanded.

WWP recognizes that the IFR establishes a criterion under which a need for caregiving can be based on a mental disorder that has been scored under a Global Assessment Functioning (GAF) test at 30 or less continuously during a 90-day period. A GAF score of 21–30 is defined as "behavior is considerably influenced by delusions or hallucinations OR serious impairment, in communication or judgment (e.g., sometimes incoherent, acts grossly inappropriately, suicidal preoccupation) OR inability to function in almost all areas (e.g., stays in bed all day, no job, home, or friends)." Requiring a GAF score of 30 or less sets an unreasonably restrictive eligibility bar, particularly given the observations set forth above regarding situations in which individuals with PTSD, anxiety and depression likely would not be deemed to need caregiver assistance under the Section 71.15 criteria on supervision or protection.

In setting a GAF "line" that is too restrictive and omitting pertinent behavioral health criteria in Section 71.15 relating to supervision or protection, the IFR will fail to cover veterans who should be deemed eligible based on a real need for caregiver assistance. As such, the IFR creates what amounts to serious disparity. Consider that the IFR, on the one hand, implicitly recognizes that a veteran with a *physical* injury may be "eligible" based on a relatively limited need for assistance with activities of daily living. (For example, a veteran may need relatively limited assistance daily based on an inability to dress himself; yet the IFR would appropriately provide for caregiver-support to the veteran's caregiver. Similarly, a veteran who experienced moderate traumatic brain injury, manifested only in limited difficulty with planning and organization, might need only limited assistance such as with maintaining a medication regimen, but caregiver support could again be authorized under the IFR.) But a veteran with anxiety, for example, would have to be almost totally disabled under the GAF-criterion—and likely need full-time assistance—to be deemed eligible. This surely unintended disparity between IFR eligibility standards applicable to a physical injury and those applicable to a common mental health condition is fundamentally inconsistent with a law that clearly recognized that both mental disorders and physical injuries can render veterans in need of caregiver assistance. It is also inconsistent with the principle of "mental health parity" which is firmly embedded in Federal law.<sup>1</sup> Such disparity should be excised from the regulation.

- b. *The "GAF eligibility provision" is not only unduly restrictive, it is an arbitrary standard that, contrary to law, has become the exclusive criterion under the IFR for determining eligibility in the case of a mental health condition.***

As discussed above, the "GAF eligibility provision" is unduly restrictive. Implicitly, the Department's position is that the *only* circumstances under which a mental health condition would require another's assistance is where mental impairment is so profound as to manifest in (1) delusions or hallucinations; (2) suicidal preoccupation; (3) gross inappropriateness; or (4) bedridden status. Given how disabling mental illness can be, such a view fails to account for the fact that individuals with less severe symptoms may also need another's daily assistance, albeit not necessarily round-the-clock or full time care. In attempting to explain this provision, the De-

<sup>1</sup>See, e.g., Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008, Public Law 110–343.



partment states that a “GAF scores in the 21–30 range is the minimum impairment standard that VA will require to consider a mental health diagnosis a serious injury.”<sup>2</sup> It states further that:

“At this assessed level of impairment, the supervision or protection of a caregiver is essential to the individual. *An individual who has been assessed as having a psychological trauma or mental disorder scored at 30 GAF or less generally requires a higher level of care that would provide constant supervision.*”<sup>3</sup>

The underscored language above surely makes the point. Nothing in the law suggests that a need for caregiver-assistance must be constant. To the contrary, Congress made it clear that the extent of personal care services needed by eligible veterans would vary substantially and directed the Secretary to provide Primary caregivers a stipend that “shall be determined . . . based upon the amount and degree of personal care services provided.”<sup>4</sup> The IFR provisions addressing the stipend clearly provide that a Primary caregiver of a veteran who is determined to need as little as 10 hours of caregiver assistance weekly would still be entitled to receive comprehensive caregiver supports. Setting a GAF score at a level that requires “constant supervision of the veteran” is contrary to the law that directs the Secretary to provide caregivers support tied to the duration of needed caregiving. In short, this standard is contrary to law.

Beyond the question whether it is lawful to set a GAF-score “bar” at 21–30 rather than a higher level, the IFR raises the more basic question: what is the foundation for establishing *any* GAF score criterion? The VA states that the GAF-eligibility provision, Section 71.20(c)(3), is authorized by 38 U.S.C. § 1720G(a)(2)(C)(iii), under which the Secretary may establish additional circumstances that create a need of personal care services other than the specific criteria identified in the law. In WWP’s view, relying on a tool used to subjectively rate social, occupational, and psychological functioning is an extraordinarily poor proxy for assessing a need for caregiver assistance. However, the GAF provision is not simply a too-restrictive, arbitrary standard. Given that the VA has established with the GAF provision a separate eligibility criterion applicable only to “psychological trauma or a mental disorder,” Section 71.20(c)(3) provides the exclusive eligibility criterion for a veteran needing personal care services because of a mental health condition. As such, Section 71.20(c)(3) has not only established a much higher eligibility threshold for a mental health condition than for any other disorder, it effectively renders meaningless the law’s “need for supervision or protection” language in the case of a veteran with PTSD or other mental health condition. Instead, the regulation sets a very specific test applicable to veterans with a mental disorder, such that—even if that veteran’s condition is so severe that it creates a need for supervision or protection—one must assume that the veteran would be deemed not to meet the IFR’s eligibility requirements.

The VA’s explanation of this provision belies the notion that GAF-criterion is simply “an alternative” avenue of eligibility. As the VA clearly explains “*GAF scores in the 21–30 range is the minimum impairment standard that VA will require to consider a mental health diagnosis a serious injury.*”<sup>5</sup> The VA has established a double standard here. In interpreting the statutory language “an eligible veteran is any individual who . . . has a serious injury (including traumatic brain injury, psychological trauma, or other mental disorder),”<sup>6</sup> the VA explains that a mental health condition is not “serious” unless it results in functional impairment that requires “*constant supervision.*” Yet for ANY other injury, including traumatic brain injury (which may manifest itself exclusively in behavioral manifestations little different from certain mental health conditions), the IFR defines “serious injury” differently: “any injury . . . that renders the veteran or servicemember in need of personal care services.”<sup>7</sup> Under this definition, a veteran suffering from traumatic brain injury could receive as little as 10 hours per week of caregiver assistance. Setting disparate standards based solely on diagnosis for determining whether an individual is in need of supervision or protection because impaired behavioral-health functioning cannot be squared with a law that draws no distinction among types of injury, and provides a specific, clearly-applicable criterion in law for determining need for personal care

<sup>2</sup> *Federal Register*, 76, no. 87 (May 5, 2011): 26150.

<sup>3</sup> *Id.* (emphasis added).

<sup>4</sup> 38 U.S.C. § 1720G(a)(3)(C)(i).

<sup>5</sup> *Federal Register* (May 5, 2011): 26150

<sup>6</sup> 38 U.S.C. § 1720G(a)(2)(B) (2010).

<sup>7</sup> 38 CFR § 71.15 (2011).

services. WWP submits that including Section 71.20(c)(3) in a final regulation would be contrary to law, and strongly urges that it be deleted in its entirety.

**c. *Contrary to law, the IFR draws so tight a link between injury and need for personal care services that veterans whose injuries (only) “lead to” the need for caregiver support will be rendered ineligible.***

The VA explains that it interprets the caregiver law to require “a causal relationship” between a veteran’s serious injury and a need for personal care services. While WWP does not suggest that the VA’s interpretation of the statute is unreasonable in principle, the IFR draws too fine a line — particularly in the absence of specific statutory language requiring any causal connection<sup>8</sup>—in defining serious injury to mean an injury that “renders” the individual in need of personal care services.<sup>9</sup>

To say, in effect, that the *injury* must have caused the need for caregiver-assistance is at best to create ambiguity, and potentially to render ineligible a veteran under circumstances where a condition *secondary to his or her injury* causes the need for personal care services. Consider the case of a veteran who sustained multiple shell fragment wounds in Iraq. While those injuries were not severely disabling and did not create a need for sustained caregiver assistance, the veteran after separation from service underwent further surgery for removal of shell fragments, and as a result of a mishap in surgery suffered loss of oxygen and now requires extensive personal care services. One can also readily imagine the instance of a warrior who lost a leg in Afghanistan, and subsequently (after separation from service) sustains a severe traumatic brain injury in a bad fall due to loss of balance.

To focus narrowly and exclusively on whether the initial injury “renders” the veteran in need of personal care services is to misread both the language and the purpose of the caregiver law. If it is to conform to law, the final regulation must clarify that a secondary condition resulting from that initial injury can provide an equally sound basis for establishing a causal link to the need for caregiver-assistance. WWP urges that the final rule make clear that eligibility extends to any serious condition that is “related to, caused by, or derived from” an injury incurred or aggravated during service.

**d. *The IFR fails to articulate clearly the manner in which “clinical eligibility” will be determined and does not ensure that the caregiver’s perspective is taken into account.***

As drafted, the IFR is singularly vague regarding how the VA is to arrive at a judgment that a particular wounded veteran requires caregiver-assistance. The VA should remedy this ambiguity.

The IFR states that “need of personal care services [will be] . . . based on . . . [specified] clinical criteria.”<sup>10</sup> It provides that “upon receiving [the required application for caregiver assistance] VA will perform the clinical evaluations required by this section.”<sup>11</sup> The IFR further states that “VA will clinically rate the eligible veteran’s need for supervision or protection . . . using the seven impairments listed in . . . sec. 71.15.”<sup>12</sup> New Section 71.25(f)—relating to approval and designation of primary and secondary family caregivers is the only provision of the regulation that speaks to the process by which at least certain clinical judgments are to be made. The provision is vague, at best:

If the eligible veteran and at least one applicant meet the requirements of this part, VA will approve the application and designate Primary and/or Secondary family caregivers, as appropriate. This *approval and designation will be a clinical determination authorized by the eligible veteran’s primary care team.*<sup>13</sup>

One infers that this language means that the primary care team (as opposed to a single non-physician, for example) is to perform the clinical evaluation. An interdisciplinary evaluation is critically important, but the IFR is certainly not clear on that point.

WWP recently conducted a survey of caregivers to understand the experience of families who had applied for comprehensive-assistance under the caregiver law during the 7-week period following the initial-application date. Among the findings, the survey responses suggest that there is variability from facility to facility as to who

<sup>8</sup>The Department acknowledges that the law imposes no such test. See *Federal Register* (May 5, 2011): 26150.

<sup>9</sup>38 CFR § 71.15 (2011).

<sup>10</sup>38 CFR § 71.20(c) (2011).

<sup>11</sup>38 CFR § 71.25(a)(2) (2011).

<sup>12</sup>38 CFR § 71.40(c)(4)(ii) (2011).

