

**MEETING THE NEEDS OF FAMILY  
CAREGIVERS OF VETERANS**

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

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## MEETING THE NEEDS OF FAMILY CAREGIVERS OF VETERANS

THURSDAY, JUNE 4, 2009

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

The Subcommittee met, pursuant to notice, at 10:11 a.m., in Room 334, Cannon House Office Building, Hon. Michael Michaud [Chairman of the Subcommittee] presiding.

Present: Representatives Michaud, Donnelly, Halvorson, Perriello, Brown of South Carolina, and Boozman.

### OPENING STATEMENT OF CHAIRMAN MICHAUD

Mr. MICHAUD. I would like to call the Subcommittee on Health to order.

I would ask the first panel to come forward, and as they are coming forward, I would like to thank everyone for coming today.

The goal of today's hearing is to identify the gaps in supportive services for family caregivers. We also seek a better understanding of the U.S. Department of Veterans Affairs' (VA's) current efforts to meet the needs of family caregivers of veterans.

Family caregivers are the true backbone of the U.S. long-term health care system with more than 50 million who provide informal caregiving for chronically ill, disabled, or aged family members or friends in any given year.

Focusing on family caregivers of veterans, it is my understanding that the VA does not collect data on this population. Therefore, the number of family members who provide care for veterans is unknown.

Additionally, studies of the general family caregiver population show the real adverse financial and physical toll that caregivers have had on these individuals.

For example, women family caregivers are more than twice as likely to live in poverty. Also, family caregivers have a chronic health condition at twice the rate of their noncaregivers' counterparts and those who provide 36 or more hours of weekly caregiving are more likely to experience symptoms of depression and anxiety than noncaregivers.

In the end, this has serious implications for our veterans. In order to ensure that our country's heroes receive the highest quality of care from their family caregivers, it is important that we arm them with the right tools and offer appropriate supportive services

so that they are less apt to be overwhelmed by the difficult day-to-day reality of being a caregiver.

Clearly family caregivers of our veterans have made great sacrifices. I have heard from family members who gave up their jobs, delayed their schooling, and made significant life-changing sacrifice in order to be with their loved ones.

This raises questions about the VA's current efforts to help these family caregivers and whether there are significant supportive services in place.

Additionally, there are concerns about the lack of coordination of caregiver benefits when the servicemembers transition to veteran status. In other words, supportive services that family caregivers may have depended upon through the U.S. Department of Defense (DoD) are suddenly discontinued when the wounded warrior transitions to the VA system.

Through today's hearing, I look forward to exploring ways to better help the family caregivers of our veterans. So I want to thank all the panelists on the different panels we have today for coming. I look forward to hearing your testimony.

[The prepared statement of Chairman Michaud appears on p. 32.]

Mr. MICHAUD. I recognize Mr. Brown for any opening statement that he may have.

#### **OPENING STATEMENT OF HON. HENRY E. BROWN, JR.**

Mr. BROWN OF SOUTH CAROLINA. Thank you, Mr. Chairman.

Our men and women in uniform put their lives on the line to defend our freedom and when they are wounded in the line of duty, it is often the family that puts their lives on hold to care for their injured loved ones.

Family caregivers are more often than not at the core of what sustains the treatment and recovery of our wounded, ill, or injured soldiers. Their commitment is strong and heartfelt. Yet, it can be an enormous challenge, especially in a prolonged recovery.

There are many struggles that family members may face when assuming this role, including job absences, lost income, travel and relocation costs, child care concerns, exhaustion, and emotional and psychological stress.

The President's Commission on Care for America's Returning Wounded Warriors, often called the Dole-Shalala Commission, and reports by both the VA and DoD Inspector General's Office has emphasized the critical role that families play in the successful rehabilitation of our wounded warriors.

Among the many recommended reforms identified in these reports was the need to initiate policies that take family caregivers into account.

As a result of these reports and Congressional direction, both VA and DoD have taken steps to implement policies to provide better support and assistance for the families and friends of wounded servicemembers.

At this hearing today, we will take a close look at the role of the family caregiver and the services VA and DoD are currently providing.

Most importantly, we will examine what more can and should be done to provide family caregivers with the information, education assistance they so urgently need and deserve.

It is vitally important to the health and well-being of our wounded warriors and their loved ones to support and preserve the critical roles of family caregivers.

I thank you, Mr. Chairman, for holding this hearing and yield back.

[The prepared statement of Mr. Brown appears on p. 32.]

Mr. MICHAUD. Thank you, Mr. Brown.

Do any other Subcommittee Members have an opening statement?

Hearing none, I would introduce our first panel with Anna Frese, who is a caregiver, of the Wounded Warriors Project (WWP); René Campos, who is a Deputy Director of Government Relations for Military Officers Association of America (MOAA); and Barbara Cohoon, who is the Deputy Director of Government Relations for the National Military Family Association (NMFA).

I would like to thank all three of you for coming here this morning. I look forward to your testimony. And we will start with Ms. Frese.

**STATEMENTS OF ANNA FRESE, FAMILY OUTREACH COORDINATOR FOR BRAIN INJURY, WOUNDED WARRIOR PROJECT; COMMANDER RENÉ A. CAMPOS, USN (RET.), DEPUTY DIRECTOR, GOVERNMENT RELATIONS, MILITARY OFFICERS ASSOCIATION OF AMERICA; AND BARBARA COHOON, RN, PH.D., GOVERNMENT RELATIONS DEPUTY DIRECTOR, NATIONAL MILITARY FAMILY ASSOCIATION**

**STATEMENT OF ANNA FRESE**

Ms. FRESE. Chairman Michaud, Ranking Member Brown, and Members of the Subcommittee, thank you for inviting the Wounded Warrior Project to testify today about the needs of family caregivers of wounded warriors.

Let me begin by asking you respectfully to think for a minute about what it took for each of you to get prepared for the day today. I am not talking about the first cup of coffee or your morning paper. I am asking you to think about more basic activities, raising your arm to reach for a bedside light switch, moving a finger to wipe the sleep from your eyes, getting out of bed, walking to the bathroom.

While most of us take this for granted, severely injured servicemembers like my brother, Eric, can no longer carry out these basic activities of daily living without assistance. Eric and other severely wounded warriors get the most intimate, devoted care from family members in the privacy of their homes 24 hours a day, 7 days a week, 365 days a year.

Ironically Eric grew up as a very independent kid who was always one to go against the grain and challenge the norm. He is a huge outdoors man. He would say, Anna, I want to be an explorer, I want to buy a horse and travel across the United States just like in the old days, meeting people and seeing new things.

Of course, like any big sister, I had to laugh and tease at him, pointing out how shy and private he is, asking him how could he do that when he does not even like sitting next to strangers in the movie theater. But he had plans.

Eric is not only my brother, but he is a husband to Stephanie, a petite and feisty young woman, and father to Gracie, a kind and lively little girl who has eyes as blue as the sky. Gracie is the light in Eric's eyes.

On hearing of his upcoming deployment to Iraq, Eric went out and bought his 8-month-old daughter a battery-powered pink Barbie Jeep big enough for a 5-year-old along with many other non-age appropriate toys and gadgets.

Stephanie questioned his judgment, but Eric explained that if anything were to happen to him, he wanted Gracie to continue to receive gifts from her dad, gifts to explore the outdoors, to have fun, and know how much fun he liked to have, but mostly to know that he was always thinking about his little girl.

I do not know if he foresaw the future or was just being realistic about the risks of war. But after an improvised explosive device (IED) attack on October 2nd, 2005, Eric ending up fighting for his life. Eric won the battle, but today he lives with a traumatic and an anoxic brain injury. He faces a new battle every day as he works to regain the ability to walk, talk, eat, and drink.

He requires full-time assistance from our father, Ed, who quit his job as a warehouse supervisor to assist his son in adapting to the new normal of life after injury and provide quality of life.

Nursing home care was the only option originally proposed for Eric's future, but our family could not bear the thought of sending Eric to a nursing facility, so he came home.

Eric and dad are a team now. Eric requires assistance with all activities of daily living, but having one's daily needs met does not capture the desired life of a 28-year-old man. Dad does help Eric with all of his physical needs, but it is the way that dad cares for Eric's spirit by supporting him in reaching his goals, creating new memories, and focusing on future dreams and adventures. That has been the driving force behind Eric's progress toward recovery, things that he would not find in a nursing home.

Eric relies on dad to assist him with everything and dad does it with pride and great respect. But there is an unseen price. Our father, now 54 years old, is no longer employed, has used up his retirement funds and savings. He no longer has health insurance and has not contributed to Social Security in almost 4 years. Even though his future has drastically been altered, he often tells me Eric would do it for me.

Mr. Chairman, enactment of H.R. 2342, the "Wounded Warrior Project Family Caregiver Act," would help ensure that these severely wounded veterans who need ongoing help can get the loving care at home and that care can be sustained.

We are very grateful for you for having introduced this important bill and for holding this hearing. The families of our severely wounded warriors must make life-altering changes as they dedicate themselves to caregiving.



But while the decision to care for a loved one may come easily, informal family caregiving can take an extraordinary toll emotionally, physically, spiritually, and economically.

Few of these family caregivers receive training. They have no formal support network. Many have no access to health care, respite care, counseling, or a way to replace lost income. These families face the common danger that over time, their ability to care for their veteran may break down, whether due to utter exhaustion, incapacitating illness, personal vagrancy, nervous breakdown, or other circumstances. There may be no other alternative for the veteran than institutional care.

Over time, informal family caregiving for a severely impaired individual is inherently fragile. Certain fundamental supports are needed to sustain it. These are training, information, and assistance to meet routine specialized and emergency needs, access to counseling and mental health services, respite care, medical coverage, and some modest level of economic support.

In our view, the VA has the capacity to provide for these needed services and supports, but it has no systematic family caregiver program. Beyond a number of pilot programs, VA gives very little attention to family caregivers even though they are vital to the veteran's lifelong rehabilitation process.

Some VA facilities provide some of the family services family members need, notably respite and some education and counseling. But with only limited, piecemeal, and inconsistent VA services, families are largely coping on their own.

When invited to comment on a caregiver program like that proposed in H.R. 2342, VA withheld support and stated a preference for contracting with agencies, but contract-provided home care is a poor alternative.

Where VA home health agencies are even available and willing to care for the often complex needs of severely wounded warriors, their services are highly variable.

In our case, Eric was assigned a home health care nurse during his transition home, but the agency's involvement was more troublesome than helpful. We encountered problems with the agency staff arriving very late or not at all. We were troubled to find that the agency staff were simply not comfortable in meeting Eric's special needs.

This may not be surprising given the fact that there is no nationwide training standard for home health care and no training to meet the unique needs of young severely wounded warriors, particularly those with traumatic brain injury (TBI), post-traumatic stress disorder (PTSD), or other psychological health issues. In short, contract home health care is not a satisfactory answer for most families.

Additionally, for family caregivers who need financial support to enable them to care for their loved ones, VA's vague suggestion that family caregivers could seek employment with local home health agencies is just implausible.

Mr. Chairman, given the profound challenges that family caregivers face and the VA's failure to respond effectively to those challenges, we welcome the introduction of H.R. 2342 and look forward

enthusiastically to working with you and the Committee to advance this critically important initiative.

That concludes my testimony. I would be happy to answer any questions you have.

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

Mr. MICHAUD. Thank you very much, Ms. Frese.

Commander Campos.

**STATEMENT OF COMMANDER RENÉ A. CAMPOS, USN (RET.)**

Commander CAMPO. Thank you, Mr. Chairman, Representative Brown, and Members of the Subcommittee, for the opportunity to present MOAA's views on these critical issues facing caregivers of wounded, ill, or injured veterans.

MOAA very much appreciates the Subcommittee's leadership and VA's and DoD's efforts at transforming health care and support systems. Yes, much has been done, but let me share the perspective of one father whose son was injured in 2007.

He states, all the Army ever wanted was a soldier. The Army got it. All we want is a little help. We got excellent care at the military treatment facility, but we had to fight to get our son in private care and take him home. There are so many problems with the VA bureaucracy. We were lucky to know people in the system, but so many other families are struggling.

Unfortunately, these barriers are still very common in the VA and DoD systems, leaving families wondering if anything has really changed.

Three recent studies I highlight in my statement offer some excellent insights to the needs of family caregivers. They desire a single, joint, one-stop VA/DoD seamless system of care and support that is focused not only on their medical but also on nonmedical needs and less focus on the preferences of government bureaucracies.

They want reliable and timely communication and information that is personalized to their situation and they need an advocate to assist with the coordination of care and services, someone to help them to navigate these complicated systems.

They also need training, certification, compensation, and they desire reimbursement for all of their out-of-pocket expenses.

We just heard and are aware that at the time of injury, there is an immediate economic impact on these families and caregivers.

MOAA believes strongly that these issues require major system fixes, not just patching the system with additional layers of programs and policies that further entrench the bureaucracies and build up barriers.

The following are recommendations to address system issues. First, we need authority to establish a permanent, single, joint seamless transition or senior oversight Committee office (SOC) or permanent authority for the SOC, which currently expires in December. VA/DoD seamless transition is a long-term project that requires consistent long-term oversight to change cultures.

Second, MOAA strongly supports the Chairman's bill, H.R. 2342, that would establish a VA family caregiver certification, training, and compensation program. We would encourage Congress, VA, and DoD, though, to also establish reciprocal programs and policies

so that caregivers would be equally qualified and eligible for both medical, nonmedical benefits in either a DoD or VA setting because these wounded caregivers' families often are caught in the middle between these two systems, having to start over at each transition phase.

We believe also that compensation for care should be paid directly to the caregivers rather than provided as a benefit to the servicemember or veteran. When the benefit is paid to the member, it often does not reach the nonspouse caregiver either because the member is unfamiliar with the payment or the caregiver does not want to take money from the member. Thus, the payment fails to meet its intended purpose.

Finally, MOAA recommends establishing an advocacy and support system that includes a Center of Excellence for caregivers and families that provides oversight on medical and nonmedical care and support programs and policies.

We also recommend a community resource coordinator program and national board or advisory committee. This is a caregiver advocacy concept proposed in a 2009 report by the Quality of Life Foundation that is outlined in my statement.

In closing, MOAA believes by building a system that is adaptable and focused on the needs of wounded warriors and their families, then we will build the right system, one needed today and one built to anticipate the future.

Thank you. That concludes my remarks and I look forward to your questions.

[The prepared statement of Commander Campos appears on p. 36.]

Mr. MICHAUD. Thank you, Commander.  
Doctor Cohoon.

#### **STATEMENT OF BARBARA COHOON, RN, PH.D.**

Dr. COHOON. Chairman Michaud, Ranking Member Brown, and distinguished Members of the Subcommittee, the National Military Family Association would like to thank you for the opportunity to present testimony on meeting the needs of family caregivers of veterans.

National Military Family Association asserts that behind every wounded servicemember and veteran is a wounded family. Caregivers of servicemembers and veterans injured defending our country experience many uncertainties.

Family members, along with the caregiver, are an integral part of the health care team and their presence has been shown to improve the servicemember and veteran's quality of life and aid in a speedy recovery.

Caregivers have a long road ahead of them. In order to perform their job well, they must be given the skills to be successful. This requires the VA to train them through a standardized, certified program and appropriately compensate them for the care they provide.

We are pleased with the two caregiver legislative proposals by both chambers that will provide these services for caregivers. Both of these proposals place VA in an active role in recognizing care-

givers' important contributions, enabling them to become better caregivers to their loved ones. It is a win-win for everyone involved.

However, the self-selection process of a caregiver occurs during the early phase of the recovery process. We recommend the designation and education of caregivers will need to be established while they are still upstream on active duty rather than wait until they have transitioned to veteran status.

Currently, there lacks a policy to compensate a caregiver for services provided to a wounded, ill, and injured veteran. A large percentage of caregivers leave work in order to provide full-time care. Others may become ineligible for TRICARE following discharge and are ineligible for CHAMPVA until the veteran reaches 100 percent disability.

We propose that new types of financial compensation be established for caregivers that could begin while the hospitalized servicemember is still on active duty and continue throughout the transition to care under the VA. The compensation should recognize the types of medical and nonmedical services provided by the caregiver.

The VA currently has eight caregiver assistance pilot programs. However, one program not addressed is the need for adequate child care. The caregiver may have nonschool age children of their own or the veteran may be a single parent. The availability of child care is needed in order to attend medical appointments.

Our Association encourages the VA to create a drop-in child care program on their premises or partner with other organizations to provide this valuable service.

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. It is also important to note if DoD has not been effective in prevention and treatment of mental health issues, the residual will spill over into the VA health care system. The VA must be ready.

We recommend the VA develop a holistic approach by including veterans' families and caregivers in providing mental health counseling, reintegration, and respite care.

The impact on the veteran's children is often overlooked and underestimated. These children experience a metaphorical death of the parent they once knew and must make many adjustments. We must remember the caregiver may not be the veteran's spouse. These children are also affected and we must recognize their psychological needs as well.

Our wounded, ill, and injured servicemembers, veterans, and their families are assigned case managers. The goal is for a seamless transition of care between and within the two governmental agencies. However, with so many case managers to choose from, families often wonder which one is the right case manager.

We often hear from families who have not yet been assigned a Federal Recovery Coordinator and are still alone trying to find the right combination of care, especially in the community. We need to look at whether the multiple-layered case managers have streamlined the process or have only aggravated it.

We request the ability for medically retired, single servicemembers to be allowed the opportunity to have their caregivers' household goods moved as part of the medically retired, sin-

gle servicemember's permanent change of duty station known as a PCS move. This allows them the opportunity to relocate with their caregiver to an area offering the best medical care rather than to move where the caregiver currently resides.

Many of our veterans from this current conflict are being cared for by their parents. Parent caregivers worry about who will care for their wounded son or daughter, as was earlier talked about by Anna, as they age.

Caregivers may reach burnout and require 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 should offer alternative housing arrangements. This will go a long way in allowing for family units to stay together, foster independent living, and dignity for the veteran.

Our Association would like to thank you again for the opportunity to present testimony today on veterans' caregiver issues and gaps in supportive services. We thank you for your support of veterans, their families, caregivers, and for the survivors of those who made the greatest sacrifice. We look forward to working with you to improve the quality of life for all of these families.

Thank you and I await your questions.

[The prepared statement of Dr. Cohoon appears on p. 42.]

Mr. MICHAUD. Thank you very much for your testimony.

Once again, I thank the other two panelists as well for their testimony.

My first question is: we talk about financial compensation for family caregivers, so what do you think that compensation should be?

Commander.

Commander CAMPO. I could not speak to a dollar value. But as I mentioned and as Barbara talked about, this needs to be addressed at the very beginning at the time of injury. And we have to recognize that I do not believe that one system will fit all, that these situations are going to change over time. The needs of families are going to change and the servicemember and the veteran.

I look at trying to get DoD and VA to work closer together and recognizing that these families are getting quite a bit of support and immediate care at the time of injury and they are pretty much in a cocoon.

So when they transition into the VA system, it needs to be easier for them and not have to try to guess all over again where to start and so on.

And that is why in terms of compensation, we want to see DoD, VA work together to build a package that is—because these folks will be going back into the DoD system and they will be transitioning between the systems several times throughout their longer-term care.

So I cannot give you a dollar value or specifically, but we should make sure that it is a package that will meet the needs of the family, the wounded as they transition over their life.

Mr. MICHAUD. Doctor.

Dr. COHOON. Our Association has really proposed as far as two different types of payment, one as far as for the nonmedical care

and also the other as far as actually care, which would be more of your hands on.

And the reason for that is that we do find caregivers are really providing two different roles and depending upon the type of injury and also the cycle of the recovery or where they are in the recovery phase kind of determines as far as how much involvement that they are doing.

If someone has a severe or moderate TBI, but other than that is functional as far as being able to get around, then the caregiver is more involved in what you would call nonmedical care. They are making the doctors' appointments. They are making sure they are getting to where they need to go. They are actually maybe looking on their Blackberry and following like a GPS to make sure they made it to Walter Reed or to Bethesda or to wherever and then making sure that they do go home.

So there is a lot of nonmedical care that goes on. So we are looking more of that as far as to be kind of a range, but basically kind of an amount that is given each month.

And as far as the medical care, we are looking more of what that would be as far as hands on, similar to nursing care that would be given, especially if someone had a spinal injury and basically from the waist down needed certain types of care. You are turning them in the bed. You are actually physically giving them medication, those types of things.

And there are systems in place right now where that is actually, you know, then compensated hourly. So we are kind of looking at those two different pieces.

But also, too, as far as the care that they are giving as far as providing them, they also have a lost significant amount of money as far as walking away from their current job that they had. So there are two different financial impacts going on at the same time.

Mr. MICHAUD. Thank you.

Ms. Frese.

Ms. FRESE. Let me work with a number that we do know. The cost per day for in-house VA nursing home care for next year is projected to rise to \$887.33 per day, making that an annual cost of \$324,000.

And while I do not want to guesstimate the cost of what enacting the caregiver legislation would be, I can comfortably express with confidence that the failure to provide such supports increase the risk that veterans would have to be institutionalized. And those costs are clearly far in excess of the relatively modest cost that caregiver assistance would be.

Mr. MICHAUD. Thank you.

My next question. I know some of you have answered this in your opening statement, but if all three of you could address it. If we were to pass legislation, what should we put in that legislation as the three most important components of a caregiver program? What would the three top priorities be?

I know you have talked about this some during your opening statement. Not knowing what we will be able to get through the House and through the Senate, if we had to pick three priorities, what would they be?

Ms. Frese.

Ms. FRESE. As we spoke about earlier, each circumstance, family dynamics of each family is so drastically different.

From what I hear from families and from our own experience, the health care, especially for the parents that are caring and those who are not a spouse and not covered under health care, they need some form of health care to take care of their own health so they can actually be around to continue to care for the veteran.

And also it comes back to the economic support as well. The time spent worrying about how they are going to continue living and paying for their needs, you spend more time focusing on the worrying than actually—you want to be able to focus your time, your strength, and your full ability on the veteran rather than worrying.

So the health care piece, the income, and the mental health to help sustain the long-term ability of the caregiver.

Commander CAMPO. As I mentioned, we are concerned about adding more programs or adding more layers on to already complicated bureaucracies. We go back to the need for and establishing some sort of permanent office or seamless transition agency of some kind.

And, again, if it is extending the current SOC out or whatever, we need some good, solid oversight that does not change when the administration changes and when—I mean, so we need the continuity of the leadership and oversight of programs. So I think that is critical to whatever we do.