<sup>13</sup>38 CFR § 17.25(f) (2011).

determines a veteran's need for caregiver assistance, as well as an apparent failure to communicate to caregivers how that determination is made. Asked their understanding of who determines a veteran's need for caregiver-assistance, more than one in five respondents 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 expressed uncertainty. Clarifying who makes the determination that a veteran needs caregiver-assistance is only a first step, however. The regulation states that VA is to "clinically rate" the veteran, but does not define that term or specify how such clinical rating is to be conducted. In considering the determinations that must be made regarding whether, and the extent to which, impairments result in a need for supervision or protection, clinical judgment must take account of how the veteran functions in his or her home and community, not simply how the veteran appears in a medical facility's examination room. Such judgment cannot, for example, be reliably based on prior VA medical records, and must necessarily rely heavily on interviewing the caregiver and the veteran. But as one caregiver's experience (reported to WWP through our recent survey) indicates, the VA's lack of guidance on the importance of obtaining a full understanding of the veteran's limitations and needs (to include obtaining the caregiver's perspective) can result in an inaccurate 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."*

WWP urges that the regulation make clear that the various clinical determinations implicit in the IFR are to be made by an interdisciplinary clinical team, and that the team must interview both the caregiver and veteran to gain an understanding of the extent and nature of the veteran's need for personal care services. In those instances in which a need for caregiving is based on a need for supervision and protection, VA should require use of the Neuropsychiatric Inventory (NPI) (or similar tool). The NPI, which VA cited as a source for its scoring methodology, would be an apt tool for interviewing a caregiver because it is structured to gain information on the frequency and severity of impairment across ten behavioral areas, as well as to assess caregiver distress. (Insight on the degree of caregiver distress would also be a useful tool in determining caregiver's need for education and training, supportive services, and respite care.)

WWP recommends that the term "clinical rating" be defined to address the above described concerns, to include identifying who makes such determinations, the manner in which such determinations are made (that is, that they are *not* to be based on inferences drawn from prior medical or compensation records, must take account of extensive interview with the caregiver, etc.), and the nature of the examinations and home assessments that must be conducted.

***The final regulation should clarify that a veteran with any service-connected condition incurred or aggravated on or after 9/11 may be an "eligible veteran" under the caregiver law.***

The IFR essentially restates the statutory language in providing an eligible veteran is "an individual [who] . . . has a serious injury, including traumatic brain injury, psychological trauma, or other mental disorder[.]"<sup>14</sup> That phrasing leaves an important issue unresolved. The final rule should clarify that caregivers of veterans who incurred a serious illness or disease in service on or after 9/11 will not be excluded from the comprehensive assistance program.

While the statute does not define the term "serious injury", the statutory language is instructive. Its key provision is "serious injury (including traumatic brain injury, psychological trauma, or other mental disorder)."<sup>15</sup> The dictionary definition of "injury" encompasses any kind of suffering, which would include diseases. See Webster's third new international dictionary 1164 (3d ed. 1976) (defining "injury" to mean "hurt, damage, or loss sustained."); random house unabridged dictionary 983 (2d ed. 1993) (defining "injury" as "a particular form or instance of harm."); Merriam Webster collegiate dictionary (10th ed. 1996) (defining "injury" as "hurt, damage, or loss sustained."). Moreover, the use of the word "including" in Section

<sup>14</sup> 38 CFR § 71.20(b) (2011)

<sup>15</sup> 38 U.S.C. § 1720G(a)(2)(B) (2010).

1720G(a)(2)(B) is not to be construed narrowly, as providing an all inclusive list of qualifying disabilities, but rather sets forth examples of the types of disabling conditions that would constitute a “serious injury” under the statute. *See Federal Land Bank of St. Paul v. Bismarck Lumber Co.*, 314 U.S. 95, 100 (1941) (“the term ‘including’ is not one of all-embracing definition, but connotes simply an illustrative application of the general principle.”). By including “other mental disorder” in addition to those caused by “psychological trauma,” the statute strongly suggests an intention to include not only disabling conditions caused by external trauma, but also conditions that may have been caused by an illness or disease process.<sup>16</sup> While it seems clear that the phrase “serious injury” cannot be read to mean only “traumatic injury,” the inquiry does not end there.

While the statute itself does not provide a more concrete definition of the phrase “seriously injured,” that term has been widely used by the Department of Defense (DoD) and Department of Veterans Affairs (VA) in relation to benefits, care and services provided to servicemembers and veterans of Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF). DoD classifies casualties for reporting purposes into one of the following seven casualty statuses: Deceased, DUSTWUN (a temporary status), Missing, Very Seriously Ill or Injured (VSI), Seriously Ill or Injured (SI), Incapacitating Illness or Injury (III), and Not Seriously Injured (NSI).<sup>17</sup> This DoD classification system is used by both DoD and VA to provide and coordinate care to servicemembers of OEF and OIF. For example, DoD uses these classifications to determine eligibility for a servicemembers’ next of kin (NOK) to receive travel at government expense to aid the servicemember’s recovery through presence at their hospital bedside.<sup>18</sup> Both VA and DoD use this classification to qualify a servicemember for the assignment of a Federal Recovery Care Coordinator, the individuals tasked with ensuring seamless transition from DoD to VA care.<sup>19</sup> As a further example, VA uses this classification to assign case managers to veterans of OEF and OIF in order to ensure that their care is well coordinated.<sup>20</sup>

The legislative history of the Veterans and Caregivers Omnibus Health Services Act, P.L. 111–163, makes clear that Congress intended for caregiver benefits under the act to extend to those servicemembers of OEF and OIF who are classified as “seriously ill or injured” or “very seriously ill or injured.” The Joint Explanatory Statement that accompanied the legislation expressly states:

The Compromise Agreement also includes an authorization for appropriations that is below the estimate furnished by the Congressional Budget Office. The lower authorization level is based on information contained in a publication (Economic Impact on Caregivers of the Seriously Wounded, Ill, and Injured, April 2009) of the Center for Naval Analyses (CNA). This study estimated that, annually, 720 post-September 11, 2001 veterans require comprehensive caregiver services. The Compromise Agreement limits the caregiver program only to “seriously injured or very seriously injured” veterans who were injured or aggravated an injury in the line of duty on or after September 11, 2001.<sup>21</sup>

The referenced study conducted by the Center for Naval Analyses (CAN), entitled “Economic Impact on Caregivers of the Seriously Wounded, Ill, and Injured,” expressly based its estimates of the need for caregiver services on the DoD classifications of “Very Seriously Injured and Ill” and “Seriously Injured and Ill.” Thus the study states:

We estimate that the average annual incidence of seriously WII servicemembers needing a caregiver is about 720. This estimate is based on the number of “very seriously ill or injured” or ‘seriously ill or injured’ (VSI/

<sup>16</sup>Psychological trauma” is not itself a psychiatric diagnosis. See *Diagnostic and Statistical Manual of Mental Disorders, 4th. Edition*, American Psychiatric Association.

<sup>17</sup>“Military Personnel Casualty Matters, Policies, and Procedures,” Department of Defense Instructions 1300.18, September 18, 2000, p. 19, <http://biotech.law.lsu.edu/blaw/dodd/corres/pdf2/i130018p.pdf>.

<sup>18</sup>“Military Personnel Casualty Matters, Policies, and Procedures,” Department of Defense Instructions 1300.18, September 18, 2000, p. 7, <http://biotech.law.lsu.edu/blaw/dodd/corres/pdf2/i130018p.pdf>.

<sup>19</sup>Memorandum from the Under Secretary of Defense for Personnel and Readiness, June 10, 2009, [http://www.health.mil/libraries/HA\\_Policies\\_and\\_Guidelines/09-021.pdf](http://www.health.mil/libraries/HA_Policies_and_Guidelines/09-021.pdf).

<sup>20</sup>VHA Handbook 1010.01, “Transition Assistance and Case Management of Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) veterans,” May 31, 2007.

<sup>21</sup>Joint Explanatory Statement Submitted by Senator Akaka, Chairman of the Senate Committee on Veterans’ Affairs, Congressional Record, April 22, 2010, S2567, <http://www.gpo.gov/fdsys/pkg/CREC-2010-04-22/pdf/CREC-2010-04-22-pt1-PgS2566.pdf#page=1>.

SI) servicemembers. If we restrict this to just VSI cases, the average annual number is 170.<sup>22</sup>

While the statute uses a truncated reference to the DoD classification system, “seriously injured,” rather than the full reference to “seriously injured and ill,” this should not be interpreted as an intent to further limit eligibility by excluding servicemembers whose need for caregiver services is based on illness. It is common for the DoD classifications of “Very Seriously Injured and Ill” and “Seriously Injured and Ill” to be truncated when referenced to “very seriously injured” and “seriously injured.” For example, in a 2005 memorandum between the Department of Defense and Department of Veterans Affairs with the express subject of “Expediting Veterans Benefits to Members with Serious Injuries and **Illnesses**,” the body of the memo truncates the reference by deleting the word “ill” as follows:

The Department of Veterans Affairs (VA) and the Department of Defense (DoD) identified an initiative to expedite data exchange between the DoD and the VA for **seriously injured** members, and those members entering the Physical Evaluation Board Process.<sup>23</sup>

Similarly, in a 2008 report the Department of Veterans Affairs Office of the Inspector General noted that the truncated reference to “seriously injured” or “seriously disabled” was meant to refer to the traditional DoD classification codes that include illness, stating:

VBA defines seriously disabled veterans as servicemembers who definitely or possibly will be discharged from military service because of **an injury or illness** and all veterans with DoD classification codes of very seriously injured, seriously injured, or a special category involving an amputation.<sup>24</sup>

Despite the use of the common, truncated reference to DoD’s classification of “Seriously Injured and Ill, Congress clearly intended the legislation to cover those individuals identified in the (CNA) study as in need of caregiver services, estimated to be 720 families annually, and appropriated funding to cover the costs of providing caregiver benefits to those families.

Finally, the caregiver law cannot be read in isolation and without regard to the carefully woven system of benefits codified in title 38 of the U.S. Code, which it amends. Importantly, with a single readily distinguishable exception,<sup>25</sup> the entire VA benefit system is structured so as not to differentiate between injury and illness as a basis for eligibility. Thus, veterans are equally eligible for monetary compensation for any injury or illness that is incurred coincident with service or is aggravated by service,<sup>26</sup> entitlement to higher levels of “special monthly compensation” may be awarded based on disabilities resulting from either an injury or disease process,<sup>27</sup> and veterans who are determined catastrophically disabled due to an injury or disease receive a higher priority access to VA health care.<sup>28</sup> The caregiver provisions should be interpreted in harmony with the general principle established in the statutory scheme, that veterans with a qualifying disability are entitled to benefits whether such disability resulted from an injury or an illness. *See Exxon Mobil Corp. v. Allapattah Services, Inc.*, 545 U.S. 546, 559 (2005) (“In order to determine the scope of [a statutory provision] . . . then, we must examine the statute’s text in light of context, structure, and related statutory provisions”); *United States v. Gomez*, 490 U.S. 858, 864 (1989) (“We interpret the Federal Magistrates Act in light of its structure and purpose.”).

## 2. The Stipend

### a. *In establishing a schedule for caregiver stipends, the IFR unreasonably applies an untested, flawed “scoring” methodology that*

<sup>22</sup>“Economic Impact on Caregivers of the Seriously Wounded, Ill, and Injured,” CNA Analysis and Solutions, April 2009, p. 3, <http://www.cna.org/documents/D0019966.A2.pdf> (*emphasis added*).

<sup>23</sup>Memorandum from the Under Secretary of Defense for Personnel and Readiness, September 27, 2005, [http://www.health.mil/libraries/HA\\_Policies\\_and\\_Guidelines/05-018.pdf](http://www.health.mil/libraries/HA_Policies_and_Guidelines/05-018.pdf).

<sup>24</sup>“Audit of Veterans Benefits Administration Transition Assistance for Operations Enduring and Iraqi Freedom Servicemembers and Veterans,” Department of Veterans Affairs Office of Inspector General, July 17, 2008, pg. i, <http://www.va.gov/oig/52/reports/2008/VAOIG-06-03552-169.pdf> (*emphasis added*).

<sup>25</sup>38 U.S.C. § 1980A (2010).

<sup>26</sup>38 CFR § 3.303(a) (2011).

<sup>27</sup>38 CFR § 3.350(a)(3),(f)(4)(i) (2011).

<sup>28</sup>38 C.F.R. § 17.36(e) (2011).

***dramatically underestimates the number of hours of caregiving needed by an individual who requires supervision or protection and is inconsistent with law.***

The caregiver law directs that the amount of the monthly personal caregiver stipend is to be determined in accordance with a VA-established schedule that is based on the amount and degree of personal care services provided. The VA explains that in arriving at a stipend amount it will determine the veteran's level of dependency by reference to the degree to which the veteran is unable to perform activities of daily living or the degree to which the veteran is in need of supervision or protection based on symptoms or residuals of neurological or other impairment or injury. The IFR methodology with reference to the criterion, need for supervision and protection, fails even to approximate the amount and degree of personal care services many wounded warriors with traumatic brain injury and other behavioral impairments need. In describing that methodology, the VA explains that its "scoring criteria" are "based on three widely accepted clinical tools for measuring ADLs and functional dependence: The Katz Basic Activities of Daily Living Scale, the UK Functional Independence Measure and Functional Assessment Measure; and the Neuropsychiatric Inventory."<sup>29</sup> We note, in that regard, that at least one of those tools, the Neuropsychiatric Inventory, is not, by its own description, a tool for measuring functional dependence, but instead an assessment tool to monitor change. The following case profiles demonstrate that, regardless of the utility of those tools in *other* settings, the scoring methodology itself has not been adequately tested, and must be revised.

1. Veteran A returned from Iraq in 2008 and has been clinically diagnosed with severe depression which began in service. He is able to perform all activities of daily living, but is unable to work or perform much in the way of gainful activity because of symptoms of depression which include utter lack of energy, difficulty in even getting out of bed or concentrating on tasks, and feelings of hopelessness. Medications have not alleviated his now-chronic symptoms, and his family members have maintained virtually full-time watch to ensure that he does not attempt to harm himself. Under the current scale, since a need for total assistance in any one domain is assigned a rating of only "4", Veteran A is rated as a "4" for safety risk, "4" for self-regulation, and "4" for difficulty with planning and organizing, for a total score of 12. Because the scoring criteria under the IFR creates an irrebuttable presumption that a veteran with a score of 12 or less requires 10 hours per week of caregiver assistance, this veteran's primary caregiver, his wife, would receive a stipend for 10 hours of caregiving per week—or about \$15 day—even though she is effectively a full-time caregiver and thus unable to pursue employment and earn any additional income.
2. Veteran B returned from Afghanistan where he sustained a severe traumatic brain injury and other wounds as a result of an IED blast. After a lengthy post-operative course during which he underwent extensive rehabilitation, he walks with a limp but is able to perform all activities of daily living. Despite his head injuries, he has no cognitive deficit, seizures, memory problems, or difficulty with planning and organizing. In fact, the single manifestation of his injuries is that he experiences severe, erratic mood swings, and unpredictably and often exhibits aggressive and even violent outbursts. He is unable to control these behaviors, even with medication, and as a result is unable to work. His wife accompanies him everywhere—serving as a buffer to avoid incidents, driving him to frequent medical appointments, and keeping him out of trouble. Under the IFR rating scale, veteran B is rated as a 4 based on total inability to self-regulate; as a result, his wife would receive the minimum stipend, based on the methodology that "the eligible veteran is presumed to require 10 hours per week of caregiver assistance." Notwithstanding that regulatory presumption, the fact is that his wife is his full-time caregiver.
3. Veteran C sustained a moderate to severe traumatic brain injury during his third tour in Iraq and suffers from severe chronic short-term memory loss. While he is able to carry out all activities of daily living, he is both very forgetful and easily distracted. As a result, he is unable to work and spends much of his time at home. Even after a lengthy period of rehabilitation, he manifests behaviors such as forgetting to turn off appliances or the stove that have frightened his family. His mother felt the need to quit her job and stay home with him to prevent any mishap. Under the current scale, Veteran C is rated

<sup>29</sup> *Federal Register* (May 5, 2011): 26150.

as 4 for difficulty with planning and organizing, a 4 for safety risks, and a 4 for difficulty with recent memory, for a score of 12. Under the IFR rating criteria, Veteran C's mother, his primary caregiver, would receive a stipend that is based on the assumption that she provides only 10 hours of caregiving assistance per week; in fact she spends approximately that much time in a caregiving capacity *daily*.

These hypotheticals underscore the fundamental flaw in the IFR scoring methodology applicable to caregivers who provide protection or supervision. If an aggregated scoring methodology is to be employed, it must recognize that deficits in a single domain—such as being a safety risk or being unable to regulate severe mood swings, for example—may create a need for total assistance and should be sufficient to result in a determination that the veteran requires full-time caregiving. Yet this model fails to recognize that, unlike a methodology that gauges caregiving need of an individual with limitations in activities of daily living, a need for full-time caregiving cannot necessarily be determined by an aggregated-scoring tool.

WWP's recent survey of caregivers demonstrates the above-cited concerns, as illustrated by a respondent's comments:

*I was told that my husband scored in the low Tier level I, with an '11.' This only allows 10 hrs 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 hrs a week is like about 1.42 hrs a day. I have to help him remember to take meds 3 x times daily, assist with cooking, driving, medical appointment; and just overall supervision for his safety. Ten hours a week is nowhere near the time I spend caring for him.*

Clearly, as the above examples illustrate, the scoring methodology is flawed as it relates to assessing the extent and degree of personal services required by veterans for whom caregiving-assistance is based on a need for supervision or protection. But the criteria suffer from a more fundamental flaw. Under the law, "the amount of the . . . stipend . . . shall be determined in accordance with a schedule established by the Secretary that specifies stipends based upon the amount and degree of personal care services provided."<sup>30</sup> The law defines the phrase "personal care services" in pertinent part to mean "services that provide the veteran . . . [a]ssistance with one or more independent activities of daily living."<sup>31</sup> Those IADL's assess the relative ability of an individual to carry out specified activities independently, to include use the telephone, shop, prepare meals, keep house, do laundry, travel, take medications correctly, and handle finances.<sup>32</sup> The law clearly requires the VA at least to include these criteria in determining the amount and degree of personal care services a caregiver is providing, as it relates to determining a stipend amount. The IFR does not do so, and, accordingly, is not consistent with law.

For the reasons set forth above, Section 71.40(c)(4) must be revised.

**b. While establishing a cap of 40 hours/week for a caregiver stipend, the IFR does not address how caregiving-needs exceeding 40 hours would be covered.**

The IFR states that an eligible veteran with a score of "21 or higher . . . is presumed to require 40 hours per week of Caregiver assistance."<sup>33</sup> But it fails to address circumstances under which caregiving-needs exceed that limit. WWP understands that the intent of this provision is to cap stipend amounts at that level. The underlying rationale, as WWP understands it, is laudatory—to avoid having caregivers work unreasonably long, strenuous hours and to give them respite by meeting those additional needed caregiving hours through home health agency services. That important policy should be specifically articulated in the regulation. However, the policy must also take account of the circumstances facing caregivers in rural and other areas where home health services are not available (as well as those instances in which agencies are not capable of providing the required specialized care a wounded warrior needs). Given those relatively frequent situations, WWP believes it would be unreasonable to fail to address this situation. We urge that the VA revise the regulation to afford caregivers a reasonable opportunity to rebut the presumption that a veteran requires only 40 hours of caregiver assistance a week, and,

<sup>30</sup> 38 U.S.C. § 1720G(a)(3)(C)(i) (2010).

<sup>31</sup> 38 U.S.C. § 1720G(d)(4) (2010).

<sup>32</sup> Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist* 1969; 9(3):179-186; <http://www.unmc.edu/media/intmed/geriatrics/nebgec/pdf/frailelderlyjuly09/toolkits/timmactivitiesdailyliving.pdf>.

<sup>33</sup> 38 CFR § 71.40(c)(6)(4)(iv)(a) (2011).

accordingly to enable a caregiver to receive a stipend amount that encompasses and reasonably approximates the additional number of caregiving hours that circumstances may require.

**c. Setting the stipend rate based only on the amount of services provided is inconsistent with law.**

In directing the Secretary to establish a schedule for determining the amount of the monthly caregiver stipend, the statute provides the VA must, to the extent practicable, ensure that the stipend amount “is not less than the monthly amount a commercial home health care entity would pay an individual in the geographic area of the eligible veteran to provide equivalent personal care services to the eligible veteran.”<sup>34</sup> Importantly, two different considerations must be built into the development of that stipend schedule: “the amount and degree of personal care services provided.”<sup>35</sup> The VA’s formulation, however, interprets the statute in a manner that effectively ignores the term “degree.” This interpretation cannot stand.

The VA explains that “the direct stipend payment is calculated based on the BLS wage rate for a Home Health Aide using the 75th percentile of the hourly wage rate in the geographic area of residence of the eligible veteran.”<sup>36</sup> The Bureau of Labor Statistics describes a home health aide as one who provides “routine individualized health care such as changing bandages and dressing wounds, and applying topical medications to the elderly, convalescents, or persons with disabilities at the patient’s home or in a care facility. Monitor or report changes in health status. May also provide personal care such as bathing, dressing, and grooming of patient.”<sup>37</sup> WWP submits the caregiving needs of many within the population of young severely wounded veterans are far more extensive than the kind of routine care described by BLS, and often cannot be met by a home health aide. In describing her role as a caregiver, one explained, “I am my husband’s accountant; occupational therapist; physical therapist; driver; mental health counselor; and life coach.”<sup>38</sup> Further, during its consideration of caregiver legislation, Congress heard testimony indicating that home health aides often lack the specialized training or capability to meet the needs of profoundly disabled veterans.<sup>39</sup>

The VA states that “[w]e determined that the 75th percentile most accurately reflects the national hourly wage rate for the competencies to be performed.”<sup>40</sup> WWP questions the basis for that determination. Family caregivers of more severely wounded veterans seldom provide simply home-health care, but typically assist (and often substitute for) the veteran in carrying out a range of other demanding responsibilities, to include financial management and running a household. The VA states that “[t]here is a large standard deviation on wage rates for home health aides depending on their experience and education as well as the economic factors in the geographic area (mainly supply and demand).”<sup>41</sup> Given the higher level of functions provided by many caregivers, and the VA’s own acknowledgement that wage rates vary depending on the complexity of duties performed, the seventy fifth percentile fails to address adequately the degree of personal care services provided.

Finally, setting the stipend at the 75th percentile fails to take account of the purpose of the stipend, which is to provide a level of financial support to ensure that the economic strains on family caregivers do not result in or contribute to families no longer being able to sustain their caregiving.<sup>42</sup> The Secretary cannot ignore the reality that setting the stipend level too low will directly result in continued economic strain for caregivers. As scholars have observed, caregiver pay provides a low living standard and “caregiver” is included in the class of low-wage jobs that leave

<sup>34</sup> 38 U.S.C. § 1720G(a)(3)(C)(ii) (2010).