The other thing we need to do is make sure that we have again a reciprocal program for caregivers. That includes both the medical and the nonmedical aspects because, again, these families that have been on active duty have child care. They have a lot of other family support, nonmedical support services that are there. So they should have a package of things that they can expect and that would also help transition over into the VA system.

And then, finally, we go back to at the time of injury, they really need an advocate. They need somebody that is going to be able to walk them through all these different things that are going to be happening to them over, in some cases, the course of their life.

So we think that there needs to be an advocacy program of some kind that is set up. I think the Quality of Life Foundation report I mentioned is a good starting point.

Dr. COHOON. First of all, this needs to start upstream, as I mentioned before, while they are still active duty, if you are going to do anything as far as the caregiver.

One of the conversations we recently had with Secretary Shinseki is that if the caregiver is not taken care of upstream, by the time he gets them, have earned their caregiver status, they are either burned out or they are so frustrated with the system that they may stop being a caregiver. And then everyone loses, especially the family.

So we want to make sure that this actually starts upstream while the servicemember is still on active duty.

The other piece is that we have to remember that the caregiver's well-being is directly linked to the veteran's well-being. So if the caregiver is taken care of, then we know that the veteran is being taken care of and vice versa.

And so ways in which we can help the caregiver is that we need to make sure and recognize that the role that they are playing is important and then the pieces that they are providing also need to be recognized. And how we go about recognizing that can be done in lots of different ways.

We have talked about the compensation as far as financial, but we also realize that they have walked away from a lot of other different things. They lose their health care. They lose their ability as far as to maintain a retirement or even lose their retirement.

We also need to make sure that they have respite care, those types of pieces. So we are looking at the well-being of the caregiver as one of those packages that you talked about.

The other is the caregiver also needs to maintain a purpose in life not only as far as taking care of the veteran but also as far as them personally.

And also remember the fact that what surrounds them is their family. It may not be mom or dad. It may be their sister or brother or if it is a mom or dad that is doing that, they have other children that they are taking care of or maybe a father that they are also taking care of.

So the family unit itself is a delicate balance. So whatever you provide the caregiver affects everybody else.

Mr. MICHAUD. Thank you very much.

Mr. Brown.

Mr. BROWN OF SOUTH CAROLINA. I would like to kind of follow through on that too. I know that we all express support for direct payment for the family caregiver. However, concerns have been raised about the administration's challenges such as the policy would create the VA include tracking caregivers and monitoring for quality and effectiveness of care and liability protection.

Along the same lines, what are your recommendations for overcoming these challenges? I think you mentioned the burnout. How would you, I guess, distribute the caregiver's responsibility if we had a direct payment to the caregiver rather than going through the serviceperson?

Dr. COHOON. The direct payment, as René had mentioned, is something that our Association has also supported for lots of different reasons, mainly 50 percent of our injured servicemembers are single, and it is the parents that are stepping up and taking the role. And so there becomes an issue as far as, as René had mentioned, not taking the money, but we are more in favor as far as for the payment to actually go directly to the caregiver on that piece.

Mr. BROWN OF SOUTH CAROLINA. But if it were multiple caregivers, would it not be a logistical problem trying to generate a good number of checks?

I am just trying to put myself in that perspective. I know my wife was a caregiver for my mother-in-law for the last 5 years of her life. She was blind, and she stayed with us. My wife sort of assumed total responsibility for her mother, although there were other siblings there that probably could have kicked in, and we did not get any compensation for it. We did it out of sense of love.

So, I would sense that that same thing would happen within a family of a wounded warrior. If you gave a direct payment to just



one, how would the other family members react, where they have some kind of responsibility, and want to be able to participate in the caregiving. That would just be my concern.

Dr. COHOON. Well, Senator Akaka's bill actually talks about that, one, a caregiver is designated and that was what we had in our opening statement and is in our written statement that you basically have a caregiver that becomes designated.

What we have been finding is that somewhere along the recovery process, one person actually finally steps forward and becomes the main caregiver. Now, you may have some supplement that is going on or some handoff that is going on. In other words, one will come in for 4 to 5 months and then basically another person comes in and fills that particular role. But if you are going to be dealing with the compensation, i.e. financial, it has to be a designated caregiver.

One of the things we have talked about is that the training should not necessarily be just for one person, that others should be given the opportunity to also be trained but not necessarily compensated in the same process so that there is, especially if you have got mom or dad or have other people that others can be providing the same role, but the compensation would only be for the one that was designated.

Mr. BROWN OF SOUTH CAROLINA. And you think the other members would be as enthused to be able to participate in caregiving if they were not compensated?

Dr. COHOON. I think it is difficult even for the caregivers themselves as far as to come up with a dollar amount as far as what they think the care is worth. It is very difficult as far as to quantify.

If you are looking at the veteran, because the caregiver has been directly involved, they are more likely to take their medications on time, more likely as far as to go to their doctors on time. There is a lot of great communication that goes on between the doctors. So the care level goes up.

So the veteran then does not utilize the care system as often and their care stays better over a long period of time. How do you quantify that particular dollar amount when they have done so much preventative care and they are not having to need what you would call urgent or emergent care?

Mr. BROWN OF SOUTH CAROLINA. I applaud that idea. I think it is a whole lot better if the person can stay within the home environment where they are with people that they are comfortable with and they have a special love and attachment to rather than putting them in, say, a nursing home or some other place.

You mentioned the respite care. Is that working for you all?

Ms. FRESE. To be honest with you, sir, the programs translate differently on paper than they actually are translating in real life for the families. You know, it is inconsistent around the country.

For families that live in rural communities, there may be a respite home health agency that may have a program, but the respite programs use their rules and regulations, it confines the veteran to their home. You know, it is not allowing—like I talked about, this is the life of these young veterans, to have someone come and relieve the caregiver, but then the veteran has to stay within the four

walls of their home because they are not allowed to—the respite person is not allowed to take them out to the community or participate in life, or their services are just not available because they do not deal with this age population.

Mr. BROWN OF SOUTH CAROLINA. My last will be more of a comment than a question. In the 2010 budget request, DoD has proposed legislation which would provide monthly compensation that catastrophically wounded servicemembers to be used to compensate designated family caregivers.

What is your view on this proposal? In fact, we were trying to get some figures that might be recommended, but we have not gotten those figures back yet. What are your thoughts on that?

Commander CAMPO. Our concern is in terms of being focused again perhaps on the wrong thing. And that is perhaps maybe moving the servicemember out of the DoD system too quickly before the servicemember or the family member and to get them into the VA system.

Again, it comes back to where the focus is. The focus should be on the servicemembers and families and what is going to be in their best interest in the long term.

They are in a crisis situation really in that point in time and they do not even know what it is they need or what the future holds. And making determinations about the future in terms of money, where you are going to live, all those kinds of things, they are just not necessarily prepared to address at that point in time.

Again, we go back to the fact that or go back to the need for a reciprocal program, one that DoD and VA come to the table and try to work out, again to make that transition and that reintegration, because there will be reintegration. Again, they will be moving in and out of both of those systems. So while we applaud DoD in looking at that and really truly it is trying to get to where we need to be, I think it still needs a little more work.

Mr. BROWN OF SOUTH CAROLINA. Thank you very much for your service and for your compassion.

Mr. MICHAUD. Mr. Boozman.

Mr. BOOZMAN. Thank you, Mr. Chairman.

I really do not have any questions. I just appreciate you all being here. The personal references and things are so helpful as we move forward with these things. So thank you very much for taking the time and for being here and sharing your thoughts on this.

Mr. MICHAUD. I also want to thank Mr. Boozman, who is the Ranking Member of the Economic Opportunity Subcommittee, for all his work and efforts on that particular Subcommittee.

Once again, I would like to thank all three of you for your testimony here this morning. I look forward to working with you as we move forward with caregiver legislation this session. So thank you.

I would ask the second panel to come forward. The second panel consists of Jill Kagan, who is Chair of the ARCH National Respite Coalition; Suzanne Mintz, who is the President and Co-Founder of the National Family Caregivers Association; and Mark Heaney, who is President and Chief Executive Officer of Addus Health Care, Inc., and National Association for Home and Hospice Care.

I would like to thank our three panelists on the second panel for coming forward today to give your testimony before the Sub-

committee on Health. I look forward to hearing what you have to say and have an open dialog.

And we will start off with Ms. Kagan.

**STATEMENTS OF JILL KAGAN, MPH, CHAIR, ARCH NATIONAL RESPITE COALITION; SUZANNE G. MINTZ, PRESIDENT AND CO-FOUNDER, NATIONAL FAMILY CAREGIVERS ASSOCIATION; AND MARK S. HEANEY, PRESIDENT AND CHIEF EXECUTIVE OFFICER, ADDUS HEALTHCARE, INC., PALATINE, IL, AND, HOME CARE AIDE SECTION REPRESENTATIVE, AND MEMBER, BOARD OF DIRECTORS, NATIONAL ASSOCIATION FOR HOME CARE AND HOSPICE, INC.**

**STATEMENT OF JILL KAGAN, MPH**

Ms. KAGAN. Mr. Chairman and Members of the Subcommittee, as stated, my name is Jill Kagan and I am Chair of the ARCH National Respite Coalition, which is a division of the ARCH National Respite Network and Resource Center.

I am extremely honored to have this opportunity today to present testimony on the importance of respite as a critical need of family caregivers of veterans.

What is respite? Respite provides temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs. Respite is also an important continuum, component of a continuum of comprehensive family support and long-term services that are available to caregivers not only on a planned basis but also in the event of a crisis or emergency situation.

Respite can and should be provided in home or out of home in a variety of settings by trained respite providers with varying degrees of medical and mental health expertise, volunteers, neighbors, other family members, or friends. Ideally this array of options would be available to families on a daily, evening, or weekend basis.

It was stated earlier that we know there are at least 50 million caregivers who are providing care at some point during the year. And while we do not know the specific number of family caregivers of veterans, we do know that out of an estimated 26 million veterans, over 9 million are 65 and older and an additional number, close to 6 million, have some form of disability.

And while not all of them may be in a situation where they are requiring a caregiver right now, the chances are that in the near future they will require one.

What we do know is that the number of family caregivers of veterans is high and continues to climb. For the soldiers who are returning from Iraq and Afghanistan in particular, new challenges are very evident because of their serious conditions that they are returning with.

According to a recent study by the VA Geriatrics and Extended Care Polytrauma Rehabilitation Task Force, and I quote, "As many of these seriously injured veterans may require support and assistance for many years, the caregivers will face many physical and emotional challenges over time. VA currently provides support to caregivers through a variety of programs. However, there are loca-

tions in which caregiver support is minimally available and the task force anticipates considerable challenges in reliably meeting the caregivers' support needs in all communities."

We all know that the trend over the last decade has been toward community and home-based services and away from institutional care. This is preferred as long as in the community there are sufficient supports necessary to make this transition a successful goal.

With family caregivers now providing 80 percent of long-term care at home, their need for support is absolutely critical and significant.

And among families we just heard, among those who ask for help, respite is often at the top of their list. It is very hard to go out and do something else if you are not even able to take a break.

Respite has been shown to be effective in improving the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placement such as a nursing home or foster care and minimizes the precursors that can lead to abusive or neglectful situations. It has been shown to strengthen marriages and family stability.

There are many other studies within my written testimony that are summarized that confirm these findings as well as the long-term economic benefits of respite, which in and of itself is a low-cost service to provide.

Yet, despite these benefits, respite remains largely unused, in short supply, inaccessible, or unaffordable to not only veterans and their family caregivers but to the majority of the Nation's family caregivers.

The barriers to accessing respite are many and have been defined in the literature. They include cost, reluctance to ask for help, failure to identify as a caregiver, fragmented and narrowly targeted services, a lack of respite options, and a lack of information about how to find or choose a provider.

There is also restrictive eligibility criteria in many Federal and State programs that preclude many families from receiving services, especially for those in the age group 18 to 60. There are almost no programs for respite for which these families qualify.

And many would have conditions such as amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), cancer, spinal cord or traumatic brain injuries. And this is the very population in which our wounded warriors are coming back from Iraq and Afghanistan and that age group for which there are the fewest respite options.

In fact, the task force that I mentioned earlier at the VA, one of their major recommendations was to improve access to and utilization of respite services for younger veterans.

Again, for this population, and we heard it from the families who spoke before, even though the VA has the authority to provide respite in home and in other settings, it is often underutilized. There may not be enough in-home providers in many communities, rural areas and urban areas alike.

And inpatient care which is generally available in a community nursing home or VA hospital is not particularly desirable among the younger veterans and their families.

But, most importantly, there is a shortage of well-trained staff who are qualified to provide respite to this population.

While family caregivers of veterans face many of the same barriers as the general population, they do face these additional special barriers and we have to find ways to specifically address them.

The VA also requires copayments for nonexempt veterans for extended care services, including respite. And for many of these families who are already under financial duress, those who have had to give up employment in order to provide their caregiving, respite is perceived as an absolute luxury that they cannot afford. It falls to the absolute bottom of the list of things that they need.

Currently the VA requires copayments ranging from \$15 per day for noninstitutional adult day health or respite care to \$97 a day for institutional respite care.

And then, of course, there are those veterans whose household income exceeds both the VA national income threshold and do not have a compensable VA service-connected disability, who may have a disability but are not eligible for VA care. Of course, they are free to turn to State or Federal or local funding sources to find respite, but that system is already overburdened and unable to keep up with the increasing demand.

There are disparate and inadequate funding streams for respite in many States and even though the largest source of Federal funds for respite outside the VA is available through Medicaid home and community-based waivers, these waivers have very restrictive eligibility criteria and long waiting lists.

There are numerous other Federal and State categorical programs that have the potential to fund respite for caregivers, again, but if you do not have a specific disability or fall into a specific age group or have a specific income, you do not qualify.

All of these piecemeal respite funding streams provide a very critical foundation on which to build systems of respite care, but they do not currently do enough to reduce the fragmentation, the inaccessibility, and the confusion that exists and families are forced to try to navigate that bureaucratic maze themselves.

Now, there has been a response. The States responded back in 1997 with Life Span Respite Systems which are coordinated systems of community-based respite services that help States use limited resources, maximize use of resources across ages and disability groups. Pools of providers can be recruited, trained, and shared. The administrative burdens can be reduced by coordinating resources and the savings used to fund new respite services.

Some of these model programs are in Oregon, Nebraska, Wisconsin, Oklahoma, and most recently Arizona. And these programs are having as their goal the ability to have respite services through a single point of entry, ensure flexibility to the—

Mr. MICHAUD. You are 3 minutes and 45 seconds over and we are going to have votes shortly, so if you could please summarize.

Ms. KAGAN. I will go right to my recommendations.

Recently Congress did enact "The Life Span Respite Care Act," which would expand those systems of care to hopefully eventually all 50 States and that funding is becoming available this week through the Administration on Aging (AoA). That would do a lot to improve the respite care system and make many more services available to veterans and their families.

And my recommendations center around collaborating with these State Life Span Respite programs, urging the VA to collaborate with State Life Span Respite programs to do more training and recruitment of providers, especially for veterans with TBI and spinal cord injuries and other polytraumas, to collaborate with State Life Span Respite programs to promote consumer direction so that families can get vouchers and have greater option of the types of respite providers they would like to use and what is most beneficial for them and the person they are caring for.

Also, it should be investigated if the VA has a possibility to reduce or eliminate some of the mandatory copayments for respite and, of course, ultimately to link these veterans directly and their families to existing Life Span Respite programs or State respite coalitions that are already out there that can help them find sources of payment as well as providers.

Thank you.

[The prepared statement of Ms. Kagan appears on p. 49.]

Mr. MICHAUD. Thank you.

Ms. Mintz.

#### **STATEMENT OF SUZANNE G. MINTZ**

Ms. MINTZ. Mr. Chairman, Members of the Subcommittee, thank you for recognizing that family caregivers play a critical role in the lives of veterans with chronic conditions and disabilities and that because of this role and its consequences, family caregivers have special needs of their own.

For those of us who advocate for family caregivers, this is an auspicious day. I am honored to have this opportunity to speak on behalf of veterans and their family caregivers.

My name is Suzanne Mintz. I am President and Co-Founder of the National Family Caregivers Association.

NFCA is the Nation's premier organization for family caregivers. We reach across the boundaries of different diagnoses, different relationships, and different life stages to address the common needs and concerns of America's family caregivers.

I am not a veteran nor is my husband, Steven, but we both have much in common with the young veteran families who are dealing with physical and/or mental disabilities that they acquired in the Iraq and Afghanistan wars. These families are the focus of my testimony.

Like them, our lives changed suddenly when we were young and had our hopes set on a bright future. When I was 28 and he was 31, Steven was diagnosed with multiple sclerosis which, as you may know, is an incurable neurologic disease that impacts function and at times cognition.

I can tell you that these young veterans who are returning from war with severe physical and mental disabilities are frightened. They and their family members are going through a grieving process, each having their own reaction to the nightmare that has become their lives. They need help and assistance individually and collectively. They need to know that their feelings and fears are normal.

More than anything else, they need to know that they do not have to work through their new challenges alone. They need the

assistance of a navigator, a coach, a community-based care team that is their designated advocate who is always available. Just knowing that the team is there for them will make a huge difference.

Those with the most extensive physical or mental disabilities need these services the most, potentially for life. Their needs must be looked at holistically and services must be provided as seamlessly as possible. They should not have to figure out which benefits they are eligible for nor should they have to go through the process of directly applying for them. Their lives are hard enough now.

And that is where the care team concept comes in. It is the team's job to help these families find a new normalcy. It takes time and plenty of support. Diminishing the hassle factor is one of the most important things that the VA can do especially as veterans move from DoD to VA. Seamlessness is definitely the goal.

Some may think of this as care management. I would describe it as care management on steroids with the recognition that this is more than a one-person job and that for the designated families, it needs to be the norm.

The VA Health Administration and Benefits Administration have put together an extraordinary number of programs to support these families, some of them specifically aimed at the family caregiver. There are 13 in all.

They can be grouped in four broad categories. There are two respite programs for family caregivers, two health care delivery programs, three nonmedical and community-based service initiatives, and six programs dealing with transportation and housing.

They all have their own criteria. Some are benefits and some are health care services. They are all wonderful programs. But to make as positive a difference as possible in the lives of these families, the appropriate ones must be bundled together into a comprehensive plan of care that recognizes all aspects of these families' lives that have been impacted. Whether the solutions for them can be found within the VA system or not, it is a complex process.

I especially like the programs that are flexible and allow the families to make their own decisions about how they want to live their lives.

The Bladder and Bowel Program allows a veteran to choose whomever he or she wants to help with these intimate details as long as the person receives some training.

The Home and Community-Based Services Program uses the cash and counseling Medicaid concept where the beneficiary receives funds to use as he or she determines would be best. Fiscal intermediaries provide assistance.

In both cases, these are not site specific. The benefit is the means to finding the solutions that work. This is especially important for veterans and their families who do not live near VA facilities and need to really think out of the box to have a meaningful quality of life. This is where the community-based care teams can help the most. They can aggregate program funds and find ways to fill gaps that stay within budget parameters while meeting the needs of beneficiaries and their families at the same time.

Priority one must be the health and well-being of these families. The challenge is to create a bundle of services that are tailored to each family as quickly as possible and with a clear focus on quality and safety. It is one thing to have programs. It is another thing to implement them well.

I think it is important that the VA create an atmosphere that fosters spirit of the law decisions and actions as opposed to hard-line interpretation of benefits.

Each family living with TBI is different. Each family living with a spinal cord injury is different. Programs need to be adaptable to meet their specific needs, to help them find the new normal.

The VA faces challenges as it strives to meet the needs of these veteran families and all of its beneficiaries, even the ones who are not part of the current returning crew. It will require the energy and dedication of all employees and the recognition that proper staffing levels can mean the difference between success or failure, an error-free program or one rife with problems.

Washington was scandalized by the news of the horrible conditions at Walter Reed, not only the physical conditions, but perhaps more importantly the procedural ones that made veterans wait an inordinate amount of time for their claims to be processed and in many cases then be denied.

And we know that this is not just the situation here. No matter how good the family programs are, they are irrelevant if vets cannot access them and if they cannot be provided in the safest and most respectful and flexible way possible.

Mr. Chairman, Members of the Committee, that is your challenge, to help put that kind of network in place. Thank you.

[The prepared statement of Ms. Mintz appears on p. 58.]

Mr. MICHAUD. Thank you.

Mr. Heaney.

#### **STATEMENT OF MARK S. HEANEY**

Mr. HEANEY. Thank you, Mr. Chairman, and thank you for allowing me to testify.

My name is Mark Heaney. I am President and Chief Executive Officer of Addus Health care. We are based in northwest suburban Chicago. Addus is a national provider of home care services, including services to a number of our Nation's veterans.

As the proud son of a World War II Naval officer medically retired, I honestly cannot think of a place I would rather be today and I am very proud to be here, frankly, to testify and contribute.

I prepared for today's hearing assuming that while the focus of the hearing may be on specific proposals to require the Veterans Administration to increase its involvement in and support of family caregivers of eligible veterans, the hearing may also cover other home-based services provided through the Veterans Administration in support of all worthy and eligible veterans.

For your information, Mr. Chairman, Addus Health care is a provider of home care services through direct contracts with and referrals from the Veterans Administration, as well as being a provider to individual veterans through the Aid and Attendance Program.

For the purpose of this testimony, I define a family caregiver as both the family member who is the primary care person, the most



responsible for continuing care for the at-risk veteran, as well as the larger family, all families engaged in the complex set of needs that need to come together to help keep a veteran at home, in the community where they want to be.

In our current services to veterans, which includes home health care, home care aid services, companion care, transportation, meal assistance, adult day care, and a host of other activities of daily living, including being a fiscal intermediary, we commonly provide guidance, respite, training, assistance and oversight to families and family caregivers.

We work with families to coordinate care, to supplement, to extend care, but not to duplicate services already provided by the family. By this, I make the point that home care agencies can and already do responsibly support and assist family caregivers, but the testimony today also indicates that home care agencies should be part of the solution and not relied upon as the solution, part of the solution especially responsive to the family.

Our services are provided by trained, often licensed personnel working in a structured, monitored, and accountable system. Employees are screened. Background checks are conducted. Pre-service and in-service training is conducted. Care is provided according to a written plan of care prepared in cooperation with the consumer or the responsible family member.

The quality and consistency of care is supervised. Changes in the veteran's need or condition are noted and responsible persons, including the family members, are notified.