<sup>35</sup> *Id.* at § 1720G(a)(3)(C)(i) (emphasis added).

<sup>36</sup> *Federal Register* (May 5, 2011): 26154.

<sup>37</sup> U.S. Department of Labor, Bureau of Labor Statistics, Occupational Employment and Wages, May 2010, 31–1011, Home Health Aides, <http://www.bls.gov/oes/current/oes311011.htm>.

<sup>38</sup> Wounded Warrior Project Statement for the Record, “Oversight Hearing: TBI—Progress in Treating the Signature Wound of the Current Conflicts,” Committee on Veterans Affairs, U.S. Senate, May 5, 2010.

<sup>39</sup> See testimony of Anna Frese, “Meeting the Needs of Family Caregivers of Veterans,” Committee on Veterans Affairs, U.S. House of Representatives, Hrg. No. 111–26, 111th Cong. 1st Sess., June 4, 2009.

<sup>40</sup> *Federal Register* (May 5, 2011): 26154.

<sup>41</sup> *Id.*

<sup>42</sup> See Sen. Rep. No. 111–080, Caregiver and Veterans Health Services Act of 2009 (September 25, 2009), [http://thomas.loc.gov/cgi-bin/cpquery/?&dbname=cp111&sid=cp111sBb3W&refer=&r\\_n=sr080.111&item=&&sel=TOC\\_0&Hearing+on+Pending+Health+Care+Legislation](http://thomas.loc.gov/cgi-bin/cpquery/?&dbname=cp111&sid=cp111sBb3W&refer=&r_n=sr080.111&item=&&sel=TOC_0&Hearing+on+Pending+Health+Care+Legislation),” Committee on Veterans Affairs, U.S. Senate (April 22, 2009); [http://veterans.senate.gov/hearings.cfm?action=release.display&release\\_id=55fa0387-887a-479f-b97618c26056444e](http://veterans.senate.gov/hearings.cfm?action=release.display&release_id=55fa0387-887a-479f-b97618c26056444e)



workers struggling.<sup>43</sup> Caregivers and other direct-service workers often do not receive livable wages, and a high proportion of these workers rely on some form of public assistance in order to make ends meet.<sup>44</sup> Considered in terms of Bureau of Labor Statistics' national estimates, a uniform per-hour stipend rate at the 75th percentile is only \$11.55/hour, more than \$2.50/hour, or 18 percent, below the national estimate at the 90th percentile.<sup>45</sup>

Given that the stipend was designed to both reflect the degree of services provided by family caregivers and afford caregivers financial support to ease their economic strain, WWP urges that the caregiver stipend be appropriately set at the 90th percentile of the hourly wage rate in the geographic area of residence of the eligible veteran rather than the 75th.

### **3. The IFR fails to address the processes for appealing adverse decisions.**

The IFR is silent with respect to both a right to appeal adverse decisions under the program and with respect to the processes for exercising that right. The omission is glaring and must be remedied. An application for caregiver assistance may call upon VA personnel to make a wide-ranging number of decisions any one of which holds the potential for damaging error.

To illustrate, the law contemplates the potential for numerous clinical determinations under the law, with clinical judgment potentially involved in such determinations as whether there is a need for personal care services; whether provision of caregiver-assistance "is in the best interest of the veteran;" the extent of caregiver-assistance the veteran requires; and the quality of the personal care services provided to the veteran. Any one of those decisions has far-reaching ramifications. Yet VA claimants are barred from obtaining judicial or even administrative review (through the Board of Veterans Appeals) of "medical determinations." It is critical, therefore, that with respect to those decisions that are truly medical determinations, the final regulation should, at a minimum, (a) specify the mechanism or mechanisms through which a caregiver or veteran may appeal such a decision, (b) require that caregivers and veterans be provided a written explanation of the basis of any clinical determination they question, (c) be afforded the right to provide independent medical evidence in support of any appeal, and (d) be afforded a reasonably prompt, independent review of such appeal.

The caregiver law, of course, states that "[a] decision by the Secretary under this section affecting the furnishing of assistance or support shall be considered a medical determination."<sup>46</sup> In our view, therefore, a final regulation must provide claimants and Department personnel clear direction as to precisely which issues under this program are actually medical determinations and which are not. We believe that the proper definition of "medical determinations" is the one provided in 38 CFR § 20.101(b): "Medical determinations, such as determinations of the need for and appropriateness of specific types of medical care and treatment for an individual, are not adjudicative matters and are beyond the Board's jurisdiction. Typical examples of these issues are whether a particular drug should be prescribed, whether a specific type of physiotherapy should be ordered, and similar judgmental treatment decisions with which an attending physician may be faced." Clearly establishing the applicability of this definition is essential to making sure that veterans do not lose their due process rights to challenge any adverse eligibility determination, as they have such rights as to other services and benefits provided by the Veterans Health Administration. *See, e.g.*, 38 CFR § 20.101(b) ("The Board's appellate jurisdiction extends to questions of eligibility [.]"). Providing a cross-reference to that regulation would limit unappealable decisions under the statute to the kinds of clinical determinations addressed in regulation. *Compare Zimick v. West*, 11 Vet. App. 45, 48 (1998) ("[S]pecific medical determinations as to the appropriate medical treatment are not adjudicative matters over which the Board has jurisdiction."), *with Meakin v. West*, 11 Vet. App. 183, 187 (1998) ("determinations as to whether the applicant is a veteran, whether he seeks treatment for a service-connected disability, and whether VA facilities are geographically inaccessible are on their face obviously not medical determinations."). Any broader limitation of appealability would raise serious due process concerns by precluding veterans from challenging eligibility and other similar determinations, to which they have property rights under law. *See*

<sup>43</sup> *See* Beth Shulman, *The Betrayal of Work: How Low-Wage Jobs Fail 30 Million Americans*, The New Press (2003).

<sup>44</sup> Hewitt et al., "A synthesis of direct service workforce demographics and challenges access intellectual/developmental disabilities, aging, physical disabilities, and behavioral health," National Direct Service Workforce Center (Nov. 2008).

<sup>45</sup> Bureau of Labor Statistics, *Id.*

<sup>46</sup> 38 U.S.C. § 1720G(c)(1) (2010).

*Mathews v. Eldridge*, 424 U.S. 319, 332 (1976); *Nat'l Ass'n of Radiation Survivors v. Derwinski*, 994 F.2d 583, 588 n.7 (9th Cir. 1992).

Certainly Congress cannot be deemed to have intended to abrogate a claimant's right to due process. Additionally, Section 1720G(c)(1) must be read to harmonize with an existing body of law, and longstanding precedent, governing appellate and judicial review. Congress cannot have intended that claimants would be denied the opportunity to pursue appellate remedies on issues that would otherwise be subject to such review. By way of illustration, Congress could not have intended to deny claimants a right to administratively appeal a decision that a veteran's injury was not (a) incurred in line of duty; (b) incurred on or after September 11, 2001, or (c) incurred in service. Congress could not have intended to deny a veteran the right to appeal a VA determination that denies his or her application for comprehensive caregiver assistance on the basis that the caregiver is not a member of the veteran's family under 38 U.S.C. § 1720G(d)(A). A VA denial of a veteran's application based on a decision under 38 U.S.C. § 1720G(d)(B) that the veteran's caregiver (who is not a member of the veteran's family) does not *live* with the veteran surely cannot be beyond review on the ground that it is a "medical determination." A decision to deny a designated Primary caregiver travel benefits or a monthly stipend to which she or he is specifically entitled by law cannot be beyond the range of administrative and judicial review. Even decisions made by clinicians cannot be shielded from administrative review as an exercise of medical judgment when they are mistakenly based on the wrong legal standard. It is not inconceivable, for example, that a clinician or clinicians might determine that a veteran not in need of personal care services based on their employing a "need for nursing home care" criterion, contrary to law.

While Section 1720(c)(1) is apt recognition that implementing Section 1720G(a) would entail a series of determinations requiring the exercise of medical judgment, the legislative history provides not a scintilla of evidence to suggest that Congress had any intention of taking the unprecedented step of depriving veterans of longstanding appellate rights. The final regulation must make that clear.

**4. *The IFR provisions regarding respite care fail to address specific requirements of the caregiver law.***

Respite is one of the most important needs caregivers face, and the caregiver law provides important direction regarding this vital support. But the IFR omits reference to a key provision of the law. While the IFR states that respite care is to include "24-hour-per day care . . . commensurate with the care provided the Family caregiver to permit extended respite," the IFR is silent regarding the critically important statutory direction that "respite care . . . shall be medically and age-appropriate and include in-home care." Department officials have advised that this omission was unintentional. WWP appreciates programmatic efforts to stress the importance of making such respite available, and certainly looks forward to having this requirement clearly articulated in the final regulation. Of course, absent language that at least restates that requirement, there is concern that VA facility personnel might at some point erroneously advise caregivers that their only extended-respite option is to place their warriors in VA nursing home units—precisely the concern that prompted the age-appropriate, in-home provisions of the law.

**5. *The final regulation should clarify CHAMPVA eligibility where a caregiver loses prior coverage.***

Section 71.40(c) aptly states that "VA will provide to Primary family caregivers all of the benefits listed in paragraphs (c)(1) through (4)." But the IFR goes on to state at Section 71.40(c)(3) that "primary family caregivers *are to be considered* eligible for enrollment in the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA), unless they are entitled to care or services under a health-plan contract".<sup>47</sup> Stating that "caregivers *are to be considered* eligible" undercuts that directive language—diluting an expression of entitlement into a vague instruction. In short, the phrase "to be considered" is ambiguous surplusage, and should be deleted from the final regulation.

The IFR phrasing has significance, however, because it highlights the fact that unidentified VA personnel will make determinations under this section as to whether caregivers "are entitled to care or services under a health-plan contract." That raises the question, what further guidance will those personnel be given in making such determinations? It would not be extraordinary, for example, particularly under current economic conditions, for a caregiver to lose health insurance coverage benefits after having begun to receive VA caregiver-assistance. (One can readily imagine,

<sup>47</sup> 38 CFR § 71.40(c)(3) (2011).

for example, the plight of a middle-aged mother who, as her warrior-son's full-time caregiver, suddenly loses health benefits when her husband loses his job. Consider also that the same caregiver, living on a fixed, limited income and facing growing expenses might lose health coverage because of being unable to afford to pay health-care premiums.) It should be made clear that entitlement to CHAMPVA coverage is not simply a one-point-in-time determination, but that this support must be provided when needed throughout the period of caregiving.

The law itself makes this clear, stating without qualification as to any point in time, "the Secretary shall provide to family caregivers . . . medical care under Section 1781 of this title." Importantly, too, the purpose of the law is "to provide assistance to caregivers of veterans" in recognition of their inherent vulnerabilities.<sup>48</sup> As WWP testified in support of the S. 801 (later incorporated into S. 1963), "studies have shown that family caregivers experience an increased likelihood of stress, depression, and mortality as compared to their non-caregiving peers" and "caregivers report poorer levels of perceived health, more chronic illnesses, and poorer immune responses to viral challenges."<sup>49</sup> Senator Daniel Akaka, the lead sponsor of S. 801 and then-Chairman of the Senate Veterans' Affairs Committee, acknowledged these vulnerabilities and stated that the purpose of S. 801 was to "help alleviate those problems [such as decreased household income and potential loss of health insurance] so as to allow the caregiver to focus entirely on caring for the veteran."<sup>50</sup> A caregiver's losing health coverage certainly creates additional vulnerability for both the caregiver and the veteran. We urge that the provision be clarified to ensure that caregivers who at any point in time lose prior health benefits can enroll in CHAMPVA.