The most effective approach to delivering care in the home to this population is one where the consumer or their designate, is to the maximum extent of their ability or desire at the center of the care delivery process. This is especially evident in delivering care or providing assistance to younger, disabled veterans and consumers where their interest in and their ability to self-direct their care is fundamental to the success of the service offering.

With self-direction and consumer involvement an important objective, the first goal of care delivery, of a care delivery system must be to assure that care is delivered safely, consistently, and accountably. We would be and are concerned with any system of care in the home to the truly needing, to the truly at risk, which does not include minimally appropriate safeguards for consumers and caregivers alike.

As such, we strongly believe that all of the steps taken by licensed home care agencies to screen, train, monitor employed caregivers should also be applied in a family caregiver program. This is the best way to safeguard the veterans, the caregivers, and the integrity of the program

Thank you.

[The prepared statement of Mr. Heaney appears on p. 62.]

Mr. MICHAUD. Thank you very much.

I have no questions, but I will be submitting questions in writing. It is my understanding Mr. Brown has none.

Mrs. HALVORSON.

Mrs. HALVORSON. Thank you, Mr. Chairman.

And thank you, panelists. It is good to see all of you.

I just have one quick one. My district in Illinois is a mix of everything, but I am specifically concerned about my rural areas.

How available is respite care in the rural areas and what are we doing for the families who cannot get it? And I do not know if there is any specific one of you that wants to answer that.

I do not know about, Ms. Kagan, if you want to start it out.

Ms. KAGAN. There are dramatic shortages of well-qualified and trained providers, especially in rural areas. Fortunately, we have just enacted a Federal law that I talked about in my testimony called the "Life Span Respite Care Act," which States are now applying for currently.

There is also an Illinois Respite Coalition that is very active in your State and they are doing a lot to try to recruit and train providers in those areas and provide transportation as well. That is a critical issue. It is one thing to have a program, but if you cannot get to it, that is another tremendous barrier.

But we need to make sure that even in those rural areas that people are thinking outside of the box on how to provide those services in a way that uses what is already there. It does not have to necessarily be an expensive effort.

Ms. MINTZ. Rural areas are challenges whether it is VA services or any services. And I think it becomes incumbent upon the community to find creative ways. There are a number of volunteer programs that are popping up around the country that help bring people together who want to help.

There is a program called Lots of Helping Hands which is essentially a Web site program that uses family and friends to help the family caregiver get a break by taking on some of the basic responsibilities. So whether it is bringing meals on Tuesdays or driving the kids, you know, to church on Sunday morning, it becomes micro tasks. It is not difficult for volunteers to say yes. And cumulatively it does then help the family caregiver.

And so we definitely need to find creative mechanisms in rural areas. It is certainly a great place for VistA type programs.

Mrs. HALVORSON. Addus does a great job in Illinois.

Mr. HEANEY. Thank you.

Mrs. HALVORSON. And, Mr. Heaney, thank you.

Mr. HEANEY. Congresswoman, I know that you know I know where your question comes from because I know your history of support to the Community Care Program in Illinois and we are very grateful for that.

I learned something today. I have actually been doing this for 30 years. This is my 30th year in home care. And I learned today, and I wrote a note to myself, the word respite.

Actually, my answer is that, and actually it is Ms. Kagan's testimony that made me realize it, the answer I will give you is that in the rural communities, we actually were able to find caregivers. Wages are going up. Appreciation for the service is increasing. We are able to find caregivers and we are able to screen them. And I think we just have to be diligent.

But the respite service is not promoted. I do not think it is known and, actually worse, I think sometimes it is seen as non-essential.

In listening to the young lady who spoke initially and to Ms. Kagan's testimony and to Ms. Mintz's testimony, I realized how critical that service is for what is a voluntary caregiver.

By the way, everybody is working. It is dual-income households, right? And I have learned something today and I will use that in my policy work.

Mrs. HALVORSON. Thank you. Thank you all very much.

Ms. MINTZ. Thank you.

Mr. MICHAUD. Once again, I would like to thank our three panelists for your testimony this morning. We look forward to working with you as we move forward to dealing with this very important issue. Thank you.

Mr. HEANEY. Thank you so much.

Mr. MICHAUD. I would ask the third panel to now come forward: Dr. Agarwal, Chief Patient Care Services Officer with the VHA; Edward Walker, who is the Acting Assistant Secretary of Aging, in the U.S. Department of Health and Human Services (HHS); and Noel Koch, who is the Deputy Under Secretary for the Office of Transition Policy and Care within the U.S. Department of Defense.

I want to thank all of you for coming here today to give testimony on this very important issue.

**STATEMENTS OF MADHULIKA AGARWAL, M.D., MPH, CHIEF OFFICER, PATIENT CARE SERVICES, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS; ACCOMPANIED BY LUCILLE BECK, PH.D., CHIEF CONSULTANT, REHABILITATION SERVICES, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS; THOMAS E. EDES, MS, DIRECTOR, HOME AND COMMUNITY-BASED CARE, OFFICE OF GERIATRICS AND EXTENDED CARE, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS; THOMAS J. KNIFFEN, CHIEF, REGULATIONS, STAFF COMPENSATION AND PENSION SERVICE, VETERANS BENEFITS ADMINISTRATION, U.S. DEPARTMENT OF VETERANS; EDWIN L. WALKER, ACTING ASSISTANT SECRETARY FOR AGING, ADMINISTRATION ON AGING, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES; AND NOEL KOCH, DEPUTY UNDER SECRETARY OF DEFENSE, OFFICE OF TRANSITION POLICY AND CARE COORDINATION, U.S. DEPARTMENT OF DEFENSE**

**STATEMENT OF MADHULIKA AGARWAL, M.D., MPH**

Dr. AGARWAL. Mr. Chairman and Members of the Subcommittee, thank you for providing me the opportunity to discuss VA's program and support of family caregivers.

I would like to thank the Committee for bringing together representatives from DoD and AoA as we continue to work closely with these organizations to ensure that best practices are shared and adopted.

Jointly administered programs like the Federal Recovery Coordination Program of the DoD and the Veteran Directed Home and Community-Based Services Program with AoA provide real examples of ways the Federal Government is working in coordination to support veterans and their caregivers.

My written statement, which I ask to be submitted for the record, describes in detail the two themes I would like to emphasize now, the strength of our current programs and the six principles that guide our present and future programs for caregivers.

VA recognizes and deeply appreciates the critical role that they play in supporting veterans. VA currently contracts for caregiver services with more than 4,000 home health and similar public and private agencies approved by Medicare or Medicaid or through some State licensure.

In these arrangements, as well as through the Veteran Directed Home and Community-Based Service Program I referenced earlier, VA contracts with the agency, which trains and pays the caregiver directly. VA also ensures these home health agencies meet and maintain training and certification requirements specific to caregivers.

This model has several advantages. First, it does not divert VA clinical resources from direct treatment of veterans.

Second, it allows direct communication between the veteran and the home health agency or State area agency on aging regarding caregiver selection and satisfaction.

Third, these agencies have expertise in training caregivers and certifying home health aides, including family members, and many operate in rural communities.

VA administers many different programs related to caregiving, including adult day health care, home-based primary care, home improvement and structural alteration grants, specially adaptive housing, and automobile grants, volunteer respite and medical foster homes. These are just to name a few.

Respite care is an essential component of caregiver support. It temporarily relieves the spouse or other caregivers from the burden of daily care for a chronically ill or disabled veteran living at home.

VA offers a comprehensive respite care program providing respite in a variety of settings, including the nursing home, the adult day health care facilities in the community, and in the veteran's home.

In addition, VA is implementing eight caregiver pilot programs that are testing new methods of support. These programs are located across the country and benefit veterans of all service eras and their caregivers.

VA believes a caregiver program should adhere to certain principles to ensure that it is veteran-centric and effective.

First, veterans should be free to choose a caregiver. The Department needs discretion to recognize the unique needs of each veteran and to honor the veteran's choice.

Second, training for caregivers should be designed to provide them with the skills needed to safely perform necessary personal care.

While VA currently works with family members or other attendants before they leave a VA facility and educates them on care related to the veteran's condition, a host of local agencies have substantial expertise in training and certification. Leveraging these resources will be most effective and responsive in meeting the current, as well as the changing, needs of the veterans.

Third, caregivers who must sacrifice employment opportunities to care for loved ones may require financial support. This support is

best provided through intermediary agencies like the homemaker home health aid organizations which can employ the caregiver directly allowing that person to accrue Social Security, health care, wages, and other benefits.

While VA programs such as Aid and Attendance and special monthly compensation do not provide payments to caregivers, these programs do provide direct payments to qualifying veterans.

Fourth, caregivers often need medical or social support to allow them to continue caring for the veteran. VA is authorized to provide medical care to nonveterans on a humanitarian basis in an emergency situation. But we are required by law to charge for this care.

We can provide mental health care and counseling to members of the veteran's immediate family, their legal guardian, and the homeowner of the property where the veteran lives so long as the care is in connection with the treatment of the veteran.

Fifth, any enrolled veteran with a serious physiological or psychological, neurological or other condition should be eligible for these benefits as determined by the Secretary.

Finally, VA should preserve its current variety of programs which have been designed to meet the diverse and changing needs of different patient populations. Elderly veterans require a different support mechanism than veterans with quadriplegia or those with traumatic brain injury. Maintaining programs tailored for different populations ensures that VA offers optimal care to the veterans.

In conclusion, Mr. Chairman, caregivers fulfill a wider role in providing quality and necessary health care to veterans with complex needs. Our current programs are striving to meet the needs of both caregivers and veterans. We will continue to enhance our programs and strengthen our collaborations with others such as DoD and HHS.

Thank you again for this opportunity. We are prepared to answer your questions.

[The prepared statement of Dr. Agarwal appears on p. 66.]

Mr. MICHAUD. Thank you.

Mr. Walker.

#### **STATEMENT OF EDWIN L. WALKER**

Mr. WALKER. Mr. Chairman and distinguished Members of the Subcommittee, I want to commend you for recognizing the important role that caregivers play.

For more than 40 years, the U.S. Administration on Aging has provided national leadership, funding, oversight, and technical support to a vast national aging network that reaches into every community in this country, plays a key role in delivering consumer-centered services, and is the leading provider of home and community-based long-term care services to vulnerable Americans and their caregivers.

You have heard from the distinguished preceding panel about the diverse characteristics and complex needs of caregivers. I would like to highlight how we are working to address them and to highlight innovative approaches to better meet their needs, including our recent collaboration with the Department of Veterans Affairs,

to establish a veteran-directed home and community-based services program.

The AoA National Family Caregivers Support Program integrates the needs of caregivers with the provision of home and community-based services and has created a multifaceted system of services for caregivers, including information about and assistance in gaining access to services, individual counseling, organization of support groups, and training, respite care, and other supplemental services.

The Caregiver Program acknowledges the central role of caregivers in our health and long-term delivery systems and has allowed the administration on Aging and its aging network the opportunity to infuse the principles of consumer direction into existing service programs, to address the challenges of serving caregivers in both urban and rural areas, to provide a broad range of services for diverse age groups, and to ensure that programs serve consumers in culturally competent ways.

Our aging network has had a positive and significant impact in the lives of caregivers by supporting the work they do. Through our Caregiver Program, we annually touch the lives of more than a million people with more than 81 percent indicating that the program enabled them to care for their loved ones longer, thereby avoiding costlier and more restrictive placement in an institutional setting, and 75 percent indicated it helped reduce their stress, with nearly half of them indicating and highlighting the importance of respite care.

And as Ms. Kagan mentioned, the administration on Aging has just made available an opportunity for States to apply for funding for Lifespan Respite Care services for persons of all ages.

The Department of Veterans Affairs and the Administration on Aging have a shared commitment to meeting the needs of consumers and their families on their terms and according to their needs and preferences. We know that both younger veterans and older adults want to be in charge of their own lives and to direct their own service needs.

Further, we recognize the importance of partnering with the VA at the local level to meet the needs of veterans.

In Maine, for example, our local area agencies on aging coordinate services and benefits for veterans in collaboration with the local veterans' homes and others throughout the State, as well as having veterans' advocates, community information staff, and adult day programs to assist veterans and their caregivers.

AoA and the VA are jointly funding our Community Living Program and the Veteran Directed Home and Community-Based Services Program. Through this collaboration, veterans of all ages are able to direct and purchase their services and supports through the aging network which assesses the needs of veterans and caregivers, develops care plans, supports veterans through the provider selection process, arranges for financial management services, and most importantly develops a professional relationship with the veterans to ensure they receive the services as planned to meet their needs and to make changes where necessary.

In FY 2009, we have funded 20 States, 10 of which provide veterans' directed services. And I am pleased to report that in Michi-

gan and New Jersey the program is producing results after just a few months.

In Michigan, for example, a 74-year-old veteran living in an assisted living facility was able to move out of the facility and into his own apartment where he has hired a personal aide who works for him 40 hours a week providing the supports he needs to remain independent and living at home. They report he is doing very well.

By building on the capacities and the infrastructure of the aging network, the VA is already helping to ensure a coordinated consumer-centered approach to serving the needs of veterans and their caregivers.

In fact, I am very pleased to announce that the Secretaries of HHS and VA today announced the provision of an additional \$10 million to expand this program to other States, taking another significant step toward the goal of nationwide home and community-based long-term supports to serve older Americans, persons with disabilities, and veterans of all ages.

As the VA and AoA move forward in our collaborative efforts, the aging network stands ready to put its years of experience honoring and serving older persons to work serving those brave men and women who have served our country so honorably.

Mr. Chairman, thank you for this opportunity. I would be happy to answer any questions you or Members of the Committee may have.

[The prepared statement of Mr. Walker appears on p. 71.]

Mr. MICHAUD. Thank you, Mr. Walker.

Mr. Koch.

#### STATEMENT OF NOEL KOCH

Mr. KOCH. Mr. Chairman, Congressman Brown, distinguished Members of the Subcommittee, I have a written statement which I would like to submit for the record. And I will just make a few brief remarks.

Mr. MICHAUD. Without objection, so ordered.

Mr. KOCH. Thank you.

Mr. Chairman, first of all, I want to say what a privilege it is to have the responsibility that we share with this Committee and with my colleagues at the Department of Veterans Affairs in addressing an issue that Secretary Gates has said is second only to the war in terms of the importance that we assign to it.

The reason that we assign such importance to it should be evident. I think it was evident in the emotionally wrenching testimony that the first panel delivered. And if that is not sufficient, there is a recent completion of a report done by the Center for Naval Analysis, which if you do not have that, we would be happy to provide it to the Committee.

But it addresses in a very scientific fashion and in a very granular way the burdens that are placed on family caregivers and these include loss of income, people having to give up their jobs. We know what the average numbers are for that and we are moving to prepare to deal with that. So that is an effort that is entrusted.

The overall function of my office, which is newly created, I must say, Mr. Chairman, for Transition Policy and Care Coordination, is to effectively make the boundaries between the Department of De-

fense and the Department of Veterans Affairs as permeable as we can get them so that we can smooth the transition of a wounded servicemember either back into active service or if it is going to be necessary for them to transition into a status as a veteran to make that run as smoothly as we possibly can. And I think we are well along in that effort.

In addition to that process which is underway, we provide other sources of information. And I have to say that as I have gone through this, the information that we provide, I am not satisfied that it is easily accessible. We are finding a great deal of duplication, of redundancy.

And so one of the things we will be trying to do is to compress this so that it is, in fact, useful, that it does, in fact, constitute information and not just so much more e-mail and ether driven stuff on Web sites. And so that is one of the issues that we are trying to address now.

Finally, we will be delivering within a little more than a month, it is in coordination now, a DoD instruction on the Recovery Continuation Program. And I think that that will contribute to the effort that we have underway with the Veterans Administration, with our recovery care coordinators, with the Federal Recovery Coordinators, with a number of initiatives which are entrained. Some are actively functioning now, but they address in to the issues that have been raised today.

I think we want to keep in mind before I conclude, sir, that we are focused on family caregivers and the institutional resources that are available to support those efforts are important. But I think what we want to not lose sight of are the individual families. Typically the mothers are the ones that are carrying the biggest burden and these are the ones that we want to consider first as we look at this issue of providing care to the caregivers.

Thank you.

[The prepared statement of Mr. Koch appears on p. 75.]

Mr. MICHAUD. Thank you very much.

And thank you to the other two panelists for your excellent testimony this morning.

If you could provide a copy of that report to the Committee, I would appreciate it.

[The Center for Naval Analysis report, entitled, "Economic Impact on Caregivers of the Seriously Wounded, Ill, and Injured," dated April 2009, by Eric Christensen, Candace Hill, Pat Netzer, DeAnn Farr, Elizabeth Schaefer, and Joyce McMahon, was received by the Subcommittee and will be retained in the Committee files.]

Mr. KOCH. Yes, sir.

Mr. MICHAUD. Thank you.

Mr. Brown.

Mr. BROWN OF SOUTH CAROLINA. Thank you, Dr. Koch, for being here this morning.

And we had some questions. I guess you heard the previous panel. For 2010, DoD has proposed legislation which would provide monthly compensation to catastrophically wounded servicemembers to be used to compensate designated family caregivers.

What is your view of this proposal and how much compensation would it actually be? Do you have a feel for it?



Mr. KOCH. Are you addressing that to me, sir? I am sorry. I am going to have to ask you to repeat the question. And I may not be familiar with the subject sufficiently that I would have to—

Mr. BROWN OF SOUTH CAROLINA. Okay. Well, I will—

Mr. KOCH [continuing]. Address it here without responding in writing.

Mr. BROWN OF SOUTH CAROLINA. Okay. Well, we can submit it in writing and let you give me an answer back would be fine, sir.

You heard the previous panel. They were talking about maybe directly paying to the caregiver rather than paying to the, you know, to the wounded veteran.

Mr. KOCH. Correct.

Mr. BROWN OF SOUTH CAROLINA. Do you have an opinion on that?

Mr. KOCH. Do I have an opinion on their concerns about our care for wounded veterans?

Mr. BROWN OF SOUTH CAROLINA. No. The method and way the caregiver is being paid. I think it goes to the veteran and then he actually pays the caregiver.

Mr. KOCH. All right. I understand. This is a somewhat complicated issue here. The question of who is the recipient of the support is the issue. And there is a point beyond which we cannot control how families function.

So in some cases, the concern is the money goes to the family and the family spends it and it is not spent on care. It is not spent on the purpose that it is being provided for.

Suggestions that we provided directly to the servicemember raised some of the same concerns. So there is a point beyond which we cannot manage the way human beings conduct their lives.

And, I mean, everybody has a suggestion and usually that suggestion is a function of some personal experience or something that they are familiar with that has worked out badly, money has been wasted, care has not been provided and so forth.

And it is difficult to come up with a solution to that because that solution is going to have second-order consequences that are going to have some disaffecting role for somebody else.

Mr. BROWN OF SOUTH CAROLINA. And I guess that is the reason we have hearings, so we can get, I guess, the issues on both sides.

Dr. Agarwal, is that correct? Okay. You heard testimony that access to resources and information for family caregivers is highly variable and there is not any standardized and ongoing training of any formal support network.

How would you respond to those concerns?

Dr. AGARWAL. Thank you for the question, sir.

We certainly are making efforts in doing better outreach about our programs. We have had an initiative known as the Combat Call Center Initiative, which was instituted by Secretary Peake last year, which reached out to about 16,000 veterans who were identified in the seriously ill category during the transition process and were given information on our current programs, particularly about the Care Management Case Management Program and other services and also offered services at that time.

The Federal Recovery Coordinator Program, again, for the seriously injured veterans, this resource has been really, I think, am-

plifying and helping us with navigating between the VA, the DoD, as well as with the private sector. They have a resource directory which I think is a useful resource for the caregivers and the families.

We have a set of liaisons in the military treatment facilities and a case management system which is very knowledgeable about the programs that we offer. And we are working to improve and align our outreach through the internet, the intranet, and My HealtheVet.

Mr. BROWN OF SOUTH CAROLINA. So you basically have a Web site which has these services that are available?

Dr. AGARWAL. We are currently working on that.

Mr. BROWN OF SOUTH CAROLINA. And how to get those resources?

Dr. AGARWAL. We are working on it, sir. It is in the development phase.

Mr. BROWN OF SOUTH CAROLINA. Okay. I know this is one of the, I guess, concerns we have most of the time. We have some needs and we have the ability to meet those needs. And sometimes it is difficult to meet those or connect those, you know, resources. But thank you.

Thank the rest of the panel, too, for being a part of this process.

Mr. MICHAUD. Mrs. Halvorson.

Mrs. HALVORSON. Thank you, Mr. Chairman.

And thank you, panelists, for being here.

What kind of challenges are you seeing with those that are older veterans versus those returning veterans that are coming back now? They are younger. They have probably got different problems. What are the challenges that you are seeing dealing with the two different—

Dr. AGARWAL. Again, thank you for that question.

We recognize the sacrifice and services of our newer generation of the veterans as well. We have an array of programs to provide care in the least restrictive settings which need to be age appropriate and person centered. And taking into account their preferences, including the families' preferences, we are looking for ways to adapt them so that we are more acceptable in meeting those expectations of this disabled veteran group.

We are becoming much more conscious and aware of it and, therefore, providing training in all our educational forums and conferences about the needs for the caregivers and what supports we can provide.

I had just previously mentioned some of the things that we are currently doing, but I am going to turn it over to Dr. Beck to give some specific examples.

Ms. BECK. Thank you.

For some of the challenges that we are facing with our younger veterans is developing and implementing a system of care that provides a lifelong set of services. We are increasingly concerned with vocational pursuits, supported work environments, and the goal of returning our younger veterans to an independent, least restrictive environment in which to provide care and services.

And for that reason, some of the programs that we have discussed, the residential rehabilitation programs, the adult day care

programs, we are individualizing those programs and specializing them so that they address our younger veterans. Our younger veterans are very technology savvy. They are very interested and concerned with sports and fitness and leisure time activities. So we are adding these services. And we have dynamic family environments. We have younger veterans who are parents. And so in addition to providing a supportive environment where we provide child care, we are using the goals that those veterans have to be good parents, to be good spouses, and incorporating those elements of care into our rehabilitative environments.

Mr. MICHAUD. Thank you very much.

They just called for votes, so you are saved by the bell.

I do have several questions but in respect for the panel's time and others in the audience, since we have several votes coming up, I will submit those questions in writing.

So I want to thank this panel and the previous two panels for your testimony this morning and look forward to working with you as we move forward on this very important issue as it relates to caregivers and our veterans. So thank you very much for coming.