**6. The final regulation should clarify eligibility for reimbursement of travel expenses.**

In comments supplementing publication of the IFR, the VA acknowledges that "VA must provide Primary and Secondary family caregivers with 'lodging and subsistence under [38 U.S.C.] 111(e),"<sup>51</sup> as amended by the caregiver law. The VA states that it has implemented that requirement by including in the IFR a provision stating that family caregivers "are to be considered eligible for beneficiary travel under 38 CFR part 70." This phrasing suffers from the same flaw as the "are to be considered eligible" phrasing employed with respect to CHAMPVA (discussed above). Moreover, the IFR fails to amend the beneficiary travel regulations at 38 CFR part 70 or to include any language addressing the scope of the travel benefit established in Section 104 of the caregiver law. However, that provision of the caregiver law makes it clear that a family caregiver is eligible for the expenses of travel in connection with (and for the duration of) a veteran's examination, treatment, or care notwithstanding that the veteran may not need an attendant to perform such travel.

WWP has received reports from caregivers indicating apparent misunderstanding on the part of VA personnel regarding caregivers' eligibility for beneficiary-travel reimbursement. In our view, failing to include in regulations the substantive changes in beneficiary-travel eligibility established in the caregiver law (beyond the vague statement that caregivers are to be considered eligible for beneficiary travel) can only compound the risk of error.

*Wounded Warrior Project have not received any Federal grants or contracts, during this year or in the last two fiscal years, from any agency or program relevant to the subject of the July 11, 2010 Subcommittee on Health Oversight Hearing on the Caregiver Assistance Program implementation.*

<sup>48</sup> Explanatory Statement: Amendment of the House of Representatives to S.1963 Caregivers and Veterans Omnibus Health Services Act of 2010. Submitted by Senator Akaka, Congressional Record 156:58 S2566 (April 22, 2010) Available from: U.S. Government Printing Office; accessed June 20, 2011.

<sup>49</sup> Hearing on Pending Health-Related Legislation, Committee on Veterans Affairs, U.S. Senate (April 22, 2009)

<sup>50</sup> Senator Akaka (HI). Congressional Record 155:56 (April 2, 2009) p. S4350 Available from: U.S. Government Printing Office; accessed June 20, 2011.

<sup>51</sup> *Federal Register* (May 5, 2011): 26153.

**MATERIAL SUBMITTED FOR THE RECORD**

Committee on Veterans' Affairs  
*Subcommittee on Health*  
 Washington, DC.  
*July 13, 2011*

Ms. Deborah Amdur, LCSW  
 Chief Consultant, Care Management and Social Work  
 Veterans Health Administration  
 U.S. Department of Veterans Affairs  
 810 Vermont Avenue, NW  
 Washington, DC 20420

Dear Ms. Amdur:

In reference to our Subcommittee on Health Committee hearing entitled "Implementation of Caregiver Assistance: Moving Forward?" that took place on July 11, 2011. I would appreciate it if you could answer the enclosed hearing questions by the close of business on August 13, 2011.


In an effort to reduce printing costs, the Committee on Veterans' Affairs, in cooperation with the Joint Committee on Printing, is implementing some formatting changes for materials for all full Committee and Subcommittee hearings. Therefore, it would be appreciated if you could provide your answers consecutively and single-spaced. In addition, please restate the question in its entirety before the answer.

Due to the delay in receiving mail, please provide your response to Jian Zapata and fax your responses to Jian at 202-225-2034. If you have any questions, please call 202-225-9756.

Sincerely,

Michael H. Michaud  
*Ranking Democratic Member*

Enclosure  
 CW:jz

  
**Questions for the Record**  
**House Committee on Veterans' Affairs**  
**Subcommittee on Health**  
**Ranking Member Michael H. Michaud**  
**Hearing on *Implementation of Caregiver Assistance:***  
***Are We Getting It Right?***  
**July 11, 2011**

***Budget***

**Question 1:** Are there any updates in the projected funding needs to implement the caregiver program and to continue to maintain through at least FY 2015?

**Response:** Updated funding needs were provided in the preamble of VA's Caregivers Program Interim Final Rule published on May 5, 2011. The updated estimates are displayed in the chart below:

**Cost of Projections for Caregiver Program—(FY 2011–FY 2015)**

| <b>Description of Costs</b>  | <b>FY 2011</b>         | <b>FY 2012</b>          | <b>FY 2013</b>          | <b>FY 2014</b>          | <b>FY 2015</b>          | <b>5 Year Total</b>     |
|--|------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|
| Caregiver Program Staff  | \$8,083,644.80         | \$19,400,747.43         | \$20,176,777.32         | \$20,983,848.42         | \$21,823,202.37         | \$90,468,220.34         |
| Caregiver Program Stipend  | \$27,617,530.00        | \$77,658,984.00         | \$83,992,329.20         | \$90,834,536.00         | \$96,215,650.00         | \$378,319,029.20        |
| Respite Care   | \$13,815,832.00        | \$35,156,000.00         | \$37,966,400.00         | \$41,107,360.00         | \$44,436,480.00         | \$172,482,072.00        |
| Mental Health Services   | \$305,660.00           | \$992,970.00            | \$1,073,088.00          | \$1,158,606.00          | \$1,254,894.00          | \$4,785,218.00          |
| General Care Educ. & Trng.   | \$6,057,760.00         | \$190,185.60            | \$205,852.80            | \$222,682.50            | \$240,683.40            | \$6,917,164.30          |
| Lodging/Mileage/Meal Per Diem (Veteran Inpatient/ Outpatient Visits) | \$466,975.52           | \$1,211,092.78          | \$1,308,547.76          | \$1,413,433.83          | \$1,528,241.79          | \$5,928,291.68          |
| Mileage for Caregiver Training                                       | \$373,085.00           | \$35,856.00             | \$37,350.00             | \$38,844.00             | \$40,338.00             | \$525,473.00            |
| Health care Coverage (CHAMPVA)                                       | \$2,752,390.92         | \$6,765,401.32          | \$6,943,472.78          | \$7,505,688.62          | \$8,205,989.03          | \$32,172,942.66         |
| Caregiver Oversight (Contract)                                       | \$0.00                 | \$1,448,846.08          | \$1,567,203.20          | \$1,694,887.36          | \$1,833,527.52          | \$6,544,464.16          |
| Caregiver Oversight (VA)   | \$4,014,070.96         | \$10,420,334.14         | \$11,271,763.58         | \$12,189,701.34         | \$13,184,910.50         | \$51,080,780.52         |
| Caregiver Support Line   | \$1,500,000.00         | \$2,500,000.00          | \$2,599,999.58          | \$2,703,999.11          | \$2,812,159.03          | \$12,116,157.72         |
| Study and Survey   | \$245,959.20           | \$238,359.20            | \$225,859.20            | \$0.00                  | \$0.00                  | \$710,177.60            |
| Outreach & Additional Supt. Programs                                 | \$3,811,561.00         | \$2,673,358.00          | \$2,772,356.00          | \$2,830,224.00          | \$2,923,433.00          | \$15,010,932.00         |
| <b>TOTAL</b>   | <b>\$69,044,469.40</b> | <b>\$158,692,134.55</b> | <b>\$170,140,999.42</b> | <b>\$182,683,811.18</b> | <b>\$196,499,508.63</b> | <b>\$777,060,923.18</b> |

**Question 2:** I understand that the Administration has provided an additional \$208 million for implementation of P.L. 111–163.

**Question 2(a):** Is that funding included in the FY 2012 Medical Care budget request?

**Response:** Yes. Of the \$208 million, over \$158 million is for the Caregiver Program and \$49 million is for the remaining requirements in the law.

**Question 3:** Would you be able to provide the Committee the number of requests that you receive for services when you have the final number?

**Response:** Yes. The Department of Veterans Affairs (VA) has developed a comprehensive tracking tool, the Caregiver Application Tracker, which enables us to track the number and status of applications received. As of August 5, 2011, VA has received over 1,729 applications for the Program of Comprehensive Assistance for Family Caregivers. VA made 528 stipend payments in the month of August. At present, 120 primary family caregivers are eligible for Civilian Health and Medical Program for the Department of Veterans Affairs (CHAMPVA) benefits, out of which 83 are eligible for CHAMPVA benefits based on the Program of Comprehensive Assistance for Family Caregivers.

Requests for Caregiver services can include those of both family and general caregivers. Under the new Program of Comprehensive Assistance for Family Caregivers, Family caregiver service requests include applications for stipend and CHAMPVA benefits, as well as requests for training (which is part of the required application process), requests for respite care, and requests for mental health services. All of these requests and related data are being recorded in our newly developed Caregiver Application Tracker and in our existing computerized patient medical record system.

In addition, requests for general caregiver services can include any of the more than two dozen existing VA services that were available to all era veterans and their caregivers prior to the enactment of P.L. 111–163. We have recently developed new funding codes to track the use of general caregiver services and their related costs along with family caregiver services and costs. Tracking and analyzing the data on both family and general caregivers will provide VA with valuable information in planning for the future needs of veterans and their caregivers.

VA will provide regular reporting to Congress on this and other caregiver-related data and information.

### **Eligibility**

**Question 1:** What other information aside from interviews, medical records, consultations with medical staff, compensation and pension examinations, etc. is assessed in determining eligibility for this benefit?

**Response:** Primarily, a determination of eligibility for the Program of Comprehensive Support for Family Caregivers is a clinical assessment. First, eligibility is determined by reviewing the veteran's demographic data to ensure the veteran incurred or aggravated a serious injury in the line of duty on or after September 11, 2001. If this information is missing, incomplete, or in question, further review may be conducted by VA's Health Eligibility Center to obtain required information from Department of Defense (DoD) records.

However, in determining an applicant's clinical eligibility for family caregiver benefits, VA takes a whole-person approach. To that extent, not only do we review records and conduct interviews with the veteran and their caregiver, but the local Caregiver Support Coordinator (CSC) also works with all the members of the Veteran's Patient Aligned Care Team, which may include the veteran's caregiver, the Federal Recovery Coordinator, the Operation Enduring Freedom/Operation Iraqi Freedom/Operation New Dawn (OEF/OIF/OND) Case Manager, service liaisons, occupational or physical therapists, mental health clinicians, and any other medical specialty provider that may be assigned to the team. If there is a question about a particular item on the assessment, the veteran can be seen by a specialist, such as an occupational therapist, to determine the level of personal assistance that the veteran requires in a specific area. VA does require that a veteran be receiving ongoing care from a VA-designated clinical team to participate in the Family Caregiver program.

Primary family caregivers who are entitled to care or services under a health plan contract, including TRICARE, Medicare, Medicaid, or a commercial health insurance plan, are not eligible for CHAMPVA as a primary family caregiver.

**Question 2:** Are there any provisions in place requiring that caregivers be informed of how their eligibility for the stipend is calculated in the event that they would like to appeal the decision?

**Response:** Caregivers are provided with information about filing an appeal when the CSC contacts them regarding a denial. This guide details the clinical appeals process, as well as the requisite steps. CSCs also will help direct caregivers to their facility's patient advocate, who will help the veteran and caregiver through the appeals process.

Based on the feedback received at the July 11, 2011 hearing, and in response to feedback from several caregivers, we are establishing a procedure where family caregivers will be mailed a stipend determination letter that will list their stipend tier (determined by the clinical assessment), their stipend amount (determined by the tier and a formula published in the Interim Final Rule), information on how the stipend was calculated, and the appeals process. The format and content of this letter will be fully developed by September 2011. VA will provide individual letters to each primary family caregiver who has received a stipend to-date, and all new primary family caregiver stipend recipients thereafter. CSCs will then follow up with each stipend recipient to explain the tier amount. During this follow-up, the clinical assessment form will be reviewed with the caregiver and veteran as a quality check and to further explain the tier calculation determination.

**Question 3:** How can a veteran or caregiver appeal an adverse medical or legal decision?

**Response:** A veteran can appeal an adverse decision through VA's clinical appeals process. 38 U.S.C. 1720G(c)(1) specifies that, "[a] decision by the Secretary under this section affecting the furnishing of assistance or support shall be considered a medical determination." Consequently, all decisions regarding eligibility for, and the provision of benefits under, the Caregiver program will be considered medical determinations, appealable through the clinical appeals process, as defined by the Veterans Health Administration (VHA) Directive 2006-057.

In the context of the Program of Comprehensive Assistance for Family Caregivers, the veteran (or designated representative) can appeal a medical decision by requesting a facility-level document review. If the veteran is not satisfied with the decision, he or she may appeal to the Veterans Integrated Service Network (VISN).

The VISN's clinical panel will review the veteran's record along with other documentation and make a recommendation to the VISN Director. The VISN panel can also request an independent external review at any time during the process. A final written report with the findings and recommendations, from the external review, will be provided to the VISN Director within 10 days of the full documentation request. A decision will be made within 30 days for internal reviews, and for external reviews, within 45 days.

In accordance with 38 CFR §20.101(b), which discusses the Board of Veterans' Appeals as they relate to determinations made by VHA, clinical decisions concerning a veteran's need for medical care or the type of medical treatment needed in a particular patient case are not within the Board's jurisdiction; as a result, such clinical decisions may not be appealed to the Board of Veterans' Appeals.

**Question 4:** Has there been discussion about beginning the application for caregiver benefits while a veteran is they are still on active-duty beginning with the start of the Medical Evaluation Board (MEB) process, rather than waiting until they have transitioned to veteran status?

**Response:** Members of the Armed Forces "undergoing medical discharge" are eligible for the Family Caregiver program under the law. However, in response to the Interim Final Rule, we have received a number of public comments regarding the application process and its initiation for current servicemembers. We are currently reviewing these comments and will respond to them pursuant to the regulatory comments process.

**Question 5:** Concerns have been raised that veterans who have incurred a severe illness as a result of their service are excluded from consideration for this program. Is this true?

**Question 5(a):** PVA testified that VA believes that they need clarifying legislation in order to include severe illnesses to be considered for eligibility to the program. Can you please comment on this?

**Response:** The law prescribes eligibility criteria that the veteran or servicemember must meet in order to participate in the Program of Comprehensive Assistance for Family Caregivers including that the veteran or servicemember has a "seri-

ous injury (including traumatic brain injury, psychological trauma, or other mental disorder) incurred or aggravated in the line of duty ... on or after September 11, 2001." 38 U.S.C. 1720G(a)(2)(B).

While "psychological trauma[s]" or "other mental disorder[s]" may be considered illnesses, the statutory eligibility criteria does not account for other conditions that are considered to be *illnesses*, but only those conditions that are considered to be serious injuries. Legislation would be required to authorize VA to include illnesses in the Program of Comprehensive Assistance for Family Caregivers eligibility criteria. Therefore veterans and servicemembers with a serious or severe illness, who do not have a qualifying serious injury, do not meet the statutory eligibility criteria for the Family Caregiver program.

### **Mental Health**

**Question 1:** I appreciate that the Interim Final Rule includes criteria for veterans with traumatic brain injury.

**Question 1(a):** In the case of a veteran who has PTSD, depression or anxiety, has VA explored ways to assist family members who must provide care for these veterans?

**Response:** Psychological trauma or other mental disorders are specifically considered to be serious injuries under 38 U.S.C. 1720G(a)(2)(B), and veterans with these conditions may be eligible for the Program of Comprehensive Assistance for Family Caregivers if all other eligibility criteria are met, including that the veteran's serious injury renders him or her in need of personal care services (as defined) for at least 6 continuous months based on any one of the following clinical criteria: (1) inability to perform an activity of daily living (as defined); (2) need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury (as defined), including traumatic brain injury; (3) psychological trauma or mental disorder that has been scored, by a licensed mental health professional, with a Global Assessment of Functioning (GAF) test scores of 30 or less, continuously for the requisite time period; or (4) service-connection for qualifying serious injury, has been rated 100 percent disabled for that serious injury, and has been awarded Special Monthly Compensation that includes an Aide and Attendance allowance.

Family members of persons with PTSD, depression, or anxiety, as well as family members of veterans with psychosis or bipolar disorder, often need assistance understanding how to support the veteran's independence and strategies to support his or her reaching their specified goals. Family members and loved ones also need support and guidance for their own health. Their needs often are distinct from those of caregivers for veterans with chronic, debilitating physical disorders such as Alzheimer's, dementia, severe cardiovascular illness, or end stage lung disease, which also typically worsen over time despite effective health care. For caregivers of this second group of veterans, obtaining assistance helping the veteran meet basic activities of daily living and instrumental activities of daily living often becomes the paramount issue.

While both groups of family members may clearly benefit from VA assistance, their individual requests usually differ. Families of persons with PTSD, depression, or anxiety, as well as family members of those with psychosis or bipolar disorder, often desire assistance in communicating better with their veteran loved one, learning how to de-escalate conflicts, and developing strategies for supporting the veteran's independence rather than strategies for directly handling the veteran's needs themselves.

Family caregivers of those with chronic physical health conditions may, in contrast, want to know about respite care, protecting the veteran's physical safety, or assuring the veteran does not wander off and become lost. Consistent with this observation, surveyed spouses of veterans with PTSD requested such services as an educational program about PTSD and couples therapy to "better support their loved ones."<sup>1</sup> In contrast, Caregivers of veterans who had had cerebral strokes reported the most unmet needs around managing behavior at home (e.g., falling), managing emotional ups and downs, and assuring the physical safety of the veteran.<sup>2</sup>

In this context of evidence-based, recovery-oriented mental health care, a basic tenet is that many individuals with mental illness are capable of living independently, setting and striving to meet their own personal goals, and handling personal

<sup>1</sup> Sherman, M. D., et al. (2005). Mental health needs of cohabiting partners of Vietnam veterans with combat-related PTSD. *Psychiatric Services* 56(9): 1150-2.

<sup>2</sup> Hinojosa, M. S. and M. R. Rittman (2007). Stroke caregiver information needs: comparison of Mainland and Puerto Rican caregivers. *Journal of Rehabilitation Research and Development* 44(5): 649-58.



challenges. In most cases, they do not need a “caregiver,” as that role is defined in the context of dementia, severe traumatic brain injury, and other chronic, debilitating physical problems. Certainly, research suggests that positive family support can be a critical aspect of recovery from mental illnesses such as PTSD, depression, and anxiety. For example, positive family attitudes are associated with successful outcomes in PTSD treatment,<sup>3</sup> as well as reduced rates of relapse in depression and schizophrenia.<sup>4</sup> Data such as these serve as the foundation for the development of VA’s continuum of family services, which support family members who are assisting with the veteran’s mental health recovery. VA has made a commitment to implementing evidence-based practices, Veteran- and family-driven care, and a recovery-oriented mental health system, where those with mental illnesses have the essential services and supports necessary to live, work, learn, and participate fully in the community.

VA also recognizes that a subset of those with mental illness do have more serious, debilitating, and treatment-resistant symptoms, that are reflected in low scores on the GAF scale. Veterans who do demonstrate sustained low GAF scores (30 or less), pose significant safety risks, or are in need of ongoing supervision, and meet the other program eligibility criteria are eligible for the full range of caregiver benefits. However, VA also is committed to meeting the array of family members’ needs that emerge as they provide care and support for any veteran with mental illness, and VA has embarked on a number of family services initiatives that complement the specific provisions of the Program of Comprehensive Assistance for Family Caregivers. These include discussing family involvement with the patient on a regular basis, offering marriage and family counseling (as provided for under 38 U.S.C. § 1782), family education, veteran-centered family consultation, family psychoeducation (an evidence-based model of family counseling and therapy), and integrative behavioral couples therapy.

#### **Home Visits**

**Question 1:** In our March hearing, it was recommended that the quarterly home visitations be reduced over time to be less intrusive for families. Has this been explored further since?

**Response:** Current guidance to the field is to complete the supportive in-home assessment at least quarterly, or as clinically indicated. In other words, if the veteran has a Home-Based Primary Care Team already providing regular home services, and if the team can also complete the in-home assessment as part of a scheduled service, a separate visit may not be necessary. In addition, if during an initial home visit, no follow-up needs or concerns were identified, the veteran’s clinical team could decide to lengthen the time between home visits. The time span between home visits will remain a clinical decision.

Although we appreciated the individual concerns reported at the hearing and we are reviewing the issues reported, the vast majority of the reports we have received concerning the home visits, have been consistently positive. In most cases, these reports have been unsolicited and support the theory of a helpful and informational home visit. One recent example of these reports includes a caregiver stating, “This was the most extensive evaluation my son has had since he was first injured almost 7 years ago.” We would not want to decrease the frequency of the visits for those who are receiving the support and benefit intended by that process.

Many of the supportive home visits have also enabled VA to identify additional resources and services that can benefit the caregiver and veteran. In several cases, additional care needs for the veteran have been identified and appointments have been scheduled in specialty clinics. Home visits have also resulted in additional equipment being provided in collaboration with the CSC and Patient Aligned Care Team. In one case, the veteran’s young children had few age-appropriate toys to play with because of competing financial decisions the family was forced to make. The nurse who completed the home visit and the CSC were able to identify community resources that provided additional toys to the veteran’s children, and this family was most appreciative. We believe these examples are in keeping with the caring intent and supportive purpose of the home visit requirement.

#### **Monthly Stipend**

**Question 1:** DAV recommends that VA determine the frequency and hours required to perform personal care services.

<sup>3</sup>Tarrier, N., C., et al. (1999). Relatives’ expressed emotion (EE) and PTSD treatment outcome. *Psychol Med* 29(4): 801–11.

<sup>4</sup>Wearden, A. J., et al. (2000). A review of expressed emotion research in health care. *Clinical Psychology Review* 20(5): 633–66.

**Question 1(a):** Can you expand on why this assessment is not used to determine the amount and degree of personal care services each veteran needs?

**Response:** VA determines the frequency and hours required to perform personal care services through a standardized review of the type and intensity of caregiver assistance required to provide a safe and supportive home environment for the veteran. The level of care required is bracketed into tiered categories that can be equated to minimum, medium, or maximum hours (maximum hours would be considered up to 40 hours per week). The amount of the stipend provided to the primary family caregiver will represent the maximum amount available for the tier to which the veteran is assigned. The standardized review is facilitated through an assessment template that includes the major components of three evaluation instruments that are widely accepted in the health care field and that have been refined and consistently validated in research. The assessment template reviews both activities and instrumental activities of daily living; functional capacity specific to mental and cognitive impairment that may be present in traumatic brain injury, post-traumatic stress disorder, or other mental disorders; the veteran's ability to live and function independently; and any need for supervision or protection that may be required to support the veteran's living at home.