The hearing is now adjourned.

[Whereupon, at 11:45 a.m., the Subcommittee was adjourned.]

## A P P E N D I X

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### **Prepared Statement of Hon. Michael H. Michaud, Chairman, Subcommittee on Health**

The Subcommittee on Health will now come to order. I would like to thank everyone for coming today. The goal of today's hearing is to identify the gaps in supportive services for family caregivers. We also seek a better understanding of the VA's current efforts to meet the needs of family caregivers of veterans.

Family caregivers are the true back-bone of the U.S. long-term care system with more than 50 million people who provide informal caregiving for a chronically ill, disabled, or aged family member or friend in any given year. Focusing on family caregivers of veterans, it is my understanding that the VA does not collect data on this population and therefore, the number of family members who provide care for veterans is unknown.

Additionally, studies of the general family caregiver population show the real adverse financial and physical toll that caregiving has on these individuals. For example, women family caregivers are more than twice as likely to live in poverty. Also, family caregivers report having a chronic health condition at twice the rate of their non-caregiver counterparts and those who provide 36 or more hours of weekly caregiving are more likely to experience symptoms of depression and anxiety than non-caregivers. In the end, this has serious implications for our veterans. In order to ensure that our country's heroes receive the highest quality of care from their family caregivers, it is important that we arm them with the right tools and offer appropriate supportive services so that they are less apt to be overwhelmed by the difficult day to day realities of being a caregiver.

Clearly, the family caregivers of our veterans have made great sacrifices. I have heard from family members who gave up their jobs, delayed their schooling, or made other significant life-changing sacrifices in order to be by their loved one's side. This raises questions about the VA's current efforts to help these family caregivers and whether there are sufficient supportive services in place. Additionally, there are concerns about the lack of coordination of caregiver benefits when the servicemember transitions to veteran status. In other words, supportive services that family caregivers may have depended on through the DoD are suddenly discontinued when the wounded warrior transitions to the VA system.

Through today's hearing, I look forward to exploring ways to better help the family caregivers of our veterans.

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### **Prepared Statement of Hon. Henry E. Brown, Jr., Ranking Republican Member, Subcommittee on Health**

Thank you Mr. Chairman.

Our men and women in uniform put their lives on the line to defend our freedom. And, when they are wounded in the line of duty, it is often the family that put their lives on hold to care for their injured loved one.

Family caregivers are more often than not at the core of what sustains the treatment and recovery of a wounded, ill, or injured soldier. Their commitment is strong and heartfelt. Yet, it can be enormously challenging, especially in a prolonged recovery. There are many struggles that family members may face when assuming this role including: job absences, lost income, travel and relocation costs, child care concerns, exhaustion, and emotional or psychological stress.

The President's Commission on Care for America's Returning Wounded Warriors, often called the often called the Dole-Shalala Commission, and reports by both the Department of Veterans Affairs (VA) and Department of Defense (DoD) Inspector General Offices have emphasized the critical role that families play in the successful rehabilitation of our Wounded Warriors. Among the many recommended reforms

identified in these reports was the need to initiate policies that take family caregivers into account.

As a result of these reports and Congressional direction, both VA and DoD have taken steps to implement policies to provide better support and assistance for the family and friends of wounded service members.

At this hearing today we will take a close look at the role of the family caregiver and the services VA and DoD are currently providing. Most importantly, we will examine what more can and should be done to provide family caregivers with the information, education and assistance they so urgently need and deserve.

It is vitally important to the health and well-being of our wounded warriors and their loved ones to support and preserve the critical role of family caregivers.

I thank the Chairman for holding this hearing and yield back.

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### **Prepared Statement of Anna Frese Family Outreach Coordinator for Brain Injury, Wounded Warrior Project**

Chairman Michaud, Ranking Member Brown and Members of the Subcommittee: Thank you for inviting the Wounded Warrior Project to testify today about the needs of family caregivers of wounded warriors and the gaps in supportive services available through the VA. Mr. Chairman, we're particularly grateful to you for introducing H.R. 2342, the Wounded Warrior Project Family Caregiver Act, a bill that would provide the critical supportive services family caregivers need.

Let me provide some context for this statement by telling you about my brother, Eric, whose life was forever changed by an IED attack in October 2005. Eric grew up as a very independent kind and shy young man with big dreams. Today he lives with a traumatic and anoxic brain injury.

Eric won the battle for his life, but he faces a new battle every day as he works to regain the ability to walk, talk, eat and drink. Eric requires full-time assistance from our father, Ed, who quit his job as a warehouse supervisor to assist his son in adapting to the "new normal" of life after injury and provide quality of life.

The only option originally proposed for Eric's future was nursing home care. But our family could not bear the thought of sending Eric to a nursing facility. So he came home.

Eric and Dad are a Team now. Eric requires assistance with all of his activities of daily living (ADL's), but having one's daily living needs met does not capture the desired life of a 28 year old man. The physical assistance required to perform ADL's and administration of medicine are addressed throughout the day, but it is the way that Dad as a parent cares for Eric's spirit by supporting him in reaching his goals, creating new memories, and focusing on future dreams and adventures that has been the driving force behind Eric's progress toward recovery. Eric relies on Dad to assist him in everything, and Dad does it with pride and great respect.

But there is an unseen price. Our father, now 54 years old, is no longer employed and has used up his retirement funds and savings, no longer has health insurance and has not contributed to Social Security in almost 4 years. Even though his future has been drastically altered, he tells me often, "Eric would do it for me."

Clearly, the casualties of war extend far beyond the battlefield.

### **Needs of Family Caregivers of Wounded Warriors**

While many wounded warriors substantially recover from their wounds and are able to live independently, some like Eric have sustained such profound injuries that they will likely need ongoing personal care and assistance for a very long time. These individuals usually want to return to, or remain in their homes, and strongly resist being institutionalized.

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

As you know, our wounded warriors are leaving hospitals and rehabilitation facilities with grievous, life-changing injuries that include severe burns, amputations, spinal cord injury, blindness, and brain injuries. Many have, of course, sustained

*multiple* injuries and may also be experiencing co-occurring psychological problems, including PTSD and depression.

Formerly independent individuals with such severe injuries now routinely require assistance with the most basic, intimate activities of daily living. Some have retained or regained the ability to carry out those activities, but brain injuries may have impaired their cognition, judgment, memory, emotional stability, or other capacity to function safely even inside the home without help or accompaniment of another.

In many cases, the wounded warrior requires personal assistance around the clock and may need specialized, daily care. At present, few family caregivers receive standardized and on-going training, and they have no formal support network. Many have no access to health care, respite care, counseling or a way to replace lost income. Those who leave the workforce to become caregivers typically lose not only income but health care coverage, savings, a retirement plan, and benefits.

Each veteran's situation and each family's experience is unique. But each family, and ultimately each wounded warrior, faces a common danger. That danger is that, over time, caregiving without reasonable supports can become unsustainable. Such a breakdown can take many forms—utter exhaustion, incapacitating illness, personal bankruptcy, nervous breakdown, or severe interpersonal strain that in some instances has led to divorce. In such cases, there may be no other alternative for the veteran than institutional care. Such outcomes would not only be tragic for wounded warriors and their families, but could become enormously costly to the VA health care system which will likely be called upon to care for them.

Through my own family's experience, and that of the many, many families with whom the Wounded Warrior Project works, we understand not only how fragile family caregiving can be, but what is needed to help sustain it and avoid its breakdown. In our experience, certain fundamental needs must be met to sustain family caregiving. These include initial caregiver training and instruction on meeting the veteran's personal-care needs, and provision of basic support services. Those needed supports are—

- An ongoing source of training, information and assistance to meet routine, specialized, and emergency needs;
- Access to counseling and mental health services;
- Respite care;
- Provision of needed medical care; and
- Some modest level of economic support.

While some families may not need the full array of services, my father's situation certainly illustrates the importance of those supports.

Let me share two other examples from among the many with whom I've worked. In late 2005, one of our "alumni" was blinded and sustained severe traumatic brain injury as a result of an IED explosion in Iraq. His wife was forced to leave her teaching job permanently to care for him. In the 3 years she has been his full-time caregiver, she has received no training of any kind, no supplemental income, and has health care coverage only because she is covered by TRICARE. Although she lives some 90 miles from the nearest VA facility, she had not been made aware of the availability of VA respite care.

The mother of another wounded warrior lost her job after 2 months of caring for her son, who had been severely injured in April 2003, and requires full-time care. She has some health care coverage through her husband's health care program, but they pay significant premiums for that care. They have gone from a two-income family to a one-income family. She has had a heart biopsy and heart catheterization done recently and stated plainly that along with the normal worry and stress that caregiving entails, that stress is compounded by the fact that there is a constant concern about their finances and health care coverage.

### **The Well-Established Research on Family Caregivers**

While I can share the experience of many, many more families of wounded warriors, the needs I've described are not simply anecdotal. The impact of long-term caregiving on the families of severely disabled individuals in the general population has been extensively studied. These findings underscore the need wounded warrior family caregivers have for the array of services provided for in H.R. 2342.

Studies indicate, for example, that proper caregiver training can reduce the chances of injury for both the caregiver and the recipient. They show further that well-trained caregivers are less likely to use costly, formal supports.<sup>1</sup>

Highlighting the need for access to counseling and other health care services, the studies also show that family caregivers experience an increased likelihood of stress,<sup>2</sup> depression,<sup>3</sup> and mortality<sup>4</sup> as compared to their non-caregiving peers. Those who provide care 36 hours or more per week are more likely than non-caregivers to experience depression and anxiety. Women who provide that level of care to a disabled spouse are six times more likely to experience symptoms of depression and anxiety.<sup>5</sup> Studies also suggest that with each incremental increase in assistance with activities of daily living (ADL's), spousal caregivers experience a greater risk for serious illness.<sup>6</sup> Caregivers report poorer levels of perceived health,<sup>7</sup> more chronic illnesses,<sup>8</sup> and poorer immune responses to viral changes.<sup>9</sup>

Finally, economic issues associated with caregiving cannot be ignored. The literature suggests that informal (unpaid) caregiving is incompatible with full-time employment.<sup>10</sup> Research shows that even small reductions in work hours to provide unpaid care can result in significant lost wages and a reduction in the caregiver's future pensions and retirement savings.<sup>11</sup> Also, a reduction in long-term wages will reduce future Social Security benefits.

### Gaps in VA's Support for Needs of Family Caregivers

The VA has the capacity to provide for the full array of supports that a caregiver would need. But the Department has no systematic Family Caregiver Program. It has mounted some pilot programs. But overall, our experience is that very little institutional attention is being paid to family caregivers even though they are a vital link in the veteran's lifelong rehabilitation process. *Some* VA facilities provide some of the services family caregivers need—notably, respite care, and some education and counseling for family members. But family caregivers need more than piecemeal services and support. Moreover, provision of those limited support services is highly variable, and, to the extent that they exist at all, these support services are simply not integrated in a comprehensive manner to support family caregivers. Given the handful of generally limited and inconsistent caregiver support services now available, families are coping largely on their own.

When invited to express support for legislation to establish a program such as that proposed in H.R. 2342, VA has been surprisingly resistant, and asserted its

<sup>1</sup>G. Smith, P. Doty and J. O'Keefe, "Supporting Informal Caregiving," in *Understanding Medicaid Home and Community Services: A Primer* (Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2000). As referenced in *The Older Americans Act National Family Caregiver Support Program (Title III-E and Title VI-C): Compassion in Action* (Washington, DC: U.S. Department of Health and Human Services, Administration on Aging, 2004), 7.

<sup>2</sup>Pinquart and Silvia Sorensen, "Differences Between Caregivers and Noncaregivers in Psychological Health and Physical Health: A Meta-Analysis," *Psychology and Aging* 18, no. 2 (2003): 254.

<sup>3</sup>Nadine Marks, and James Lambert, "Transitions to Caregiving, Gender, and Psychological Well-Being: A Prospective U.S. National Study," February 1999, working paper no. 82, Center for Demography and Ecology, University of Wisconsin-Madison, pg. 15.

<sup>4</sup>Richard Schultz and Scott Beach, "Caregiving as a Risk Factor for Mortality," *Journal of the American Medical Association* 282, no. 23 (1999): 2218.

<sup>5</sup>C. Cannuscio et al, "Reverberation of Family Illness: A Longitudinal Assessment of Informal Caregiver and Mental Health Status in the Nurses' Health Study," *American Journal of Public Health* 98, no. 8 (2002): 305-1311.

<sup>6</sup>W. S. Shaw, T. L. Patterson, S. J. Semple, S. Ho, M. R. Irwin, R. L. Haugler et al., "Longitudinal Analysis of Multiple Indicators of Health Decline among Spousal Caregivers," *Annals of Behavioral Medicine* 19 (1997): 105.

<sup>7</sup>R. Schulz, A. T. O'Brien, J. Bookwala and K. Fleissner, "Psychiatric and Physical Morbidity Effects of Dementia Caregiving: Prevalence, Correlates, and Causes," *Gerontologist* 35 (1995):771-791, as referenced in Thomas Patterson and Igor Grant, "Interventions for Caregiving in Dementia: Physical Outcomes," *Current Opinion in Psychiatry* 16 (2003): 629-630.

<sup>8</sup>A. Pruchno and S. L. Potashnik, "Caregiving Spouses: Physical and Mental Health in Perspective," *Journal of American Geriatric Society* 37 (1989): 697-705, as referenced in Thomas Patterson and Igor Grant, "Interventions for Caregiving in Dementia: Physical Outcomes," *Current Opinion in Psychiatry* 16 (2003): 630.

<sup>9</sup>R. Glaser, J. K. Kiecolt-Glaser, "Chronic Stress Modulates the Virus-Specific Immune Response to Latent Herpes Simplex Virus Type I," *Annals of Behavioral Medicine* 19 (1997): 78-82, as referenced in Thomas Patterson and Igor Grant, "Interventions for Caregiving in Dementia: Physical Outcomes," *Current Opinion in Psychiatry* 16 (2003): 630.

<sup>10</sup>R. W. Johnson and A.T. Lo Sasso, *The Trade-Off between Hours of Paid Employment and Time Assistance to Elderly Parents at Midlife* (Washington, DC: The Urban Institute, 2000), 25.

<sup>11</sup>*Ibid.*, 27-28.

preference for contracting for home health services. But many of the families of our newest generation of wounded warriors consider such services (even assuming they are available locally and could meet the often complex needs of the veteran) a poor alternative to the care provided by a devoted parent, sibling, spouse, or friend. Local services vary greatly in both quality and quantity. (When Eric was assigned a home health care nurse during his transition home, the family found the agency's involvement to be more troublesome than helpful. Due to the large amount of patients assigned to each staff, there immediately was an issue with showing up considerably late or not at all. We also found the agency staff to be uncomfortable in meeting Eric's specialized needs.) There is no nationwide training standard and no cultural training for local agencies addressing the unique needs of young, severely wounded veterans, particularly those with TBI, PTSD or other psychological health issues. Additionally, for family caregivers who need financial support to enable them to care for their wounded loved ones, VA has no answer other than to suggest vaguely that they might seek employment with a local home-health agency. In short, the VA offers an inadequate answer for those of us who have dedicated ourselves to providing what we believe is the best care available—that provided by a loving family.

Sending young men and women into battle has its costs; bringing our severely injured veterans home also has its costs. Families provide home-care out of love. But given the profound challenges that family caregivers face and VA's failure to respond effectively to those challenges, we applaud your development and introduction of H.R. 2342, and look forward enthusiastically to working with you and the Committee to advance this critically important initiative.

In closing, let me explain that I have shared our family's story not to call attention to our situation but to speak for the many other wounded warriors whose futures will be brighter if their families are provided support to assist them in continuing the dedicated, loving vigil of caregiving.

That concludes my testimony; I would be happy to answer any questions you may have.

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**Prepared Statement of Commander René A. Campos, USN (Ret.) Deputy  
Director, Government Relations, Military Officers Association of America**

**EXECUTIVE SUMMARY**

**CAREGIVER/FAMILY NEEDS:**

**DoD-VA Seamless System of Care and Support**

- Care and support that is focused on both active duty and reserve servicemembers and veterans that are wounded, ill or injured and their family/caregivers.
- Single, joint, one-stop Departments of Veterans Affairs (VA) and Defense (DoD) management system of care and support. Caregivers/families desire a seamless and transparent transition experience between the two systems.
- Standardization/consolidation of systems that produce high quality, comprehensive, responsive, and accessible medical and non-medical services.
- Continuum of care and support that is consistent, reliable, easy to navigate, and is proactive, anticipating needs over a lifetime.

***“I had to navigate everything. The lack of communication and coordination are still the biggest challenges. Much can be done to streamline and navigate the system to help improve the quality of life for families.”*** (Mother of Navy son injured in 2007)

**Communication & Information**

- Reliable, accurate, and personalized/customized information tailored to individual/family situation.
- Timing, amount, format, frequency, and delivery of information is crucial.
- Bi-directional sharing of information among providers and staff, and between providers, staff and families.

***“I don't have the time to research how to get help, how to provide the best therapy for my son—I need one place to go—my toolbox—with resources for whatever I or my son need. Take away the responsibility of researching the issues when someone out there al-***



***ready knows the answers. Make it easier for me to find answers.***  
(Parent Caregiver, 2009 Quality of Life Foundation Report, *Wounded Warrior Family Care, Establishing a Model of Family Support*)

#### **Advocacy & Assistance Coordination**

- One VA–DoD care coordinator/manager that is assigned at the time of injury and remains with family/caregiver providing continuity of support to the family long-term if needed.
- Assistance in navigating and coordinating medical care, benefits, support services, and available resources within and outside the VA and DoD.
- Standard VA–DoD caregiver training, certification, and compensation programs for full-time family caregivers, including reimbursement of all expenses associated with caregiving and recognition of caregivers' earnings forfeiture; compensation should be paid directly to the caregiver and not be considered a servicemember-veteran benefit.

***“Right now I’m fighting a battle. I’m going to [a VA facility] with my son; he’s still an inpatient. I’m going by myself. I have a mortgage, bills. I quit my job to take care of my baby, my only son. I’m coming from another States . . . I can’t find a job here because I’m always in the hospital.”*** (Parent caregiver, 2008 DACOWITS report)

Chairman Michaud, Ranking Member Brown, and Distinguished Members of the Subcommittee, on behalf of the 370,000 members of the Military Officers Association of America (MOAA), I am grateful for the opportunity to present testimony on the issues facing caregivers of veterans and to offer recommendations to better meet their needs, and those of their family.

MOAA does not receive any grants or contracts from the Federal Government.

MOAA commends the Departments of Veterans Affairs (VA) and Defense (DoD) for the significant progress made in transforming health care and support to meet the needs of our wounded warriors and their families. There has been much emphasis on trauma care, acute rehabilitation, and basic or short-term rehabilitation during this transformation. It is now time to take a longer view of how we will care for our most severely wounded, injured or ill, including strengthening support to caregivers and family members over the life-cycle of the member.

#### **FINDINGS OF KEY STUDIES**

**2009 Quality of Life Foundation Report, “Wounded Warrior Family Care, Establishing a Model of Family Support” & Working Group Meeting, May 18–19, 2009 on Community Resource Coordination Program**—Identified underserved/unmet needs for families of the severely injured, offered recommendations to address shortfalls, and provided a model of support and nationwide private-sector community resource coordinator program concept for transitioning to long-term, if not a lifetime of intensive home-based family care.

##### **• Key Findings**

- *Not currently provided by VA or DoD:*
  - Replacement for family caregiver loss of income;
  - Replacement for family caregiver loss of medical, dental and life insurance;
  - Private sector community resource coordinator for unmet/underserved needs;
  - Home visit to prepare home and family for veteran’s arrival; and
  - Long-term care tailored to the veteran’s age, medical, and rehabilitation needs.
- *Currently provided, but improvements needed:*
  - No in-person support/assistance officer or notebook to provide guidance at time of injury;
  - Pre-paid lodging/meals, child/dependent care, legal assistance, respite care, transportation assistance, and reimbursement for out-of-pocket expenses;
  - Preparation in DoD pay and benefit changes and assistance obtaining VA benefits, compensation, and grants;
  - Communications support;
  - Education regarding treatment options;
  - One overall/single point of contact—lifelong case manager;

- Emotional/mental health support;
- Community integration plan/local connections and continued rehabilitation therapy for veteran;
- Medical appointment, transportation assistance/reimbursement; and
- Caregiver vocational assistance—biggest issue is compensation for caregivers—VA has some programs, but more are needed via legislation.

• **Recommendations**

- Collaborative effort needed at the Federal, State, private sector, and community levels, using a national Community Resource Coordinator Program model of support.
- VA, DoD and Congress need to continue to press for legislative changes and increased funding for caregiver/family support/programs.
- Non-profits should collaborate to identify best-practices in delivery of community-based services to meet needs.

**April 2009 CNA Study, “Economic Impact on Caregivers of the Seriously Wounded, Ill, and Injured”**—The study was done by the Assistant Secretary of the Air Force for Manpower and Reserve Affairs, who was tasked to look at the economic impact on caregivers of seriously wounded, ill or injured by the Joint DoD–VA Senior Oversight Committee (SOC), under the area of responsibility, Line of Action 8 (Personnel, Pay & Financial Support).

**Findings**

- Caregivers provide benefits in overall patient recovery.
- Injury has an immediate economic impact on servicemembers and family member caregivers
  - Servicemembers’ pay and tax status change as they move from deployment to hospitalization to outpatient status to eventual return to duty or transition to VA.
  - Financial challenges on caregivers begin to mount as they leave work and educational pursuits to be a caregiver.

**Survey Results**

- 57 percent of caregivers provided at least 10 hours a week.
- 3 out of every four caregivers had to quit or take time off from work or school.
- 11 percent of caregivers dealt with housing/location changes.
- 1/3 of caregivers had to make new child care arrangements.
- 37 percent of caregivers had unmet financial obligations (positively correlated with the number of hours of assistance the caregiver provides each week).
- Annual average number of very seriously injured/seriously [VSI/SI]
  - VSI/SI servicemembers = 720
  - VSI servicemembers only = 170
- Duration of caregiver support
  - Average = 19 months
  - Survey respondents expecting to give long-term care = 43%

Average economic loss by caregivers (covers lost earnings/benefits only)

- 19 months of care per caregiver = \$60,300
- 19 months of care for 720 VSI/SI caregivers = \$43.4 million
- 19 months of care for 170 VSI caregivers = \$10.2 million

**Other findings**

- Access to information and resources vary.
- Benefits eligibility is a concern—generally more resources for OIF/OEF veterans; little financial support for those suffering solely from post-traumatic stress disorder (PTSD) or mild to moderate traumatic brain injury (TBI) because they don’t qualify for Traumatic Servicemembers’ Group Life Insurance (TSGLI) or for non-medical attendant (NMA) funding.