The three evaluation instruments that were used to develop VA's Caregiver clinical eligibility assessment template are the *Katz Basic Activities of Daily Living Scale*, the *UK Functional Independence Measure (FIM)* and *Functional Assessment Measure (FAM)*, and the *Neuropsychiatric Inventory (NPI)*.

#### *Katz Index of Independence in Activities of Daily Living*

The Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL, is the most appropriate instrument to assess functional status as a measurement of the client's ability to perform activities of daily living independently. Clinicians typically use the tool to detect problems in performing activities of daily living and to plan care accordingly. The index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. In the 35 years since the instrument has been developed, it has been modified and simplified and different approaches to scoring have been used. In that time, the Katz ADL has gained increased acceptance as an accurate measure of physical functioning. National databases, state long-term care programs, insurers who offer private long-term care insurance policies, Federal legislation, and a body of research literature routinely use limitations in the ADLs identified by Katz as appropriate proxies for an individual's level of physical impairment.

#### *UK Functional Independence Measure (FIM)*

The FIM is the product of an effort to resolve the long standing problem of lack of uniform measurement and data on disability and rehabilitation outcomes. It was designed to assess areas of dysfunction in activities which commonly occur in individuals with any progressive, reversible or fixed neurologic, musculoskeletal and other disorders. The Functional Assessment Measure (FAM) was developed by clinicians representing each of the disciplines in an inpatient rehabilitation program. The FAM was developed as an adjunct to the FIM to specifically address the major functional areas that are relatively less emphasized in the FIM, including cognitive, behavioral, communication, and community functioning measures. In clinical research studies, the FIM+FAM scales have demonstrated high internal reliability and prove adequate for most clinical and research purposes in comparable samples of patients with head injury.

#### *Neuropsychiatric Inventory*

The Neuropsychiatric Inventory (NPI) is a tool for assessment of psychopathology in patients with dementia and other neuropsychiatric disorders. The NPI is based on a structured interview with a caregiver who is familiar with the patient. The following neuropsychiatric domains are evaluated: delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability, apathy, aberrant motor activity, and night-time behavior disturbances.

Content validity, concurrent validity, inter-rater reliability, and test-retest reliability of the NPI are established in research. The NPI is a useful instrument for characterizing the psychopathology of dementia syndromes, investigating the neurobiology of brain disorders with neuropsychiatric manifestations, distinguishing among different dementia syndromes, and assessing the efficacy of treatment.

#### **Training**

**Question 1:** In regard to training, I understand there is a basic self-guided workbook.

**Question 1(a):** Will there be efforts to provide workbooks for more specialized instruction?

**Question 1(b):** Will there be efforts to help tailor training to individual veterans' needs?

**Response:** The workbook is one modality of the comprehensive curriculum that was designed in partnership with Easter Seals to provide family caregivers with the basic information necessary to be successful in their responsibilities. Additional curriculum modalities include the supportive CD that accompanies the home study workbook, traditional classrooms which are scheduled nationwide and are available for scheduling per caregiver request, and a soon-to-be-launched online version of the comprehensive training. The core caregiver training is designed to supplement individual and general training information and services VA has continued to offer.

Training on the individual veteran's needs is a separate process that remains the responsibility of the Patient Aligned Care Team or other assigned provider at the local VA medical center (VAMC). This specific training on individual medical or mental health conditions and needs is presented to the veteran and caregiver at ongoing appointments, in the home, or may have taken place prior to discharge from a VAMC facility or Polytrauma Center. For example, prior to discharge from an inpatient unit, a family caregiver may be taught to change a dressing or assist with intravenous (IV) antibiotics that the veteran will need when they return home. On rehabilitation units, such as spinal cord injuries and disabilities centers, there are apartments available where veterans and caregivers may stay prior to discharge to "test" their new skills before the veteran is discharged.

Additionally, VA has an extensive array of condition-specific training and resources, including classroom and small group training, pamphlets, guidebooks and coordination with local resources, for specific medical or mental health conditions in general. All of this information and these resources are available to any veteran or caregiver as requested or appropriate.

**Question 2:** We heard from one caregiver with 6 plus years of care giving, that she was insulted by the workbook.

**Question 2(a):** Is there a plan to expedite training for those caregivers who already have significant experience?

**Response:** VA understands the frustration experienced by this caregiver and has been mindful of these sensitivities in developing the Easter Seals Caregiver training curriculum. VA believes the training material accurately acknowledges and respects the time and sacrifice of both new and experienced caregivers. Beyond a very small number of similar reports on the workbook, VA has received an unprecedented number of unsolicited reports from caregivers that have been most appreciative and complimentary of the training material.

A recent example of such reports is from a father of a post-9/11 veteran who wrote: "Eight years after embarking on the toughest role of my life, and the most rewarding, I am grateful to see such a user friendly, thorough, simple, encouraging, uplifting, Caregiver training tool. In the span of an hour, I reviewed lessons I was forced to learn on my own (but was grateful for the validation), I was reminded of skills/tips I learned along the way (and sometimes forget to practice) but, most importantly, was provided with an easy-to-navigate workbook that can sit on my kitchen desk as a reminder to our entire family that all of the information necessary to care for [our veteran] (and ourselves) is easily accessible."

While VA recognizes that many caregivers may have already received skills and knowledge through training or experience, it is important to establish a standard baseline of understanding for all family caregivers. We believe this is facilitated through the various training modalities so caregivers can decide independently if they would like to spend 10 to 15 hours in a traditional classroom, or navigate training online or through a self-paced workbook. Since the training includes a brief self-assessment with answers that validates the completion of required training, we believe caregivers can use their own discretion in how much time they spend on the training, and in doing so, they confirm they have received the basic or core training required.

VA and Easter Seals continue to evaluate the caregiver training and will make modifications, as appropriate.

**Question 3:** How many hours long is the training?

**Response:** Current family caregiver classroom training lasts approximately 10 to 15 hours spread over 2 days. The time it takes to complete the workbook will vary significantly from caregiver to caregiver, depending on their existing knowledge and

experience. Again, Family caregivers determine which mode of training they prefer, and many family caregivers have stated they prefer completing the home workbook at their own pace while others have opted for the workbook and plan to attend the classroom training at a later date. An online version of the curriculum will be available shortly.

Family caregivers who have completed the classroom training have reported exponential benefit beyond the training material in being able to meet and network with other caregivers or to learn more about existing VA services and benefits of which they were not previously aware. It should also be noted that the training content and course length was designed with input from caregivers beforehand, and we have actively sought input and feedback from all caregivers completing the training so we can continue to refine the process to best meet the needs of caregivers while also completing the baseline training objective for all caregivers.

#### **CHAMPVA**

**Question 1:** What guidance is given to personnel making determinations regarding CHAMPVA?

**Response:** The CSC at the VAMC receives guidance through training, fact sheets, and procedures to advise the primary family caregiver that eligibility for CHAMPVA health care benefits is limited to those primary family caregivers who are not entitled to care or services under a health plan contract such as TRICARE, Medicare, Medicaid, or other health insurance. The CSC asks the caregiver if he/she has other such coverage, and this information is entered into a database for use by the CHAMPVA program staff. The staff at CHAMPVA, utilizing detailed desk procedures for guidance, verifies that the primary family caregiver is not entitled to care or services under a health plan contract and also reviews the veterans' record to determine if the caregiver may qualify for CHAMPVA based on other eligibility category (other than the individual serving as a designated primary family caregiver).

**Question 2:** Of this first pool of recipients, approximately how many will be receiving CHAMPVA benefits?

**Response:** The first pool of stipend recipients contained 215 primary family caregivers, out of which 80 primary family caregivers were enrolled in CHAMPVA. 65 primary Family caregivers, out of the 80, were eligible for CHAMPVA benefits based on the Program of Comprehensive Assistance for Family Caregivers. At present, 120 primary family caregivers are eligible for CHAMPVA benefits, out of which 83 are eligible for CHAMPVA benefits based on the Program of Comprehensive Assistance for Family Caregivers.

#### **Implementation**

**Question 1:** What training materials are available for secondary caregivers?

**Response:** Currently all the training material available to primary family caregivers is also available to secondary family caregivers. This includes the home-based workbook for the core family caregiver curriculum, the traditional classroom instruction, and the online course. To date, the workbook has been the most requested mode of training, and additional copies of the workbook can be made available upon request. We continue to encourage family caregivers (which can include the primary or secondary caregiver) to attend the classroom instruction when possible because VA has observed additional benefits to caregivers in peer networking and raised awareness of VA services and benefits.

**Question 2:** I commend your partnership with Easter Seals to provide the comprehensive Caregiver Training. How long is this partnership expected to last or will the VA eventually be able to provide this training in house?

**Response:** VA's comprehensive family caregiver training was developed through a contract with Easter Seals, which ends around May 2012. The current partnership has been very beneficial for caregivers, since both VA and Easter Seals have combined efforts and resources to make classrooms, trainers, and networked resources available to caregivers nationwide. VA will review the quality and progress of the Easter Seals training as we move forward and will use that information in determining whether or not to renew the contract or to consider other options in the future.

**Question 2(a):** Are there other organizations also assisting in this training?

**Response:** Yes, several other organizations worked in collaboration with VA and Easter Seals in developing the core caregiver training which included research, de-

sign, development, revision, and now includes ongoing review and quality assurance. These additional organizations include: Atlas Research, the National Alliance for Caregiving, the Family Caregiver Alliance, the National Alliance for Hispanic Health, and the National Family Caregivers Association.

**Question 3:** Would you comment on the variability at the local level that we have heard about in rolling out the program?

**Question 3(a):** How are you monitoring implementation at the VA medical centers?

**Response:** VA researched the issue of variability that was reported in the recent hearing and has continued to review the issue on a broader scale.

As part of our broader review on quality, validity, and inter-rater reliability, VA randomly sampled various caregiver clinical assessments completed at 21 different VAMCs representing each national region, and found that there was a variance of less than 16 percent between similar decisions made by facilities. Of that 16 percent variance, more than half of those would have been rated at a lower stipend tier by the quality reviewer, so the variance that existed was in the veteran's favor. There were three cases identified that the quality reviewer would have rated higher, and each of those cases has been reviewed and adjusted, as necessary, by the Patient Aligned Care Team.

VA will continue to monitor the consistency of implementation of the program across VAMCs. We will also continue to train all staff involved in the assessment and application process to maintain accurate and consistently high quality assessment.

#### *Miscellaneous*

**Question 1:** The National Military Families Association recommends that VA offer these caregivers the opportunity to participate in VA's vocational rehabilitation programs and to help retool the caregiver's resume.

**Question 1(a):** Has this idea been explored?

**Response:** Currently, VA's Vocational Rehabilitation and Employment (VR&E) program may only provide educational and vocational counseling to a family caregiver if the caregiver is eligible for education benefits under Title 38 of the United States Code, Chapter 35, Survivors' and Dependents' Educational Assistance, or is eligible as a veteran for Chapter 31 or education benefits. The President's Commission on Care of America's Returning Wounded Warriors recommended strengthening family support systems and improving the quality of life for families. The availability of educational and vocational counseling, coupled with the supportive counseling provided by VHA, can help caregivers cope with the changes caused by an injury to a family member. These resources facilitate career and life planning by helping caregivers understand available options and explore potential resources for their families.