- Members in transition to VA often suffer period of lapse in pay and benefits.
- Families need more education on medical conditions like TBI and financial matters to prepare for the future.

**Defense Advisory Committee on Women in the Services (DACOWITS) October 17, 2008 Report, “Support for Families of Wounded Warriors: Summary of DACOWITS Focus Groups”**—By memorandum dated August 1, 2008, the Principal Deputy Under Secretary of Defense for Personnel and Readiness requested that DACOWITS conduct a short but intensive study on the level and consistency of military support experienced by family members of wounded warriors. DACOWITS conducted focus groups and interviews during August and September of 2008.

#### **Findings/Recommendations**

- *Finding:* Services and resources designed for wounded warriors and their families/caregivers are extensive, but lack integration (synchronization); as a result they often don’t reach the people they are designed to serve.  
*Recommendation:* Integration—better integration of existing programs/resources.
- *Finding:* Systems are working tirelessly to meet needs of the wounded, but need more information about the specific needs of the families—can’t fix what they do not know.  
*Recommendation:* Feedback—need multiple, dynamic and innovative feedback mechanisms to gather and respond to information.
- *Finding:* Many families do not know how to assist their wounded warrior with their recovery.  
*Recommendation:* Training—educate family members on the specific injury, what they can do to help, and resources that are available for assistance.
- *Finding:* Families do not know about the services available to them.  
*Recommendation:* Information dissemination—better advertising of services available, including providing family members civilian-friendly pocket guides that contain flow chart, name, function, local contact data and next step information for each stage of the recovery process.
- *Finding:* Programs should be measured for effectiveness and to provide details for next steps.  
*Recommendation:* Metrics—systematically assess the needs of wounded warrior families and use results to perform continuous process improvement.
- *Finding:* Family members/caregivers’ input and participation in some cases is not valued by medical providers or information is withheld by non-medical support personnel due to misunderstanding of confidentiality requirements.  
*Recommendation:* World class client care—educate individuals involved in the care of wounded warriors to communicate in a way that allows free exchange of important information and recognizes the integral role of family members/caregivers in the treatment and recovery process.
- *Finding:* Families expressed more satisfaction with the tangible aspects of their support, but less satisfaction with the intangibles like lack of educational information, emotional support, assistance, and advocacy.  
*Recommendation:* Augment support—by partnering with non-profits and other agencies and individuals and establishing support groups to meet these needs.

**June 2008, Interim Report of the “Department of Veterans Affairs Advisory Committee on Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) Veterans and Families”**—An independent advisory Committee established in 2007 to assess the current situation of OIF/OEF veterans and families; reviewed issues affecting families and caregivers; and transition from DoD to VA care.

#### **Recommendations—VA should:**

- Maintain contact with returned National Guard/Reserve members and units, and families of injured servicemembers.
- Provide counseling services to caregivers and family members whose mental health may be adversely affected while providing care to the severely disabled veteran.
- Seek authority to include counseling services for caregivers and families over a prolonged period of time (may require legislation).

- Provide financial counseling to caregivers and fiscal support while caring for the severely disabled veteran.
- Provide direct support to include reimbursements for lodging, per diem, and transportation when the caregiver is at the veteran's bedside at a VA facility (may require legislation).
- Duplicate caregiver reimbursement and training programs that already exist for spinal cord injury patients in San Diego throughout the VA system and expand to include TBI and Level One polytrauma patients.
- Enhance efforts to ensure caregivers are appropriately informed of all benefits and entitlements for themselves and the severely disabled veteran in their care.
- Ensure the recovery care coordinator (RCC) informs the caregivers of all available benefits and provides assistance and follow-up throughout the transition process.
- Ensure caregivers have ongoing contact and support from the RCC upon returning home with the veteran.
- Designate the RCC to act as ombudsman for the caregiver in navigating benefits and entitlements.

#### WHAT CAREGIVERS/FAMILIES SAY

*"There's no human factor. Due to technology, we as people get lost in the process . . . If they would just speak to you about things . . . People don't speak to each other . . . I recommend they more proactively keep the family member informed . . . We need a person that guides us through the process."*

*"Right now I'm fighting a battle. I'm going to [a VA facility] with my son; he's still an inpatient. I'm going by myself. I have a mortgage, bills. I quit my job to take care of my baby, my only son. I'm coming from another State . . . I can't find a job here because I'm always in the hospital."* (DACOWITS Report, Army family member)

*"I asked them at the VA [where his single son has been followed for several years for PTSD] whether they could provide us as his parents any counseling, and they said that they didn't have anything for us."* (DACOWITS Report, Navy Family Member)

*"I worry about how to plan for long-term care for my son should something happen to me and my husband. There is not age-appropriate care in the VA."* (Mother of Navy son injured in 2007)

*"All the Army ever wanted was a soldier—the Army got it, all we want is a little help. We got excellent care at the MTF. But we had to fight to get our son in private care and take him home. There are so many problems with the VA bureaucracy. We were lucky to know people in the system, but so many other families are struggling."* (Father of an Army son injured in 2007)

#### RECOMMENDATIONS FOR IMPROVING CARE & SUPPORTIVE SERVICES

Congress passed a number of provisions in the last 2 years to address the myriad issues facing those wounded or disabled. Many of these initiatives are aimed at helping members and their families navigate the often complex military and veterans' health care and benefit systems. While members and families tell us they are pleased with the care and support they receive in the military system, they are less than confident or secure when they leave the system. The safe haven and resources that troops and their families grow accustomed to while on active duty are inconsistent or in some cases, non-existent when the veteran enters longer-term care in the VA.

Yes, much has been done. But caregivers, family members and those wounded and disabled continue to be frustrated with a large number of barriers and bureaucracies that still exist within and between the two departments. They wonder if anything has really changed, or if the government will be there to care and support them for the longer haul.

**DoD-VA Joint Seamless Transition Office.** Congress extended the Senior Oversight Committee (SOC) only through December 11, 2009. However, the 2009 NDAA requires the Departments to submit a report in June 2009, providing recommendations for continuing the operations of the SOC, including any modifications to its responsibilities, composition, or support.

MOAA believes strongly that many of the issues that we continue to hear about require major system fixes, not just patching the system with additional layers of programs and policies that further entrench the bureaucracies and buildup barriers.

It is of overriding importance to authorize and implement a permanent, single, Joint Seamless Transition or SOC Office, responsible for managing, implementing,

monitoring, and reporting to senior VA, DoD and congressional leaders on all aspects of the seamless transition process, including but not limited to:

- Joint, single separation physical;
- Consistent disability evaluation system (fairly evaluating/compensating visible and invisible medical conditions);
- Bi-directional electronic medical and personnel records transfer;
- Medical centers of excellence and operations/research collaboration; and coordination of care, treatment, and information, including VA–DoD Federal/recovery coordinator, clinical and non-clinical services, caregiver/family support services, and case management programs.

**System of Care and Support.** It is essential to have a single, joint system of care and support that:

- Focuses on servicemembers, veterans, and their caregivers and family members;
- Provides simple, easy to understand, consistent, and frequent information, when and where it is needed;
- Changes the current VA–DoD cultures from passive to proactive—one that is dynamic, flexible, and adaptable, providing a continuum of care; and,
- Provides bi-directional care and support—members, caregivers/families move in and out of VA–DoD systems over time, and data, services, and records must transfer seamlessly between and within the system for continuity of care and support.

#### **Family Advocacy and Support**

- Establish a VA–DoD Center of Excellence for Veteran/Military Caregivers/Families to provide oversight, policy and programs for medical and non-medical care and support;
- Assign a single point of contact to the caregiver/family, to be an advocate and help navigate personnel, benefits, health care and support systems; and
- Establish the Community Resource Coordinator Program (CRCP) and National Board or Advisory Committee recommended by the Quality of Life Foundation.
  - CRCP provides daily living caregiver support from time of injury, during transition to community-based living, and long-term if needed.
  - National Board or Advisory Committee would provide oversight and evaluate the effectiveness of the program.

***MOAA strongly supports H.R. 593, the Enhanced Disability Severance Correction, to extend the authorized concurrent receipt of disability severance pay from the Department of Defense (DoD) and compensation for the same disability under any law administered by the Department of Veterans Affairs (VA) to include all veterans with a combat-related disability.***

**Caregiver Compensation and Benefits**—MOAA recommends the Subcommittee take action to:

- Authorize consistent VA–DoD compensation, training, certification, and respite care for full-time family/caregivers;
- Authorize health care coverage for full-time caregivers and their families;
- Improve information outreach for referral and direct services for child care, legal and financial assistance, counseling for full-time caregivers (DoD’s Military OneSource and Military Family Life Consultants Programs could be models for VA use); and
- Require VA–DoD to conduct research and submit a joint report on the impact of combat stress, TBI, and other war injuries on full-time caregivers and family members, including children, along with appropriate action to address the resultant family member needs.

***MOAA strongly supports the Chairman’s “Wounded Warrior Project Family Caregiver Act of 2009” (H.R. 2432), which would direct the Secretary of the VA to establish a family caregiver program that furnishes support services to family members certified as family caregivers who provide personal care services for certain disabled veterans. MOAA encourages the Subcommittee to work with other Members of Congress, VA and DoD to develop and implement identical programs and policies for caregivers of Members on active duty and in retired/veteran status so that caregivers/family mem-***

***bers would be equally qualified and eligible whether they are caring for their loved one in either a DoD or a VA setting.***

MOAA is particularly concerned that compensation for caregivers should be paid directly to caregivers rather than being provided as a benefit to the wounded, ill or injured servicemember or veteran.

When the benefit is paid to the veteran, it too often does not reach the caregiver and thus fails to serve its intended purpose. Many servicemembers and veterans are either unaware that the payment is intended to cover the caregivers' needs or are incapable of understanding the situation by virtue of incapacitation.

In other cases, the caregivers express great reluctance to accept money from the wounded servicemember.

Caregivers who find their own lives and financial futures devastated, in some cases permanently, by the grievous service-caused wound, illness or injury of a loved one are owed a special debt by the Nation. And, extraordinary efforts are appropriate to recognize the extraordinary and wholly unforeseeable sacrifices that national service requirements have imposed on them through no fault of their own.

This terrible burden has fallen on a parent or sibling or friend when a spouse has abandoned hope for any substantive recovery by the servicemember/veteran. In such cases, caregivers have forfeited not just their jobs, but their homes, savings, and retirement accounts and have been left penniless.

The only reasonable answer to this extraordinarily unfair situation is to ensure that recognized and qualified caregivers receive appropriate compensation directly rather than through the servicemember/veteran.

#### CONCLUSION

MOAA is grateful to the Subcommittee for its leadership on these difficult issues and for the commitment of the Congress, VA and DoD to addressing the pressing needs of wounded warriors and their families and other caregivers. It's clear from what we have heard today, and in recent hearings, that we've got more work to do.

We believe if we focus more on the needs of the wounded and disabled and their families and less on the preferences of the multiple government bureaucracies and their systems administrators, then we will build the right system—one that is needed today and one built to anticipate the future.

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#### **Prepared Statement of Barbara Cohoon, RN, Ph.D., Government Relations Deputy Director, National Military Family Association**

The National Military Family Association is the leading nonprofit organization committed to improving the lives of military families. Our 40 years of accomplishments have made us a trusted resource for families and the Nation's leaders. We have been at the vanguard of promoting an appropriate quality of life for active duty, National Guard, Reserve Members, retired servicemembers, their families, and survivors from the seven uniformed services: Army, Navy, Air Force, Marine Corps, Coast Guard, Public Health Service, and the National Oceanic and Atmospheric Administration.

Association Representatives in military communities worldwide provide a direct link between military families and the Association staff in the Nation's capital. These volunteer Representatives are our "eyes and ears," bringing shared local concerns to national attention.

The Association does not have or receive Federal grants or contracts.

Our Web site is: [www.MilitaryFamily.org](http://www.MilitaryFamily.org).

#### **Barbara Cohoon, Deputy Director, Government Relations**

Ms. Cohoon was hired as Deputy Director of Government Relations for the National Military Family Association in July 2006. In that position, she monitors issues relevant to the quality of life of families of the uniformed services and represents the Association at briefings and other meetings. Ms. Cohoon currently serves on The Military Coalition's Veterans Affairs and Health Care Committees. She is a Member of the Department of Defense's (DoD) Uniform Formulary Beneficiary Advisory Panel. She has been appointed to DoD's Defense Health Board's TBI Family Caregivers Panel, Health Care Delivery Subcommittee, and the TBI Subcommittee. Her activities on behalf of the Association directly contribute to sustaining the TRICARE health care benefit for military servicemembers, retirees, and their families. Her expertise is used to provide independent advice and valuable recommendations to the Subcommittees and develop resource materials for TBI caregivers. She has also been appointed by the Alexandria City Council of Virginia to

represent the city as a health care expert to the Health Systems Agency of Northern Virginia.

Ms. Cohoon is originally from Andover, Massachusetts. She received a Diploma of Nursing from Lowell General Hospital, and a Master's of Science in Nursing and a Doctorate in Philosophy from the College of Health and Human Services with a concentration in health policy from George Mason University. She has more than 20 years of nursing experience in both military and civilian health care facilities. She is a member of the Honor Society of Nursing, Sigma Theta Tau. She has been published in peer-reviewed health care journals and writes regularly for the National Military Family Association.

Ms. Cohoon has been a Navy submariner's spouse for over 30 years, which included 19 moves. She has been active in military spouses' clubs, various fund raisers, in the development and implementation of the first Joint Women's Conference for military spouses in Hawaii and an active mentor for the Command Spouses Leadership Course (CSLC). She has completed both the Ombudsman and Advanced Ombudsman Training courses. She was an Executive Advisor for the Fleet and Family Service Center, American Red Cross, Navy Relief Society, King's Bay Naval Base Medical Clinic and various fundraising events from 2002—2004. She worked as a volunteer for the CNO directed Task Force Navy Family for Hurricane Katrina evacuees. She is a member of the Naval Officers' Spouses' Club of Washington, DC, the National Military Family Association, and a lifetime Member of the Navy League. She has two boys. One is a graduate of Lynchburg College in History and the other from Georgia Tech in Mechanical Engineering. She currently resides in Old Town Alexandria, VA where she and her husband have renovated a 115+ year-old home.

Chairman Michaud and Distinguished Members of this Subcommittee, the National Military Family Association would like to thank you for the opportunity to present testimony on "*Meeting the Needs of Family Caregivers of Veterans.*" National Military Family Association will take the opportunity to discuss several issues of importance to family caregivers of the wounded, ill, and injured servicemembers, veterans, and their families in the following subject areas:

- I. Wounded Servicemembers Have Wounded Families
- II. Who Are the Families of Wounded Servicemembers?
- III. Caregivers
- IV. Mental Health
- V. Case Management
- VI. Senior Oversight Committee

### **Wounded Servicemembers Have Wounded Families**

The National Military Family Association asserts that behind every wounded servicemember and veteran is a wounded family. Spouses, children, parents, and siblings of servicemembers injured defending our country experience many uncertainties. Fear of the unknown and what lies ahead in future weeks, months, and even years, weighs heavily on their minds.

Transitions can be especially problematic for wounded, ill, and injured servicemembers, veterans, and their families. The Department of Defense (DoD) and the Department of Veterans Affairs (VA) health care systems, along with State agency involvement, should alleviate, not heighten these concerns. The National Military Family Association believes the government must take a more inclusive view of military and veterans' families. Those who have the responsibility to care for the wounded servicemember and veteran must also consider the needs of the spouse, children, parents of single servicemembers, siblings, and especially the caregivers.

### **Who Are The Families of Wounded Servicemembers?**

In the past, the VA and the DoD have generally focused their benefit packages for a servicemember's family on his/her spouse and children. Now, however, it is not unusual to see the parents and siblings of a single servicemember presented as part of the servicemember's family unit. In the active duty, National Guard, and Reserve almost 50 percent of the Members are single. Having a wounded servicemember is new territory for family units. Whether the servicemember is married or single, their families will be affected in some way by the injury. As more single servicemembers are wounded, more parents and siblings must take on the role as caregiver, helping their son, daughter, or sibling through the recovery process. Family Members are an integral part of the health care team. Their presence has been

shown to improve the servicemember and veteran's quality of life and aid in a speedy recovery.

The National Military Family Association recently gathered information about issues affecting our wounded servicemembers, veterans, and their families through our *Operation Purple*<sup>®</sup> Healing Adventure Camp in August 2008 and a focus group held in March 2008 at Camp Lejeune. Families said they find themselves having to redefine their roles following the injury. They must learn how to parent and become a spouse/lover of someone with an injury. Spouses talked about the stress their new role as caregiver has placed on them and their families. Often overwhelmed, they feel as if they have no place to turn to for help. We found many have put their own lives on hold while caring 24/7 for their loved one.

### **Caregivers**

Caregivers need to be recognized for the important role they play in the care of their loved one. Without them, the quality of life of the wounded, ill, and injured servicemembers and veterans, such as physical, psycho-social, and mental health, would be significantly compromised. They are viewed as an invaluable resource to VA and DoD health care providers because they tend to the needs of the servicemembers and the veterans on a regular basis. Their daily involvement saves VA, DoD, and State agency health care dollars in the long run.

Caregivers of the severely wounded, ill, and injured services members who are now veterans have a long road ahead of them. In order to perform their job well, they must be given the skills to be successful. This will require the VA to train them through a standardized, certified program, and appropriately compensate them for the care they provide. National Military Family Association is pleased with the *'Family Caregiver Program Act of 2009'* (S. 801) legislation recently proposed by Senator Daniel K. Akaka (D-HI), Senator Richard Burr (R-NC), and Senator John D. Rockefeller (D-WV), and Congressman Michael H. Michaud's (D-2nd/ME) *'Wounded Warrior Project Family Caregiver Act of 2009'* (H.R. 2342) that will provide for the training, certification, and compensation for caregivers of wounded veterans. Both of these proposals place VA in an active role in recognizing caregivers' important contributions and enabling them to become better caregivers to their loved ones. It is a "win win" for everyone involved.

National Military Family Association is appreciative of the two "Caregiver" proposals by both Chambers. However, the time to acknowledge the caregiver's important role and to implement a standardized, certified program, and begin compensation 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 branches of the Services 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 these important programs and services. Therefore, we recommend that the designation and education of caregivers will need to be established while they are still upstream on active-duty, rather than wait until they have transitioned to veteran status.

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

A recent report by the Center for Naval Analysis determined there were approximately 720 wounded, ill, and injured servicemembers needing a caregiver, of which 170 would be classified as caring for the very seriously wounded, ill, and injured. They stated: caregivers provided on average 10 hours of care per week; care was needed for approximately 19 months; and 43 percent expected to need a caregiver for life. Eighty-five 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. 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 and the veteran receives an additional monthly stipend. Currently, there lacks a policy to compensate a caregiver for services provided to a wounded, ill, and injured servicemember or veteran.

Our Association proposes that new types of financial compensation be established for caregivers of wounded, ill, and injured servicemembers and veterans that could begin while the hospitalized servicemember is still on active duty and continue throughout the transition to care under the VA. This compensation should recognize the types of medical and non-medical care services provided by the caregiver, travel to appointments and coordinating with providers, and the severity of injury. It should also take into account the changing levels of service provided by the care-



giver as the veteran's condition improves or diminishes or needs for medical treatment changes. These needs would have to be assessed quickly with little time delay in order to provide the correct amount of compensation.

We believe the caregiver should be paid directly for their services, but the compensation should be linked to training and certification paid for by the VA and transferrable to employment in the civilian sector if the care is no longer needed by the servicemember or veteran.

Consideration should also be given to creating innovative ways to meet the health care and insurance needs of the caregiver, with an option to include their family. Citing the Center for Naval Analysis report, a large percentage of caregivers leave work in order to care fulltime for the wounded, ill, and injured servicemember and veteran. This action may create a situation where the caregivers are no longer eligible for their employers' health care plans. Our Association has also seen situations where the wounded, ill, and injured servicemember was discharged following a Physical Evaluation Board (PEB) without qualifying for medical retirement. This creates the environment where the family is ineligible for TRICARE following discharge, and they are ineligible for CHAMPVA until the veteran reaches 100 percent disability. The veteran's family and caregiver have the option to purchase TRICARE through the Continued Health Care Benefit Program but only a limited time period. Our concern is there could be a significant time lapse between discharge and qualification by the VA for CHAMPVA. This places the family and caregiver in a vulnerable situation because the ability to purchase TRICARE may have expired and may no longer be available. However, the family and the caregiver still need health care coverage. Unfortunately they are unable to work outside of the home due to their caregiver duties and they have limited options to purchase health care insurance for themselves or their family. Perhaps, caregivers of severely wounded, ill, and injured servicemembers or veterans can be given the option of buying health insurance through a civilian or government insurance program or receiving health care through enrollment in CHAMPVA.

The financial strain placed on the family of our wounded, ill, and injured servicemember and veteran by the caregiver leaving outside employment has a ripple down effect. Caregivers who have been saving for retirement now find they are ineligible for their employers' 401ks. 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 be competitive in today's workforce. We recommend VA offer these caregivers the opportunity to participate in their 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 done by NGOs and charities.

There must also be a provision for transition for the caregiver if the caregiver's services are no longer needed, chooses to no longer participate, or is asked by the veteran to no longer provide services. The caregiver should still be able to maintain health care coverage for 1 year. Compensation would discontinue following the end of services/care provided by the caregiver.

Our Association looks forward to discussing details of implementing such a plan with Members of this Subcommittee.

#### ***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 both proposed legislations, S. 801 and H.R. 2342, 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.

### ***Relocation Allowance***

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.

National Military Family Association is requesting the ability for medically retired single servicemembers to be allowed the opportunity to have their caregiver's household goods moved as a part of the medical retired single servicemember's PCS move. This should be allowed for the qualified caregiver of the wounded servicemember and the caregiver's family (if warranted), such as a sibling who is married with children or mom/stepmom and dad/stepdad. This would allow for the entire caregiver's family to move, not just the caregiver. The reason for the move is to allow the 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 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 be able to provide all the health care services required for treating and caring for the medically retired servicemember. Instead of trying to create the services in the area, a better solution may be to allow the 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 Federal Recovery Coordinator (case manager), the servicemember's physician, the servicemember, and the caregiver. All aspects of care for the medically retired servicemember and their caregiver shall be considered. These include a holistic examination of the 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 medically retired servicemember and his/her caregiver.