While VA supports the idea of helping caregivers prepare for and obtain suitable employment, their participation in a VA program of vocational rehabilitation cannot be implemented without the enactment of new legislation.

**Question (2):** Because 17 percent of applicants for these benefits are parents of veterans, what is VA's long term plan in regards to ensuring that veterans are cared for as they age and no longer can be cared for by their families?

**Response:** VA works with the Department of Health and Human Services' Administration on Aging on many initiatives, including Veteran Directed Community Based Care, which allows aging and disabled veterans to remain at home with assistance. In addition, VA has pilot programs such as the Assisted Living Pilot, which allows eligible veterans to be placed in Assisted Living settings that can provide a level of care that is needed well before a veteran requires placement in a skilled nursing facility.

VA will provide ongoing assistance and evaluation of caregivers as they age to ensure appropriate assistance for the veteran as part of the ongoing supportive home visit process.

**Question 3:** Can you provide us with an update on the eight caregiver assistance pilot programs?

**Response:** VA concluded the eight Caregiver Assistance Pilot Programs on August 31, 2009. The outcomes of the pilot programs have guided our development of evidenced-based support programs and services for family caregivers.

The outcome or current status of the eight Caregiver assistance pilot programs includes:

1. REACH VA—Resources for Enhancing Alzheimer’s Caregiver Health: The REACH VA pilot was able to demonstrate a significant decrease in caregiver burden, depressive symptoms, and impact of depressive symptoms on daily life. Improved outcomes for veterans included a decrease in reported troubling dementia related behaviors, and in the potential for abuse as measured by caregiver frustration. There was also a 2-hour decrease in the amount of time the caregiver spent on duty, which represented a trend toward significance. The pilot demonstrated improvement of veteran and caregiver quality of life.

VA is funding the ongoing implementation of REACH VA. Sixteen (16) sites are currently trained in and are using REACH VA as an intervention. VA is planning to expand REACH VA to all VAMCs within the next 5 years. REACH VA is also currently being adapted for use with caregivers of veterans with spinal cord injuries and disabilities, and will be piloted with this population later in 2011. A plan to adapt the program for use with caregivers of veterans with traumatic brain injury is also under review.

2. Transition Assistance Program (TAP): Findings indicate that as caregiver satisfaction with TAP increased, self-efficacy increased and caregiver burden and depression decreased. When coupled with the very high rate of program satisfaction, this pattern suggests TAP participation increased caregivers’ ability to cope with the demands of their roles. Veteran motor function was significantly linked to caregiver satisfaction suggesting that as satisfaction with TAP increased, so did veteran functional ability. These associations occurred across TAP participants and non-participants alike. The pilot did not demonstrate significant differences in resource utilization linked to participation in TAP.
3. VA California Office on Caregiving:
  - a. VA Cares Caregiver Centers of Expertise
  - b. California Caregiver Resource Center
  - c. Powerful Tools’ Caregiver Training Program
  - d. Building Better Caregivers

The pilot identified several new, potentially effective and efficient approaches to providing support to caregivers. General results of the pilot revealed good satisfaction with the Powerful Tools Training (PTC) Course, the Building Better Caregivers (BBC) Workshop, and the Tele-Educational Conferences. Results continue to be collected for the PTC and BBC Internet workshop. Use of the BBC Workshop demonstrated significant improvement in stress, strain, depression, sense of self-efficacy, and reduction of caregiver burden. Although there was no demonstrated impact on health care utilization, it is felt that additional data is required to demonstrate a linkage and a longer period of follow-up beyond the 3-month assessments (originally planned for 6 months) performed in these studies would be needed to properly assess the effects on health services utilization by the caregiver and the veteran.

Both the Building Better Caregivers Workshop and Powerful Tools Training Course are under consideration for national implementation.

4. Tampa and Miami VA Medical Centers Respite and Caregiver Support Program Service: Veterans and caregivers using the pilot respite programs at both Tampa and Miami VAMCs reported high levels of satisfaction with services. Caregiver burden was significantly lower after participation in the pilot respite programs than at baseline. The caregivers at both Miami and Tampa reported significant improvements in mental health and decreased caregiver burden. Decreased use of inpatient services and shorter lengths of stays were both positive outcomes at both Tampa and Miami after the respite program than at baseline.
5. Communicating Effectively with Health Care Professionals: The pilot did not demonstrate any significant impact on the caregiver as a result of the workshop or written materials provided. In addition, the pilot did not demonstrate an impact on veteran health outcomes, provide measurable improvement in health care communication between the caregiver or veteran and VA, or demonstrate a cost savings to VA as a result of the intervention.
6. Telehealth Technology to Support Family Caregivers: The participants (other than the wait list control group) all rated “satisfied” or “very satisfied” with the Health Buddy. However, the pilot failed to demonstrate any impact on health care utilization and caregiver depression and burden measures. This

could be due to the low number of participants or the inability of some participants to complete post-baseline data.

7. Use of Caregiver Advocates: The pilot showed a positive impact on the health care of the caregiver, the caregiver's ability to accept assistance, and a decrease in overall stress or burden experienced by the caregiver. This pilot provided one impetus for the creation of the CSC positions at VAMCs.
8. Heroes of the Heart: The pilot's post-intervention scores seem to suggest that caregiver burden was lowered 2 weeks following the respite intervention, but the overall findings are not significant enough to generalize for all respite interventions. The pilot also found that geographic barriers present many challenges to providing respite care and alternative respite options available in rural areas are limited. VA is currently exploring alternate options for respite care in rural areas.

**Question 4:** To what extent has the U.S. Department of Defense been consulted to ensure seamless transitional caregiver benefits?

**Response:** VA has worked actively with DoD in developing VA's Program of Comprehensive Assistance for Family Caregivers. VA maintains a mutually beneficial working relationship with DoD and is assisting DoD in its development of a similar program. Currently, VA is assisting DoD in discussions with Easter Seals to establish a caregiver training program for active duty servicemembers and their caregivers.

Additionally, VA maintains multiple programs that communicate and liaise with DoD in the seamless transition process for veterans and their caregivers. Federal Recovery Coordinators work actively with servicemembers and their families as they transition from active duty, while VA Liaisons work from Military Treatment Facilities to coordinate transition to VAMCs where they are then assisted by OEF/OIF/OND Program Managers and Social Work Case Managers, as appropriate.

**Question 5:** What sort of outreach has been conducted over the past few months to spread the word about this program?

**Response:** VA is committed to ensuring that stakeholders are informed of the benefits and services available to support family caregivers and the veterans they care for at home. Veterans Service Organizations and caregiver-focused non-governmental organizations have been partners in outreach efforts on the expanded VA services including family caregiver benefits, respite, and other new or existing benefits and services. Many of these organizations have actively hosted information related to the Caregiver program authority in P.L. 111-163 in their publications and on their Web sites. In collaboration with VA, these organizations have also included direct online links to the new Comprehensive Assistance for Family Caregiver program application. Multiple national press releases and media interviews have resulted in the posting of information about VA caregiver benefits and services and the application process in multiple venues. VA's caregiver information is also posted on the main VA Web site.

The Caregiver Support Program established a toll-free National Caregiver Support Line (1-855-260-3274), which opened February 1, 2011, at the Canandaigua VAMC campus. This Support Line is available to respond to inquiries about the new caregiver services associated with P.L. 111-163 and to serve as a resource and referral center for Family Caregivers. The Caregiver Support Line provides referrals to local VAMC CSCs, VA, and community-based resources. The Support line also provides emotional support to family and general caregivers. The Support Line is staffed by licensed social workers and has received more than 12,000 calls since it was established.

In addition to the Caregiver Support Line, the Caregiver Support Program launched a new Web site on May 31, 2011, [www.caregiver.va.gov](http://www.caregiver.va.gov), which provides a wealth of information and resources for veterans, families and the general public. The Web site receives more than 1,000 visits daily with each visitor reviewing more than six separate pages on the Web site per visit.

The Caregiver Support Program has provided multiple national education and training events to VA staff throughout the country and to a wide range of Federal, State, and local organizations. Within each medical center, CSCs have contacted veterans known to their medical center who may be eligible for the Program of Comprehensive Assistance for Family Caregivers. In addition, CSCs have contacted veterans who receive VA's Aide and Attendance benefit who may be eligible for the Program of Comprehensive Assistance for Family Caregivers to provide information on applying for the Comprehensive Program and its benefits, and also to provide support and assistance with other benefits and services.

**Question 6:** Can you provide more information regarding the Peer-Support Mentoring Program?

**Question 6(a):** Is this the same program as the Caregiver Support Advisory Board that is being implemented at the Syracuse, NY, Department of Veterans Affairs (VA) Medical Center, as indicated by Ms. Cheryl Cox?

**Question 6(b):** Will this program be required at all VA Medical Centers?

**Question 6(c):** What would this Board do?

**Response:** VA strongly endorses peer-support mentoring and is facilitating the creation of such programs at its facilities. According to the National Alliance for Caregiving's 2010 survey of caregivers, more than 45 percent of caregivers reported seeking most of their information and support from other caregivers, peers, and online resources. VA is in the process of developing a Peer Support Mentoring Program to harness the power of these relationships and provide a forum and a network of peers who can support and learn from one another. More experienced caregivers will be matched with newer, less experienced caregivers. Peer mentors will be provided with training and ongoing support as they work with caregivers of veterans. Peer mentors can also be bridge builders for caregivers by empowering them to form new supportive relationships and linking them to resources available within VA and the community. We have researched many peer programs both within VA and in the community, allowing us to identify best practices. We will work with caregivers to develop this program and integrate these best practices in the final design of the Peer Mentoring Program. The Caregiver Support Program plans to train the first group of peer mentors by the end of 2011.

A separate initiative is the creation of local Caregiver Advisory Boards, which VA anticipates will support education of and collaboration with veterans, caregivers and VA staff; support the National Caregiver Support Program's mission and goals; and recognize National Family Caregiver Month by providing assistance with an annual event each year. The successful implementation and ongoing support of caregiver services mandated in P.L. 111-163 will be supported by these Boards. In addition, the Boards will support VA in its recognition of the significant contributions caregivers make in caring for veterans, which allows them to safely remain in their homes. VA is working to establish a Caregiver Advisory Board at each VAMC through the CSCs, to ensure compliance with the Federal Advisory Committee Act and any other applicable policies and laws.

#### ***Moving Forward***

**Question 1:** Obviously VA did not meet the timelines set forth in P.L. 111-163 concerning the submission of the implementation plan or the actual implementation of the law.

**Question 1(a):** Moving forward, would you tell the Committee what your next steps are?

**Response:** VA's next steps are to continue refining the current processes recently developed under the new law and the Interim Final Rule. Part of the refinement process involves reviewing the public comments submitted in response to VA's Interim Final Rule published in the *Federal Register* on May 5, 2011. VA will determine an appropriate response and related actions to these comments while also moving forward with planned expansions to VA's existing caregiver services and identified best practices. VA will host focus groups with caregivers, professionals, and stakeholders to review current services and resources and to plan for future services and resources. VA is currently reviewing the workload and performance of the CSC at each VAMC to determine if a second full-time CSC is required.