The consideration for a temporary partial shipment of caregiver's household goods may also be allowed, if deemed necessary by the case management team.

### ***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 firsthand trying to juggle the needs of the parents along with the needs of the 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 now unable to fulfill the role of caregiver. Caregivers may reach burn out 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 needs 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 and their families and caregiver that will require VA's attention over the long-term. National Military Family Association recommends Congress require Vet Centers and the VA to develop a holistic approach to veteran care by including their families and caregivers in providing mental health counseling and other programs.

National Military Family Association is especially concerned with the scarcity of services available to the veteran's families and caregiver 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. We recommend the VA establish similar programs to help the caregiver and the veteran's family deal with the residual effects from long frequent deployments.

We appreciate S. 801 and H.R. 2342 will provide counseling and mental health services; however, many will choose to locate in rural areas where there may be no mental health providers available. We ask you to address the distance issues veteran's families and their caregiver face in linking with mental health resources and obtaining appropriate care. Many isolated veterans, caregivers, and their families do not have the benefit of the safety net of services and programs provided by MTFs, VA facilities, Community-Based Outpatient Centers, and Vet Centers. Our Association recommends the use of alternative treatment methods, such as telemental health. Another solution is modifying licensing requirements in order to remove geographical practice barriers preventing mental health providers from participating in telemental health services outside of a VA facility.

The VA must educate their health care and mental health professionals, along with veterans' families and caregivers of the effects of mild Traumatic Brain Injury (TBI) in order to help accurately diagnose and treat the veteran's condition. Veterans' families and caregivers are on the "sharp end of the spear" and are more likely to pick up on changes contributed to either condition and relay this information to VA providers. Our Association recommends caregivers, spouses, parents, and family members of veterans need programs providing education on identifying mental health, substance abuse, suicide, and Traumatic Brain Injury (TBI).

### ***Reintegration Programs***

Reintegration programs become a key ingredient in the veteran, caregiver, and the family's success. In spring of 2008, our Association held a focus group composed of wounded servicemembers and their families to learn more about issues affecting them. As we stated earlier, families find themselves having to redefine their roles following the injury of the servicemember. They must learn how to parent and become a spouse/lover with an injury. Each Member needs to understand the unique aspects the injury brings to the family unit. Parenting from a wheelchair brings a whole new challenge, especially when dealing with teenagers. Parents need opportunities to get together with other parents who are in similar situations and share their experiences and successful coping methods. Once these families fall under the VA's realm of responsibility, the VA needs to provide family and individual counseling to address these unique issues. Opportunities for the entire veteran family,

along with time for the couple to reconnect and bond as a family again, must also be provided by the VA.

### ***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.

### **Case Management**

Our wounded, ill, and injured servicemembers, veterans, and their families are assigned case managers. In fact, there are many different case managers: Federal Recovery Coordinators (FRC), Recovery Care Coordinators, each branch of Service, TBI care coordinators, VA liaisons, etc. The goal is for a seamless transition of care between and within the two governmental agencies: VA and DoD. However, with so many to choose from, families often wonder which one is the "right" case manager. We often hear from families, some who have long since been medically retired with a 100 percent disability rating or others with less than 1 year out from date-of-injury, who have not yet been assigned a FRC. We need to look at whether the multiple, layered case managers have streamlined the process, or have only aggravated it. Our Association still finds these families alone trying to navigate a variety of complex health care systems trying to find the right combination of care. Many qualify for and use Medicare, VA, DoD's TRICARE direct and purchased care, private health insurance, and State agencies. Once discharged from in-patient status our wounded, ill, and injured servicemembers and veterans often find themselves relying on community resources. The National Resource Directory has been established to address this need; however, many families and caregivers state there still lacks a person they can contact for local medical and non-medical resource information. The Quality of Life Foundation's report "*Wounded Warrior Family Care Report*" (<http://www.qolfoundation.org/docs/wwfcr—report—web2.pdf>) suggested a Community Resource Coordinator be created. We believe this option may be a viable solution and recommend this should be examined further to fully explore its effectiveness in the case management process.

### **Senior Oversight Committee**

Our Association is appreciative of the provision in the National Defense Authorization Act for Fiscal Year 2009 (NDAA FY09) continuing the DoD/VA Senior Oversight Committee (SOC) for an additional year. We understand a permanent structure is in the process of being established and manned. We urge Congress to put a mechanism in place to continue to monitor VA and DoD's partnership initiatives for our wounded, ill, and injured servicemembers, veterans, their families, and caregivers while this organization is being created.

National Military Family Association proposes the top agenda items that would benefit veterans, wounded servicemembers, their families, and caregivers are:

*Coordination and collaboration of health care and behavioral health care services between the VA, DoD, and State and governmental agencies in sharing of resources;*

*Train, certify, compensate, and provide benefits to include health care for the caregivers of our severely wounded servicemembers and veterans;*

*Increased respite care and 24-hour supervision for wounded, ill, and injured veterans and their caregivers;*

*Eligible for health care services for caregivers and their families;*

*Encourage the VA to develop alternative housing and living arrangements for veterans and the families who care for them. These projects will need to be funded by Congress;*

*Increased access to behavioral health services for caregivers of wounded, ill, and injured veterans and their families;*

*Provide opportunities for the entire family to reconnect and bond as a family again;*

*Increased outreach to veterans, their families, and the communities they live in about available benefits and services, including education on the signs and symptoms of behavioral health conditions and available resources;*

*Examine whether the multiple, layered case managers have streamlined the process, or have only aggravated it, and the effectiveness of creating a Community Resource Coordinator; and*

*Continued oversight of the SOC by Members of Congress.*

National Military Family Association would like to thank you again for the opportunity to provide testimony on veteran's caregiver issues and gaps in supportive services. 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 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 veterans, their families, and caregivers.

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#### **Prepared Statement of Jill Kagan, MPH Chair, ARCH National Respite Coalition**

Mr. Chairman and Members of the Subcommittee,

My name is Jill Kagan and I am chair of the ARCH National Respite Coalition. The Coalition is the policy division of the ARCH National Respite Network and Resource Center, a Membership organization of respite providers, family caregivers, and representatives of public and private State and local agencies across the country. Twenty-two State respite coalitions and five State Lifespan Respite Programs are also currently affiliated with the NRC. I am honored to have this opportunity to present testimony on the importance of respite as a critical need of Family Caregivers of Veterans.

#### **What is Respite?**

Respite care provides temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs. As a preventive strategy, respite helps strengthen families, protects their health and well-being, and allows them to continue providing care at home. Respite is also an important component of a continuum of comprehensive family support and long-term services that are available to caregivers not only on a planned basis, but also in the event of a crisis or emergency situation.

Ideally, a variety of respite models would be available in a given community to provide an array of options for family caregivers, depending on their evolving needs over time. Sometimes in-home services are required so family caregivers can tend to obligations, medical or other critical appointments, or recreation outside the home. At other times, the care recipient may benefit from out-of-home services to engage in social activities or therapeutic services, which allows the family caregiver

time to do household tasks, tend to other family members, or simply take a much-needed break. Out-of-home services may take place in facility-based settings, such as adult day services or hospitals, or churches, schools, camps, foster homes, or the homes of relatives, friends or neighbors. Some out-of-home services are facilities designed specifically to provide respite. In the best of circumstances, services would be available on an hourly or weekly basis, and also provide evening or weekend care. Services can be provided in-home or out-of-home by trained respite providers with varying degrees of medical or mental health expertise, volunteers, neighbors, other family members or friends.

### ***Who Needs Respite?***

In 2004, a national survey found that 44 million family caregivers provide care to individuals over age 18 with disabilities or chronic conditions (National Alliance for Caregiving (NAC) and AARP, 2004). AARP's most recent survey estimates that in 2007, about 34 million caregivers age 18 or older are providing an average of 21 hours of care per week to adults with limitations in daily activities. The estimated 34 million caregivers represent the number giving care at any given point. An even higher number, about 52 million, provided care at some point during the year (Gibson and Hauser, 2008).

Today, we are talking specifically about the respite and support needs of family caregivers of veterans. In 2007, there were an estimated 26.3 million veterans; 9.3 million were 65 and older. Six million veterans are estimated to have a disability; 2.7 million received compensation for service-connected disabilities as of 2006. Their compensation totaled \$28.2 billion (U.S. Census Bureau, 2008). According to the 2001 National Survey of Veterans, the average age of the veteran population was 58 years old in 2000, with the largest group of veterans between the ages of 45 and 64.

The number of family caregivers of veterans is high and climbing. For the most recent victims, the soldiers returning from Iraq and Afghanistan, new challenges are evident because of the extremely serious nature of their disabling conditions. According to the VA Geriatrics and Extended Care Polytrauma Rehabilitation Task Force: "The care requirements of severely injured OEF/OIF veterans will vary throughout the veterans' lives. In some instances, the care needs will diminish or cease, and in other instances the care needs will broaden and intensify. As many of these seriously injured veterans may require support and assistance for many years, the caregivers will face many physical and emotional challenges over time. VA currently provides support to caregivers through the following programs: inpatient and home respite, homemaker/home health aide, and ADHC. However, there are locations in which caregiver support is minimally available through any resource, and the Task Force anticipates considerable challenges in reliably meeting the caregiver support needs in all communities (U.S. Department of Veterans Affairs, Veterans Health Administration, Report of the VA Geriatrics and Extended Care Polytrauma Rehabilitation Task Force, February 2008).

It has been estimated that family caregivers overall provide \$375 billion in uncompensated care, an amount almost as high as Medicare spending (\$432 billion in 2007) and more than total spending for Medicaid, including both Federal and State contributions and both medical and long-term care (\$311 billion in 2005) (Gibson and Hauser, 2008). Family caregivers are providing an estimated 80 percent of all long-term care in the U.S. This percentage will only rise in the coming decades with increasing numbers of severely wounded veterans returning home from the ongoing wars in Iraq and Afghanistan, the greater life expectancies of individuals with Down Syndrome and other disabling and chronic conditions, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes. This decline is due partially to the growing number of individuals moving to privately funded assisted living facilities (about 1 million individuals are in assisted living), but even more older individuals, with fewer disabilities and more wealth, are choosing to stay at home with support from home and community-based services and supports (Alexih, L, Lewin Group, 2006).

This trend toward home and community-based services among individuals of all ages and disabling conditions has been encouraged by the advent of the Supreme Court's *Olmstead* decision which required that individuals with disabilities be able to live and work in the least restrictive environment, and an emerging Federal policy direction that focuses on home and community-based care rather than institutional placement. States wishing to reduce Medicaid long-term care expenditures have also refocused their policies to support home and community-based services.

### ***Respite Benefits Families and is Cost Saving***

Respite has been shown to be effective in improving the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, such as nursing homes or foster care, minimizes the precursors that can lead to abuse and neglect, and strengthens marriages and family stability. A recent report from the U.S. Department of Health and Human Services prepared by the Urban Institute found that higher caregiver stress among those caring for the aging increases the likelihood of nursing home entry. Reducing key stresses on caregivers, such as physical strain and financial hardship, through services such as respite would reduce nursing home entry (Spillman and Long, U.S. DHHS, 2007).

Respite for the elderly with chronic disabilities in a study group resulted in fewer hospital admissions for acute medical care than for two control groups who received no respite care (Chang, J.I., et al, 1992). Sixty four percent of caregivers of the elderly receiving 4 hours of respite per week after 1 year reported improved physical health, 78 percent improved their emotional health, and 50 percent cited improvement in the care recipient. Forty percent said they were less likely to institutionalize the care recipient because of respite (Theis, S.L., et al, 1994). Caregivers of relatives with dementia who used adult day care experienced lower levels of caregiving related stress and better psychological well-being than a control group not using the service. Differences were found in both short-term (3 months) and long-term (12 months) users (Zarit, S.H., et al, 1998). In a study to determine whether adult day service use was related to decreases in primary caregiving hours, it was found that adult day service users reported greater decreases in hours spent on behavior problems when compared to nonusers, and decreased frequency of behavior problems in relatives who attended adult day program. Findings suggest that adult day services, if used over time, are effective in restructuring caregiving time and may offer benefits to family caregivers and to older adults with dementia (Gaugler, JE, Jarrott SE, Zarit, SH, 2003).

The budgetary benefits that accrue because of respite are just as compelling, especially in the policy arena. Delaying a nursing home placement for just one individual with Alzheimer's or other chronic condition for several months can save Medicaid and other Federal and State government long-term care programs thousands of dollars. In the private sector, a study by Metropolitan Life Insurance Co. and the National Alliance for Caregivers, found that U.S. businesses lose from \$17.1 billion to \$33.6 billion per year in lost productivity of family caregivers (MetLife and NAC, 2006). A family's personal economic situation can also be drastically affected. Offering respite to working family caregivers could help improve job performance and employers could potentially save billions of dollars.

### ***Barriers to Respite***

While most family caregivers take great joy in helping their family members to live at home, it has been well documented they experience physical and emotional problems directly related to their caregiving responsibilities (Keller, 2004; Butler, 2005; Family Caregiver Alliance, Fact Sheet, 2006; Loretta-Secco, M, et al, 2006; 2006; Pinguart and Sorensen, 2007). Three-fifths of family caregivers ages 19–64 surveyed by the Commonwealth Fund reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non-caregivers (Ho, Collins, Davis and Doty, 2005). A study of elderly spousal caregivers (aged 66–96) found that caregivers who experience caregiving-related stress have a 63 percent higher mortality rate than noncaregivers of the same age (Schulz and Beach, 1999).

State and local surveys have shown respite to be the most frequently requested service of the family caregivers who ask for help. (Evercare and NAC, 2006; Brazil, K, et al, 2005; Fox-Grage, W, Coleman, B, Blancato, R, 2001; ongoing personal communications with State Respite Coalitions). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the Nation's family caregivers. The 2004 NAC/AARP survey of caregivers found that despite the fact that the most frequently reported unmet needs were "finding time for myself," (35 percent), "managing emotional and physical stress" (29 percent), and "balancing work and family responsibilities" (29 percent), only 5 percent of family caregivers were receiving respite (NAC and AARP, 2004). In rural areas, the percentage of family caregivers able to make use of respite was only 4 percent (Easter Seals and NAC, 2006).

While these surveys did not specifically ask why families were not using respite services, barriers to accessing respite have been well defined in the literature. They include cost, reluctance to ask for help, failure to identify as a caregiver, fragmented and narrowly targeted services, feelings of social isolation, lack of respite options, and the lack of information about how to find or choose a provider (Whitlatch, CJ,

et al, 2006; Yanitz, NM, et al, 2007; Damiani G., et al; 2004; Sharlach, S, et al, 2003). Even when respite is funded, a critically short supply of well trained respite providers may prohibit a family from using a service they so desperately need (Larson, SA, 2004; ongoing communication with State respite coalitions).

Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services they once were eligible for, especially for those in the age group 18–60. Trained respite providers and/or funding sources may not exist at all in some States for individuals, including veterans, under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries.

In this age group 18–60, those most at risk for limited access to respite are the families of the wounded warriors—those military personnel returning from Iraq and Afghanistan with traumatic brain injuries, post-traumatic stress syndrome and other serious chronic and debilitating conditions. A recent report from the Department of Veterans Affairs at the Veterans Health Administration concluded: “Challenges remain, as the men and women who experience serious debilitating injuries, polytrauma, or traumatic brain injury (TBI) may require treatment spanning multiple health care systems and may need long-term care, personal assistance, and family support spanning decades.”

To facilitate the transition from institutional care to the home and community and plan for the ensuing needs for long term services and supports for severely injured veterans of the current war, the Geriatrics and Extended Care Polytrauma Rehabilitation Task Force (GECPR) was established in May 2007. One of the major recommendations of the Task Force was to “Improve access to, and utilization of, respite services for younger veterans.” (U.S. Department of Veterans Affairs, Veterans Health Administration, Report of the VA Geriatrics and Extended Care Polytrauma Rehabilitation Task Force, February 2008).

For the growing number of veterans with TBI or other polytrauma, VA has authority to provide respite both in home and in other settings, yet respite is often underutilized. In-home providers may not be available in many communities, and inpatient respite, generally available in a community nursing home or VA hospital, may not be amenable to young veterans and their families. The shortage of well-trained staff qualified to provide respite to this population is especially critical given their complex diagnoses. Identifying and ameliorating special barriers for this population should be addressed.

#### ***Current Federal and State Resources Are Limited or Nonexistent***

Disparate and inadequate funding streams exist for respite in many States. The largest source of Federal funds for respite outside the VA is available through various State Medicaid Home and Community-Based Waivers, but services are capped, eligibility criteria are restricted by age or disability, and waiting lists prevail (Friss Feinberg, 50–State Survey, 2004). Numerous other Federal and State categorical programs have been identified which have the potential to fund respite for caregivers, but only for caregivers of individuals with specific disabilities, ages, or incomes, or for one narrow purpose. These efforts provide a critically important foundation on which to build systems of respite care, but they currently do not do enough to reduce the fragmentation, the inaccessibility, and the confusion that exists around multiple eligibility criteria, numerous funding streams, and qualified provider shortages.

In 1999, the Millennium Health Care Act was amended to expand respite services for veterans who qualify for health benefits. Public Law 106–117 expanded the array of community-based respite services available to veterans to include community nursing homes and non-institutional settings for respite care. Prior to the passage of Pub. L. 106–117, respite care authorization was limited to VA inpatient CLC (formerly known as VA nursing homes) or hospital beds. The Veterans Health Administration is now committed to the provision of clinically appropriate respite care services through the use of various institutional and non-institutional programs such as: CLC, Community Nursing Home (CNH), Homemaker and/or Home Health Aide (H/HHA), Adult Day Health Care (ADHC). Respite services are primarily a resource for veterans whose caregivers are neither provided respite services through, nor compensated by, a formal care system (i.e., Community Residential Care (CRC) program agreements, Medicaid waiver programs, Hospice programs, and others for which the veteran is dually eligible). While respite options for veterans have certainly expanded in the last decade, administrative criteria still limit the type, extent and availability of services. From the VHA Handbook dated November 10, 2008:

- a. Veterans seeking respite services must be enrolled for VHA health care and receive established, on-going, routine health care services from a VA or contracted VA health care provider or care team.



- b. The respite care benefit provides respite services to eligible veterans for up to 30 days in a calendar year. This 30-day program limit includes the sum of all respite-specific resources provided, regardless of the setting.
- c. For VA program purposes, "a day" of respite is defined as any single day in which respite services are provided to the veteran, that is, up to 6 hours of care per day in the home, greater than 4 hours of care in adult day health care, or 24 hours of care per day in an inpatient setting.
- d. Veterans who are in need of respite services in excess of 30 days because of unforeseen difficulties, such as the illness or death of a primary caregiver, with the approval of the medical center Director, or designee, may be granted additional days.
- e. When inpatient respite care is provided in VA CLCs or medical centers, beds may not be designated exclusively for respite care. VA medical centers are not authorized to provide respite services in any ambulatory care clinic settings other than the formal ADHC Programs.
- f. When a veteran is admitted for respite care, services provided are subject to the applicable standards of care for that care setting. For example, in the VA CLC, services must meet The Joint Commission's long-term care standards. **NOTE:** *State and Federal standards must be met by VA-contracted CNHs and in the delivery of home health services.*
- g. Respite care is available in a variety of settings; therefore, program access and admissions must follow the same guidelines for admission currently applicable within VHA and non-VHA inpatient and outpatient programs.
- h. Long-term Care (LTC) copayments apply to respite care regardless of the setting or service that provides such care. A LTC copayment test must be completed for each veteran requesting extended care services, to determine the extended care copayment exemption or non-exemption.

Eligibility criteria also mean there are veterans who would not qualify at all for respite benefits under the Millennium Health Care Act. For admission to respite care the following criteria must be met:

- a. The veteran has a diagnosed chronic disabling illness or condition.
- b. The veteran lives at home and requires substantial assistance in ADL in order to continue to reside safely in the home.
- c. The veteran's caregiver is in need of temporary or intermittent relief from day to day care tasks in order to sustain this care-giving role.
- d. The veteran must meet clinical criteria, as well as eligibility criteria for nursing home and long-term care (Pub. L. 106-117). Clinical criteria include:
  - 1. Dependence in three or more ADLs or significant cognitive impairment, and
  - 2. Two or more of the following conditions:
    - a. Dependence in three or more IADLs.
    - b. Recent discharge from a nursing home.
    - c. 75 years old, or older.
    - d. Identification as a high utilizer of medical services (defined as having three or more hospitalizations in the past year, or utilizing outpatient clinics or emergency evaluations twelve or more times within the preceding 12 months).
    - e. Is clinically depressed.

In addition, the VA requires copayments for non-exempt veterans for extended care services, including respite. Co-payments for respite care can also be prohibitive for many veterans and their family caregivers, especially if they are older and living on fixed incomes, or are already under financial distress because family members have given up employment to provide continuous care and support. For these families, respite is perceived as a luxury they cannot afford and even minimal copayments can be extremely burdensome. Currently, VA-required copayments range from \$15 per day for non-institutional adult day health or respite care to \$97 per day for institutional respite care.

Veterans whose household income exceeds both the current year VA national income threshold (\$34,117, with one dependent), and who do not have a compensable VA service-connected disability, are not eligible for VA care. Family caregivers of veterans who do not qualify for respite through the VA may turn to State or local respite funding sources. However, the system is already overburdened and unable to keep up with the increasing demand. Twenty of 35 State-sponsored respite programs surveyed in 1991 reported that they were unable to meet the demand for respite services. In the last 15 years, we suspect that not too much has changed. A

study conducted by the Family Caregiver Alliance identified 150 family caregiver support programs in all 50 States and Washington, DC funded with State-only or State/Federal dollars. Most of the funding comes through the Federal National Family Caregiver Support Program. As a result, programs are administered by local area agencies on aging and primarily serve the elderly. And again, some programs provide only limited respite, if at all. Only about one-third of these 150 identified programs serve caregivers who provide care to adults age 18–60 who must meet stringent eligibility criteria. As the report concluded, “State program administrators see the lack of resources to meet caregiver needs in general and limited respite care options as the top unmet needs of family caregivers in the States.” The State respite coalitions and other National Respite Network Members confirm that long waiting lists or turning away of clients because of lack of resources is still the norm.

In 2006, in the reauthorization of the Older Americans Act, the National Family Caregiver Support Program’s definition of family caregivers was expanded by including caregivers caring for anyone with Alzheimer’s or related neurological condition of any age, by lowering the eligibility age of grandparent caregivers to 55, and by allowing eligibility for grandparents or other relative caregivers to care for children over the age of 18 with disabilities (Older American Act Reauthorization, P.L. 109–365). The funding for the program, however, has not increased.

These limitations in existing respite funding streams are confusing not only to families, but to the States that rely on them. In addition, while many of these programs have the potential to fund respite, they are not mandated to do so. Competing demands for these funds or lack of information on the part of consumers often result in no or limited Federal funds from these various programs being used to support respite (Day, S., ARCH, 1999; Whirrett, T., ARCH, 2002; Baker, L, ARCH 2004). The result is a complicated bureaucratic maze of services that families must navigate to find or pay for services, as well as duplication and fragmentation of respite services. Even when family resources are available to pay for respite, finding quality respite that meets a family’s needs and preferences, and is appropriate, safe, culturally acceptable, or geographically accessible may be impossible.

#### ***States Respond with Model Lifespan Respite Systems***

Lifespan Respite, which is a coordinated system of community-based respite services, helps States use limited resources across age and disability groups more effectively, instead of each separate State agency or community-based organization being forced to constantly reinvent the wheel or beg for small pots of money. Pools of providers can be recruited, trained and shared, administrative burdens can be reduced by coordinating resources, and the savings used to fund new respite services for families who may not currently qualify for any existing Federal or State program. Model statewide Lifespan Respite Programs in Oregon, Nebraska, Wisconsin, Oklahoma, and most recently, Arizona, provide easy access to an array of affordable, quality respite services; ensure flexibility to meet diverse needs; fill gaps and address barriers; and assist with locating, training, and paying respite providers (Baker, L and Edgar, M, 2004). In anticipation of funding from the new Federal program, State Lifespan Respite Legislation is pending in Texas. Michigan passed Lifespan Respite legislation in 2004, but it has never been funded because of limited State dollars. The Delaware State Respite Coalition was successful in obtaining significant funds from a private foundation to begin implementing a statewide lifespan respite program this year.

Each program has been adapted to meet individual State needs, but the defining characteristic of each is the statewide, coordinated approach to ensure respite services for all who need it. Many of the lifespan respite programs have established community-based networks that rely on the development of local partnerships to build and ensure respite capacity. These local partnerships include family caregivers, providers, State and federally funded programs, area agencies on aging, non-profit organizations, health services, schools, local business, faith communities and volunteers. These networks are the central point of contact for families and caregivers seeking respite and related support regardless of age, income, race, ethnicity, special need or situation. Providing a single point of contact for families to access respite is crucial to assisting families in helping themselves. Services typically offered by Lifespan Respite Programs are providing public awareness information to the community and building diverse respite partnerships, recruitment of paid and volunteer respite providers, coordinating respite related training for providers and caregivers, identifying gaps in services and creating respite resources by building on existing services, and connecting families with respite providers and payment resources.

The State Lifespan Respite programs provide best practices on which to build a national respite policy. The programs have been recognized by prominent policy or-

ganizations, including the National Conference of State Legislatures, which recommended the Nebraska program as a model for State solutions to community-based long-term care (Fox-Grage, 2001). The National Governors' Association and the President's Committee for People with Intellectual Disabilities also have highlighted lifespan respite systems as viable solutions (Friss-Feinberg, 2004; President's Committee for People with Intellectual Disabilities, 2004). The 2005 White House Conference on Aging recommended enactment of the Lifespan Respite Care Act to Congress (2005 White House Conference on Aging, 2006).

### ***Oregon***

In 1997, Oregon enacted the first State Lifespan Respite Care Program into law to address the multi-faceted barriers faced by families in accessing and paying for quality respite services regardless of age or disability. The Oregon Department of Human Services (DHS) is charged by State law to develop and encourage statewide coordination of respite care services. The Department works with community-based nonprofits, businesses, public agencies and citizen groups to identify gaps in services, generate new resources and develop community programs to meet the need. The Program offers technical assistance, works directly with 22 local Lifespan Respite Networks in 36 counties, and promotes the State respite agenda.

While the Oregon Lifespan Respite program has not had staff or funding resources to conduct outcome-based evaluation, they have compiled personal testimonials from families expressing program satisfaction (Oregon Lifespan Respite Program, 2003). The Oregon Lifespan Respite program was identified by the Family Caregiver Alliance as one of five best practice models among 33 family caregiver programs surveyed in fifteen States (Friss-Feinberg, Family Caregiver Alliance, 1999).

### ***Nebraska***

With passage of the Nation's second State lifespan respite bill in 1999, the Nebraska Health and Human Services System established the Nebraska Respite Network, a statewide system for the coordination of respite resources that serve the lifespan. Six regional entities are responsible for information and referral for families who need access to respite, recruitment of respite providers, public awareness, coordinating training opportunities for providers and consumers, quality assurance and program evaluation.

Initially, Lifespan funds appropriated by the State legislature to fund the program were used to set up the structure for a statewide respite system. The NE State Legislature saw the success of the effort and appropriated additional funds to establish a respite subsidy program to help families pay for respite. The Respite Subsidy across the Lifespan is available to families who do not qualify for any other respite services. Families choose their own providers and set their own schedules. State funds are also used to expand new respite services in each Service Area.

The six regional networks recruit respite providers, offer training for providers and consumers, provide information and referral, market respite availability and need, and match families with appropriate respite providers. More than 1400 new respite providers have been recruited since the program began. Network coordinators meet regularly with Medicaid Service Coordinators, representatives from Development Disabilities, Area Agencies on Aging, Independent Living Centers and the Early Development Network to identify gaps and barriers and to recruit providers as needed.

A survey of family caregivers receiving respite was conducted by the Munroe-Meyer Institute in Nebraska. Caregivers were identified from a diverse group of State programs including the Aged and Disabled waiver, the Nebraska Alzheimer's Association and the Area Agencies on Aging. After just 1 year of Lifespan, 63 percent of the families with family members over 21 reported they were more likely to place their family member in out-of-home placements if respite services were unavailable. Respite was shown to reduce stress and feelings of isolation, possible precursors to poor caregiver health and in extreme cases, even abuse or neglect. Two-thirds (65 percent) of caregivers with family members over 21 reported decreased isolation once respite services were available (Jackson, 2001).

### ***Wisconsin***

In 1999, Wisconsin became the third State to enact Lifespan legislation. The program was created through Wisconsin Act 9 (the 1999-2001 Biennial Budget Act). The legislation provided for the Wisconsin Department of Health and Family Services (DHFS) to contract with an organization for the administration of lifespan res-

pite care projects. The statewide nonprofit, the Respite Care Association of Wisconsin (RCAW), is charged with implementing the program. Funding of \$225,000 per year allowed RCAW to establish five Lifespan Respite Care pilot projects, one in each of the five Department of Health and Family Services regions of the State, with each project serving between one and three counties.

Data from an Outcomes Evaluation Project conducted in collaboration with the ARCH National Resource Center for Respite and Crisis Care and the University of North Carolina at Chapel Hill, along with data from quarterly and annual reports, collected by RCAW, demonstrate that the Lifespan Respite Care model in Wisconsin is effective. The study found that provision of respite significantly reduced caregiver stress, stress-related health problems and social isolation. Furthermore, respondents reported reduced likelihood of institutionalization of the person with special needs and reduced likelihood of divorce. Respondents also reported that respite led to significantly improved relationships with the dependent family member and with other family members and increased opportunities to build friendship and support networks. Finally, reports from the Lifespan Respite Care projects demonstrated that they effectively leveraged the relatively small amount of funding received through the program to raise additional funds locally and through other grants, that they effectively integrated local, State, Federal and private sources of funds, and effectively coordinated provision of care regardless of age, disability, or other characteristic. The project serves as a "One-stop Shop" for respite care in their communities, replacing previously fragmented systems where families were forced to navigate an "alphabet soup" of funding sources and programs in order to obtain needed relief (RCAW, 2003).

However, annual funding for the program has never exceeded \$225,000. Unlike other State Lifespan Respite programs, Wisconsin's program is not statewide. While local lifespan respite programs are able to leverage additional dollars to help families pay for respite, there simply are not sufficient funds to establish programs in the remaining Wisconsin counties. In a recent statewide survey of 44 county health and human service agencies and Head Start programs conducted by RCAW, it was projected that referrals would increase 443 percent if the program was fully funded and staffed. (RCAW, October 2006)

### **Oklahoma**

The Oklahoma Respite Resource Network (ORRN), as the State's Lifespan Respite program is called, relies on an already existing statewide resource and referral system (OASIS) to link families to the program, to respite services and to training opportunities. The Network is a collaboration of 34 partners including three public agencies (Department of Human Services, the Health Department and the Mental Health Department), caregivers, advocacy agencies, private foundations and providers. The network has redirected almost \$2 million in public and private funds to respite care in Oklahoma and is able to serve families across age and disability categories. The State's Family Caregiver Support Program is one of the networks most vital and supportive partners, having contributed almost \$1 million to go directly to family caregivers of the aging population to help them pay for respite.

The network was built on family support principles and focuses on consumer-directed respite. Caregivers are given vouchers to purchase respite care from anyone they choose and negotiate the rate of pay. The provider can be another family member, friend, next door neighbor, daycare center, home health agency, or a private provider. A survey completed in August of 2003 for the Oklahoma Respite Resource Network showed that 85 percent of the caregivers chose a respite provider from within their own natural support system (Moss, J, 2004). If families need help in finding a respite provider, or finding out which programs they might be eligible for, they can turn to the Oklahoma Respite Resource Network. If a family desires training for a respite provider of their choosing, the State will provide that as well. The Oklahoma model has flexible funding, so the State can find the most cost effective way to deliver services, and allow caregivers control over resources.

This program currently serves approximately 2200 caregivers annually. The average cost for the respite vouchers has been between \$5.62 and \$5.87 per hour, compared with \$12.80 to \$26.50 per hour if the caregiver had chosen a provider from a private/public agency. This program has proven that caregivers are much more cost efficient with resources and that respite is a cost effective way to meet the needs of caregivers. In Oklahoma, caregivers are eligible for \$400 in vouchers every 3 months. A 2003 survey found that 47.7 percent of the caregivers said this amount was adequate to meet their needs; 52 percent said they could use more, but added that they needed just another \$100. This means that \$1600-\$2000 per year would meet the needs of 97.7 percent of the caregivers in Oklahoma (Moss, J, 2004).

The ORRN survey found that the program has demonstrated benefits: 88 percent of caregivers agreed that respite allowed their loved one to remain at home, 98 percent stated that respite made them a better caregiver, 98 percent said respite increased their ability to provide a less stressful environment, and 79.5 percent of caregivers said respite contributed to the stability of their marriage (Moss, 2004).

### ***Arizona***

The Arizona Lifespan Respite Program was enacted into law in 2007 and was allocated \$500,000 annually for implementation. The Arizona Department of Economic Security is the lead State agency. Each of eight local Area Agencies on Aging are functioning as the local Lifespan Respite Program. Primary caregivers of individuals who do not currently qualify for other publicly funded respite services are eligible, including: Family Caregivers of: persons who are seriously or terminally ill, who do not currently qualify for hospice care; persons under 60 who have significant functional impairments, but are not eligible for disability services; persons with early cognitive deficit resulting in functional impairment, who have not yet received a "likely" diagnosis of dementia; grandparents or relative caregivers less than 55 years of age caring for children 18 and younger; and veterans not qualified for Veteran Administration (VA) care (e.g., no service-related disability or income eligibility) who do not qualify for other services. Although income is not a disqualifying factor, services will be targeted to individuals in greatest economic and social need. Because funding is limited and in order to offer respite to the maximum number of caregivers, cost sharing will be required and is based on the care recipient's household income, beginning at 250 percent above Federal Poverty Guidelines.

### ***State Respite Coalitions***

If a State does not yet have a statewide Lifespan Respite Program, there may be a State respite coalition that can offer assistance and act as the central contact point for gathering initial respite information. At least 22 active State respite coalitions are affiliated with the ARCH National Respite Coalition and can provide varying degrees of assistance to family caregivers of veterans whether or not the veterans are eligible for VA benefits. Most of the coalitions provide networking, educational activities, and respite resource guides for providers and family caregivers. Some have developed training curricula and offer respite and family caregiver training across the State. A few, including Alabama, Iowa, and Tennessee Respite Coalitions have developed voucher systems to assist families in paying for respite and for promoting consumer choice. Consumer choice respite has been shown to offer the greatest satisfaction among families, who with the voucher in hand and acting as the employer, can select, train, hire and fire their own respite providers from their own natural support systems or from local agencies.

### ***Lifespan Respite Care Act***

The Lifespan Respite Care Act was signed into law in 2006, but did not receive any funding until this current fiscal year. The initial funding of only \$2.5 million has not yet been awarded by the Administration on Aging, but will probably be targeted to States for planning purposes only.

The purpose of the Lifespan Respite Care Act is to expand and enhance respite services, improve coordination, and improve respite access and quality. Under a competitive grant program, States are required to establish State and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining access. Those eligible would include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond that required by children generally to meet basic needs. Congressional intent requires that States ensure that respite is made more available and accessible regardless of age or disability of the care recipient (U.S. House of Representatives, Committee on Energy and Commerce, 2006).

The Federal Lifespan Respite program would be administered by the U.S. Department of Health and Human Services (HHS), Administration on Aging, which will provide competitive grants to State agencies through Aging and Disability Resource Centers working in mandated collaboration with State respite coalitions or other State respite organizations.

The NRC and its national, State and local partners are urging full funding (\$71.1 million) in FY 2010. This will enable:

- State replication of best practices in Lifespan Respite systems so that all family caregivers, regardless of age or disability of the care recipient, will have access to affordable respite, and will be able to continue to play the significant role in long-term care that they are fulfilling today;
- Improvement in the quality of respite services currently available;
- Expansion of respite program capacity to serve more families by building new and enhancing current respite and crisis options, including recruitment and training of respite workers and volunteers; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

***Recommendations for Improving Respite for Family Caregivers of Veterans:***

1. VA should collaborate with State Lifespan Respite Programs, State Respite Coalitions, universities and community colleges to recruit and train respite providers and volunteers to assist families caring for veterans, especially veterans with TBI, post-traumatic stress, mental health conditions, spinal cord injuries, and other polytraumas.
2. VA should collaborate with State Lifespan Respite Programs or State Respite Coalitions to promote consumer direction and administer respite voucher programs where available.
3. VA should reduce or eliminate mandatory copayments for respite for all veterans.
4. VA should collaborate with State Lifespan Respite Programs or State Respite Coalitions to work with family caregivers of veterans to help them find, train and pay for respite services, and to expand the range of respite options currently available to these families.
5. VA should collaborate with State Lifespan Respite Programs and State Respite Coalitions to provide public awareness and education among family caregivers of veterans about the value and availability of respite.

**Complete References Are Available Upon Request**

*For more information, please contact Jill Kagan, ARCH National Respite Coalition at [jbkagan@verizon.net](mailto:jbkagan@verizon.net), by phone at 703-256-9578 or via regular mail at 4016 Oxford St, Annandale, VA 22003, USA. Visit [www.archrespite.org/nrc.htm](http://www.archrespite.org/nrc.htm).*

**Prepared Statement of Suzanne G. Mintz, President and Co-Founder,  
National Family Caregivers Association**

Mr. Chairman, Members of the Committee, thank you for this opportunity to speak on the critical subject of the needs of our veterans' family caregivers. My name is Suzanne Mintz. I am President and Co-founder of the National Family Caregivers Association (NFCA).

NFCA is the Nation's premier organization for family caregivers. We reach across the boundaries of differing diagnoses, different relationships and different life stages to address the common concerns of all family caregivers. Our mission is to empower family caregivers to act on behalf of themselves and their loved one and remove the barriers to their health and well being. NFCA strives to meet its mission by providing family caregivers with education, support, and a public voice.

I am not a veteran, nor is my husband Steven, but we both have much in common with the young veteran families of the Iraq and Afghanistan wars. These families are the focus of my testimony. Like them our lives changed suddenly when we were young and had our hopes set on a bright future. When I was 28, and he was 31, Steven was diagnosed with multiple sclerosis, which as you may know is an incurable neurological disease that impacts function, and at times cognition. Many of these veterans' spouses serve as their family caregivers. In some cases their children may lend a hand. For those vets who are unmarried and don't have a significant other, their primary caregiver may be their parents, or perhaps a sibling, or good friend.

I can tell you that these young veterans who are returning from war with physical or mental disabilities are frightened. They and their family members are going through a grieving process, all in their own way and probably on different schedules. Just at the time when they most need to be pulling together, they are all dealing with their own reactions to the nightmare that has become their lives.

They need help and assistance, individually and collectively. They need to know that their feelings and fears are normal. More than anything else they need to know

that they don't have to work through their new challenges alone. They need the assistance of a navigator, a coach, a community-based care team. Those with the most extensive physical and/or mental disabilities need these services the most.

The VA Health Administration (VHA) and the VA Benefits Administration (VBA) have put together an extraordinary number of programs to support these families, some of them specifically aimed at family caregivers. There are 13 in all, and this doesn't count the eight programs currently underway through the VA's *Pilot Programs in Caregiver Assistance*, a grant initiative designed to develop new programs to expand and improve caregiver assistance services. I am proud to say that the Stratton VA in Albany, New York has one of these grants and is working with NFCA to compare the impact of NFCA's *Communicating Effectively with Health care Professionals* curriculum to standard VA care. Results of this study will be available in the fall.

The VA's 13 caregiving-related programs can be grouped together in a number of categories. My colleagues at the Veterans' Administration who are testifying here today are far better versed in the details of these programs than I and will be talking about them during their testimony; I want to focus here on how these categories of programs, and the specific programs themselves fit into the intricate web of the lives of caregiving families.

*It is important to note at the outset that as good as these programs are, they are only available to a small proportion of veteran families. As good as these programs are, they do not reach all the veterans and families who are in need of these services. The VA should enlarge the service areas for these programs so they benefit more veteran families.*

There are two different types of respite programs, in recognition of the need for family caregivers to have some time for themselves away from the responsibilities of caregiving. One program provides for home-based respite; the other in institutional settings. You and I, and I would venture to say, all those in this room who are employed receive paid vacations. Family caregivers do not. Nor do they receive other benefits for that matter. Their toil can go on 24/7 365 days a year. For these family caregivers respite isn't a luxury. It is a necessity to maintain health and well being and needs to be available to as many family caregivers as possible, but especially those with the most intensive caregiving responsibilities.

There are two home and community-based services programs in recognition of the fact that most long-term care is provided by family caregivers, not by institutions. In fact 80 percent of all long-term care is provided by families and friends in the community. Providing access to adult day services gives family caregivers the opportunity to go to work, visit their own doctor, and take care of other responsibilities and needs while knowing their loved one is safe. With so many of these new veterans in their twenties and thirties, the VA should consider ways to tailor adult day programs for this demographic, as this population's needs are far different from those of older vets.

There are three different programs to help veterans who need accessible and disability-friendly housing. Many families need ramps, grab bars or major renovations. Most people in these circumstances prefer to stay in their homes, but these modifications can be quite costly. Assistance with these modifications is a critical service for these families and is a great benefit for them.

One particularly outstanding program provides a generous grant to purchase an accessible vehicle. To give you some idea of the cost that can be involved in such a vehicle I frequently tell people that I drive a Mercedes Dodge. The price of a van with the conversion added on does indeed add up to the price of a lower-end Mercedes. The cost of these vehicles is strictly out of pocket for those of us with private insurance. This \$11,000 payment is indeed a wonderful VA benefit because having easy access to transportation permits a level of normalcy and freedom that cannot be achieved any other way. If my husband and I didn't have an accessible minivan it would be very difficult for him to continue to work, go to Baltimore twice a week for an intensive physical therapy program and for us to have a social life. In short, to be participants in the kind of life that able bodied people take for granted.

*The VA has great programs to support caregiving families. The challenge is to make them available to as many veterans as possible, without unnecessary conditions, as quickly as possible, with top priority placed on quality and safety. It is also crucial to, recognize that flexibility is perhaps the greatest virtue that any program for caregiving families can have. The more services and programs that are built on the "money follows the person" concept, with few stipulations of exactly where and from whom services need to be purchased and provided, the easier it will be for these families to regain control of their lives.*

The remaining four programs fit under the umbrella of health care. One that assists families needing to travel away from home for medical treatment, like the ve-

hicle grants, shows the VA's recognition of the emotional, physical, and financial costs associated with getting places. The other three are truly part of the health care experience for chronically ill or disabled persons, and these are the three I want to comment on more fully because of their importance to the primary concerns of veterans and their loved ones—the quality of the health care they receive and the ease of obtaining it.

The three programs I am referring to are home-based primary care, bowel and bladder care, and homemaker/home health services. These programs address core needs of veterans with extensive disabilities and the needs of their family caregivers. These are the families with the greatest need of a comprehensive and holistic approach to their care over the ensuing years of their lives.

#### ***Home Based Primary Care***

Home-based primary care saves time and money, minimizes the health care risks to the patient by minimizing the introduction of pathogens into their environment, and it eases the physical, financial, and time burden on patient and caregiver that comes with having to physically travel to an appointment. This program is not necessary for all veterans of course, but it is for those with multiple chronic conditions and significant disabilities.

The Independence at Home Act currently before Congress recognizes the importance of home-based primary care and would bring these valuable services to designated Medicare beneficiaries.

#### ***Bowel and Bladder Care Initiative***

The bowel and bladder care initiative permits a veteran to have anyone of his/her choosing receive training from VA personnel to be able to provide bowel and bladder care services. This program is an example of the type of flexibility and logical thought that is critically important to families as they try to develop a new normalcy. Catheterizing someone's bladder is not complicated and is no more than a 10-minute exercise. If the rules required it be done by a visiting RN it would become a major undertaking in terms of scheduling, health care processes, and paperwork. Letting nature take its course and allowing families be able to deal with these matters as they see fit in the course of their day, just as those of us without bowel or bladder problems do, provides the closest situation to normalcy that there is, and this needs to be the primary goal for these families and all VA families touched by war.

#### ***Homemaker and Home Health Services***

Finally homemaker/home health services address the daily needs of disabled individuals by providing assistance with instrumental activities of daily living, such as preparing meals, paying bills, and activities of daily living such as dressing, transferring and bathing etc. In the non-VA world these services cost families thousands and thousands of dollars a year, at least for those who can afford to pay for help. In those families that can not pay for these assistants, caregivers are more likely to experience burn-out and other negative impacts of caregiving. This is a very important program.

Currently, however, this program specifies that services must be provided by a homecare agency or a family member who becomes an employee of such an agency. This requirement hinders the positive impact of the program by blurring the line between family caregiver and provider. Training and support for the designated family caregiver can build their confidence and help them be better prepared to provide these services, but forcing a family caregiver to become an employee of an agency as a prerequisite for getting funds for these services ignores the differences in the roles of family and provider caregivers, and could result in a family caregivers not being allowed to help their loved one due to some infraction of the employer's rules. As with all programs for this population erring on the side of flexibility and trust makes the most sense. This program should be modified to provide the same combination of training and freedom that is provided in the bowel and bladder program.

#### ***Community Care Teams***

Having addressed the family caregiver programs associated with the VHA and VBA, I want to comment now on what I believe is by far the most important service that can be provided to chronically and seriously disabled veterans and that is the provision of a life-long community care team that works with the family on both an



as-needed and regular check-in basis to help them manage their everyday lives and ward off crises before they occur. A sense of isolation and lack of ability to navigate the system and public programs are among the major difficulties that caregiving families face. A tethered relationship along the lines of the community care teams described in Senate Finance Chairman Max Baucus' White Paper provides a framework for such a service.

The care team concept brings together all of the services needed for an individual that have been noted in their initial care plan. As the person's situation changes, it prevents information from falling through the cracks. Extending such a program to designated veterans and their family caregivers for as long as they need it, potentially for the rest of their lives, is the missing link for these families. It is not the role of the family caregiver to manage this coordination and bring together the health care and social services that they and their loved one need. It is the job of trained professionals who are educated to manage this process and work closely with their assigned caregiving families. The overriding reason for such a program is to prevent unsafe and careless care. Care team programs with Medicaid beneficiaries in North Carolina, Vermont and elsewhere have also been shown to save money. This concept is further explained in a one page document I recently prepared. The document focuses on the general family caregiver population, but its principles are transferrable to the VA. It is appended to this testimony.

The VA is ahead of the curve when it comes to having successful care coordination programs and electronic medical records, but ultimately health care comes down to people doing what they are supposed to do in the most effective and efficient way possible. Unfortunately this isn't always the case. When care isn't all it could be for the most disabled vets the results can be catastrophic. Providing care teams for these veteran families is something the VA should seriously consider. Given the systems and programs the VA already has in place, such as electronic medical records and its home-based care monitoring program, the navigation, coaching, and coordinating services that would be a critical part of a care team's function will be that much easier to implement.

I want to thank the Committee again for the opportunity to present my views on the care needs of family caregivers of veterans. It is a complex topic. I have focused my remarks on the new generation of veteran families, but the complex and specialized needs of senior veteran families, especially those in the rapidly growing category of 85+ cannot be overlooked.

The VA faces a number of challenges as it strives to meet the needs of these diverse populations. It will require the energy and dedication of all its employees, from those providing janitorial services, up to those who perform brain surgery, and everyone in between to make sure its obligations are met. Unfortunately there are gaps in the VA safety net that must be addressed.

We've all heard about the horrible conditions at Walter Reed, not only the physical conditions, but perhaps more importantly the procedural ones that have made veterans wait an inordinate amount of time for their claims to be processed and in many cases be denied services. Just last year the VA's Office of the Inspector General reported that 76 percent of the claims of seriously disabled Iraq and Afghanistan veterans did not meet the 30-day processing goal, and 20 percent exceeded 181 days. In 2005, the VA Regional Office reported that even those veterans assigned case managers didn't fare much better. The variance was only 3 percent with those having access to a case manager not meeting the processing schedule 74 percent of the time, versus 77 percent of the time for those without a case manager.

In addition to slow processing times, we know that many vets, especially those with PTSD were denied benefits that would have provided them with getting monthly disability payments and lifelong health care for themselves, their spouses, and dependent children (DoD action on 10/14/08). It is critical that these issues, and ones like it, are resolved as quickly as possible. No matter how good the family caregiver programs are, they are irrelevant if vet families can't access them and if they can't be provided in the safest, most respectful, and flexible way possible. This needs to be the VA's top priority.

Once again thank you for this opportunity.

#### ***Support Care Coordination Teams and Family Caregivers***

**Caregiving families dealing with significant medical issues need to be assured that all patient information is coordinated across providers and care settings to minimize the potential for error and poor quality care. Currently coordination is left to family caregivers to provide.**

***The Issue***

More than 50 million people provide care for a chronically ill, disabled or aged family member or friend during any given year. Patients with chronic conditions have health care and social needs that require coordination among many health care providers across different health care settings and across the home and community-based service networks, as well. When patients transition from one health care setting or provider to another, crucial information is often lost or is not properly communicated to other members of the health care team.

If we are to achieve comprehensive care and support for all those with chronic conditions, our system must be person-centered and family-focused and not provide solely for the treatment of a specific disease, but rather as a way to achieve physical, emotional, and social well-being, while also returning economic savings to Medicare. Today family caregivers are the primary providers of care for persons with chronic conditions and disabilities. Proper coordination between providers and across all settings requires specialized knowledge as well as continual effort. This is a job for health care and social service professionals, not family caregivers, the majority of whom have jobs of their own in addition to their caregiving responsibilities.

***The Solution***

Providing continuity during these transitions can decrease medical errors, reduce re-hospitalization and use of emergency rooms, improve patient's satisfaction, and ultimately reduce health care costs. Community Health Teams have proven to be an effective model to achieve cost savings and improve quality of care in the Medicaid context. These programs utilize a strong focus on coordination and continuity of care across settings and provide a good model for implementing similar programs for Medicare's most complex patients.

A member of the team would stay in contact with designated patients and their primary caregivers so they may assist that patient/caregiver during periods of crisis, or transition. The team would steer the family through the health care/social support maze by being their advocate with the various entities involved, getting them information so they can better make decisions, providing them with support, and ensuring that coordination is comprehensive, continuous, and holistic so that patient safety, high-quality care and the health and well-being of family caregivers and the Medicare or Medicaid beneficiary is achieved.

**Care Coordination and Health Care Reform:** In upcoming health care reform legislation, NFCA recommends investing in care coordination teams comprised of nurses, nutritionists, social and mental health workers, and others as deemed appropriate, that are assigned to patients and their primary family caregiver. This will achieve the important health reform objective of improving quality of care, promoting efficiency, and lowering costs.

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**Prepared Statement of Mark S. Heaney, President and Chief  
Executive Officer, Addus Health Care, Inc., Palatine, IL, and,  
Home Care Aide Section Representative, and Member,  
Board of Directors, National Association for Home Care  
and Hospice, Inc.**

The National Association for Home Care and Hospice, Inc. (NAHC) respectfully submits this statement to the Subcommittee on Health of the Committee on Veteran's Affairs of the U.S. House of Representatives. The statement relates to the Subcommittee hearing, "Meeting the Needs of Family Caregivers of Veterans." NAHC understands that the Subcommittee is considering bills that expand the Veterans Administration health benefits to include financial support for family caregivers providing care to veterans in their homes.

NAHC is the largest trade association representing the interests of home care and hospice providers in the United States. In that capacity, NAHC represents the vast majority of home health agencies participating in VA home care programs. The NAHC Membership includes home health agencies and home care providers in all of the states and U.S. territories, small and large agencies, rural and urban providers, nonprofit and proprietary organizations. These agencies and providers deliver home care to over 12 million people of all ages each year. In doing so, the agencies and providers work closely with family caregivers as often the family caregiver is the backbone in the care delivery. Although the vast majority of family caregivers provide care without compensation, home care agencies have, on limited occasions

employed these caregivers or supplied a fiscal agent role for those caregivers directly employed by the individual under their care. As such, NAHC is uniquely capable of addressing the issues that exist regarding the provision of home care services through outside agencies and family caregivers.

The family caregiver is instrumental to many home care patients/clients as outside caregiving is generally part-time or intermittent rather than a full-time or live-in service. Such full-time care is often privately purchased or through one of the few home care programs sponsored by a State Medicaid program. NAHC strongly supports efforts in Federal or State programs that are designed to provide training, respite opportunities, and other supportive functions to family caregivers. However, the decision to provide remuneration to family caregivers is outside the purview and scope of NAHC as it represents a societal choice that balances the propriety of and need for supplying compensation with traditional family values wherein such caregiving is an uncompensated family responsibility.

Nevertheless, given the Subcommittee's present consideration of bills that would provide a means to tender compensation to family caregivers of selected veterans in need of care to remain in their own homes, NAHC can offer a number of recommendations that are borne out of the decades of experiences that home care agencies have had with both paid and unpaid family caregivers. In many respects, these experiences mirror those where the caregivers are unrelated. In either situation, NAHC believes that adequate safeguards must be established in order to protect the patient, the caregiver, and the funding program.

The structural weaknesses in direct care services programs (with or without family caregivers) need to be addressed in basic mechanisms of integrity and accountability. The steps set out below address essential minimum-level elements of accountability.

All federally funded directed care programs should be structured to:

- A. Ensure quality of care
- B. Maintain the personal security of the care recipient
- C. Assure protections and rights for workers
- D. Achieve efficiency and efficacy in care with the avoidance of waste
- E. Pay only for bona fide care

To achieve the basics of accountability, NAHC recommends that all self-directed care programs include the following:

1. **A professional care manager must be assigned to each recipient with responsibilities for ongoing monitoring, support and supervision of care.**
2. **A care plan should be established and care authorized to meet the consumer's needs without regard to the mode of care delivery.**
3. **Oversight and audit systems must be employed for periodic review of care plans, the provision of services, and the qualifications of caregivers.**
4. **Care should be adjusted periodically by the case manager to ensure that the authorized care is consistent with the continuing changing needs of the recipient.**
5. **Consumers must be evaluated to ensure that they are independently able and willing to utilize direct care. For those consumers who are unable or unwilling to self-direct, alternative agency-model care should be available.**
6. **Caregivers must meet minimum standards of training, competency, and health screening verified by an objective entity.**
7. **Caregivers should be subject to full and periodic criminal background checks prior to and during employment.**
8. **Personal care aides should be afforded all the legal rights and protections granted to all workers regardless of any relationship to the person under their care.**
9. **A grievance/complaint system should be created for consumers and workers to address all problems.**
10. **Fiscal management safeguards must be developed to ensure that payment for services is made to the proper party, in a proper amount for services actually provided.**
11. **These safeguards should apply to all consumers and workers regardless of the mode of care delivery.**

The risk of harm is high to a very vulnerable population of disabled veterans in need of personal care support for basic activities of daily living. An unstructured

and unsupervised program of self-directed care using paid family caregivers where the consumer is the “responsible” employer can lead to:

- Improper care
- Physical abuse
- Mental abuse
- Exploitation
- Predatory behavior by caregivers
- Benefit fraud
- Inadequate service delivery or utilization
- Over-utilization

As has been stated before, all home care programs carry these risks. However, direct care programs generally lack any structure or process for protecting patients, caregivers, and the fiscal integrity of the funding. The VA should develop a compensated family caregiver program only if it also includes the basic safeguards suggested herein.

**Historically, direct care programs have been initiated without:**

- Established standards of care
- Regular continuous monitoring of care and the consumer’s safety
- Evaluation of consumer’s ability or willingness to self-direct care
- A choice for consumers to self-direct or not
- Verification that services provided are limited to those called for by the case-worker
- Verification that consumers actually receive the care they are authorized
- Any structural effort to reduce dependency on services
- Coordination with other government funded health services already being provided to the consumer such as hospitalization, rehabilitative care, nursing home care, and Medicare home health services, resulting in duplicate care and cost to the government
- Criminal background checks of caregivers with consistent standards for what constitutes a “background check”
- Licensing or certification of caregivers to verify they are qualified to provide the care they deliver
- Basic caregiver training standards
- Ongoing competency and performance assessment of caregivers
- Cost containment controls

These risks are not limited to circumstances where the caregiver is a stranger to the consumer, whether selected out of a government-run registry, or more likely, from a classified ad. Many recipients receive their care from family members or friends who are paid directly by the government. Very often, these friends and family members make the decision that the consumer will “self-direct” even though the consumers themselves are incapable of making important decisions on their own. As a paid caregiver, these persons have a financial stake in the consumer’s continuing need. Additionally, in cases where the consumer is frail, afraid or cognitively impaired, it is very often the paid caregiver who attests to the consumer’s “satisfaction” with their care. Studies show that the greatest risk of physical, financial or emotional abuse to the frail elderly actually comes from family.

Two examples highlight the risks attendant to the operation of a direct care program in the absence of adequate safeguards, both established and utilized.

**Washington State**

In 1984, Linda A. David, then 36, applied for personal care services benefits through her husband. The alleged basis for eligibility was continued physical deterioration resulting from Multiple Sclerosis. A physician who examined Ms. David on behalf of the State raised doubts about the alleged diagnosis and expressly warned the State that the individual may have been subjected to longstanding abuse and recommended an evaluation of the home environment. Despite this warning, the State simply approved the application and began issuing payments to the spouse to provide personal care. Over the years, there were repeated warnings of suspected abuse from the State-hired physician.

The State was required to conduct periodic assessments of client eligibility and need. State rules mandated in-home evaluations at least annually. Between 1984 and 1987, the State visited the client on a few occasions, but only in the presence of her caregiver spouse. Starting in 1987 until 1997, no in-home evaluations were conducted by the State. The client’s home was isolated from other people. It was

a boat moored 200 feet offshore where the client had no human contact other than her husband. Throughout this time, the State paid Mr. David under the self-directed personal care services program run by the State.

In January 1997, Linda A. David was liberated by the county fire department. At that time she was emaciated and covered with dog feces, vomit, and urine. The smell was described as “rotting flesh.” Ms. David had multiple untreated major bone fractures and blindness due to untreated glaucoma and retinal hemorrhaging. Her ears were deformed and cauliflowered from beatings. She was permanently unable to ambulate in any way. She was brain damaged as well.

In 2001, the State of Washington Department of Health and Human Services settled a lawsuit based in negligence regarding the personal care services program for \$9 million.

#### **TENNESSEE:**

The Tennessee Medicaid Fraud Control Unit announced in February 2007 that the mother of a mentally retarded son pleaded guilty to theft of funds used to pay for the in-home care of her mentally retarded son from TennCare, the State’s Medicaid program, through a TennCare waiver. The woman allegedly billed for care using names and Social Security Numbers of dead people, people who provided services under other contracts, and people she knew but had no involvement with her son.

The use of family caregivers does not immunize patients or funding programs from the risks inherent in a publicly funded home care program. In fact, the familial relationship may add risks due to the emotional and trusting nature of the connection. At the same time adequate safeguards can be established that control or minimize these risks. However, NAHC suggests that the issue is not whether safeguards are necessary, but rather how to establish and employ the safeguards.

#### **Options for the VA**

There are a variety of ways that direct care programs can operate where reasonable safeguards have been established to address the risks presented.

1. The VA can assume the role of “employer” of the family caregiver, thereby meeting all of the employer responsibilities including tax withholding, unemployment compensation, workers’ compensation, and payroll management. As an employer of the worker, the VA can share supervision and direction of the caregiving with the veteran. The VA would be directly responsible for training and oversight of the caregiver.
2. The VA could utilize a “fiscal agent” model that has the agent handle all the employer administrative responsibilities while not assuming them. The family caregiver remains the employee of the veteran. This model could also utilize a third party for a care management and oversight role. The third party could provide caregiver training and resolve any conflicts that may surface between the patient and family caregiver.
3. The VA could establish a program wherein the family caregiver is employed by a home health agency. This method would relieve the veteran of employer responsibilities and establish day to day oversight of care at the agency. NAHC’s investigation indicates that few home health agencies would be willing to employ family caregivers. Agencies indicate that it would be difficult for an employment status to be maintained because of the familial connection of the caregiver. Among the reasons expressed by agencies is their belief that the caregiver would not be objective in their employee status, given their relationship to the patient. Further, it has been expressed that an employed family caregiver would not accept a subordinate position to the agency management, a necessary element to effective supervision and oversight.
4. The VA could continue to utilize the services of non-family caregivers from home health agencies. Generally, the VA has used either Medicare certified or State licensed home health agencies that meet comprehensive standards designed to deliver quality care and ensure patient rights. Currently, there are over 9,800 Medicare certified home health agencies throughout the Nation. Over 98 percent of all zip code areas have service from at least two home health agencies.

Each of these models still need to operate with the elements of integrity set out above, including caregiver credentialing and competency testing and third party care management.

## Conclusion

NAHC is ready to work with the Subcommittee on whatever direction it chooses to take. No home care program can be effective unless it considers the role of family caregivers. NAHC applauds the Subcommittee's recognition of both the value and seriousness of family caregivers. In the end, the patient's interests in quality of care and a safe home environment are paramount. Thank you for the opportunity to present this testimony.

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### Prepared Statement of Madhulika Agarwal, M.D., MPH, Chief Officer, Patient Care Services, Veterans Health Administration, U.S. Department of Veterans Affairs

Mr. Chairman and Members of the Subcommittee, thank you for providing me this opportunity to discuss the Department of Veterans Affairs' (VA's) programs and support of family caregivers. I am accompanied today by Dr. Lucille Beck, Chief Consultant for Rehabilitation Services, Veterans Health Administration (VHA), Dr. Tom Edes, Director of Home and Community-Based Care, Office of Geriatrics and Extended Care, VHA and Thomas J. Kniffen, Chief, Regulations Staff, Compensation and Pension Service Veterans Benefits Administration. Caregivers 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. VA shares Congress' interest in providing the necessary support to caregivers, particularly when family members of Veterans assume that role to tend to a loved one. We are very enthusiastic about working with Congressional Members and staff to strengthen VA's already robust programs.

My testimony will describe how VA supports caregivers, including discussions about VA's current programs and the population needing caregiver services, VA's eight ongoing caregiver pilot programs, definitions of eligible caregivers, information on caregiver training, travel benefits and compensation for caregivers, and medical care and counseling for caregivers. I will then discuss another important element of VA's caregiver programs: our respite care services. While VA is currently undertaking a comprehensive reassessment of caregiver programs, this statement will elaborate on our current approaches and raise principles for possible improvements. We look forward to working with Congress to identify the most feasible and effective caregiver program improvements.

#### *Caregivers: Current Programs and Populations*

VA currently contracts for caregiver services with more than 4,000 home health and similar public and private agencies approved by the Centers for Medicare and Medicaid Services (CMS) or through State licensure. The contractor trains and pays the caregiver directly, affording them liability protection while overseeing the quality of the Veteran's care. VA provides remuneration pursuant to agreements with the home health agencies, thus in some cases compensating family caregivers indirectly. Importantly, VA also ensures that these home health agencies meet and maintain training and certification requirements specific to caregivers. This model has several advantages. First, it does not divert VA clinical resources from the treatment of Veterans. Second, it allows direct interaction between the Veteran and the Home Health Agency or State Area Agency on Aging regarding caregiver arrangements and satisfaction. Third, these agencies have expertise in training and certifying home health aides, including family members, and many operate in rural communities.

VA knows these services are important to Veterans and families alike. To determine the population affected, VHA conducted a survey of Veterans Integrated Service Networks (VISNs) and VA medical centers in April 2009 to determine how many family caregivers have been referred to home care agencies for training, certification, and employment as home health aides and as a paid caregiver for a Veteran. In Fiscal Year (FY) 2008, VA referred 233 family caregivers for training and certification in homemaker/home health aide services, which represents approximately 5 percent of all home care referrals. Twenty-nine percent of family caregivers were a Veteran's spouse. In the first 7 months of FY 2009, 168 family caregivers were referred to home care agencies for training and certification; of this group, 26 percent were spouses. At the time of the survey, the three VA medical centers participating in the Veteran Directed Home and Community-Based Services Program reported 70 family caregiver referrals (17 percent of whom were spouses) through the first 7 months of the fiscal year. VA favors the current system of eligibility for caregiver

services that retains flexibility to allow us to provide benefits to Veterans who are unable to live independently, whether their specific condition is physiological, psychological or neurological in nature.

VA administers many different programs related to caregivers:

- VA recently has begun contracting for home care services with local Area Agencies on Aging (AAA) through the Veteran Directed Home and Community-Based Services Program. We work in close partnership with the administration on Aging to support and expand this program. Under this program, the AAA works with the Veteran to purchase caregiver services. The Veteran may choose a family member, friend or neighbor to deliver care, or may choose to have some care provided by a traditional agency. This program allows Veterans to remain in their community, and local VHA facilities cultivate relationships with the local AAA to pay for case management, financial and other support for Veterans. This program currently operates in 15 VA medical centers, and VA plans to expand to additional sites in the future.
- Temporary Lodging for caregivers and family members is provided in Fisher Houses, VA-run hoptels, and non-VA lodging facilities, such as hotels or motels. Temporary lodging may be furnished when the Veteran travels to a VA health care facility for care or a Compensation & Pension examination. VA maintains this program directly and with support from Veterans Service Organizations, other volunteer agencies, and donations from the community. This benefit, provided at no cost to the family member or other person accompanying the Veteran who provides the equivalent of familial support, is provided on a first-come, first-serve basis. As a condition of receiving temporary lodging, this benefit is limited to those who reside either 50 or more miles, or at least 2 hours from the VA health care facility. In 2008, the VA Fisher House Program served 5,949 families.
- Additionally, although VA programs such as Aid and Attendance and Special Monthly Compensation do not provide payments to caregivers, these programs do provide direct payments to qualifying Veterans who require assistance with activities of daily living, reside in nursing homes, are bedridden, or are blind. Housebound benefits are also available to qualifying Veterans who are permanently disabled and substantially confined to their homes.
- VA also provides a payment of up to \$100,000 to Veterans who sustain certain injuries through the traumatic injury protection offered under the Servicemembers Group Life Insurance Traumatic Injury Protection Program (TSGLI). This helps enable Veterans' loved ones, who may also provide caregiver support, to be with the Veteran during recovery.

Additionally, VA and the Department of Defense (DoD) have developed the Federal Recovery Coordination Program to help severely wounded, ill or injured recovering servicemembers, Veterans, and their families access the care, services, and benefits provided through the various programs in VA, DoD, other Federal agencies, states, and the private sector. As of May 12, 2009, 257 Veterans and servicemembers have enrolled in the program. VA has 14 Federal Recovery Coordinators (FRC) at six military treatment facilities and two VA Medical Centers. These individuals work virtually and manage clients across the U.S. If a family caregiver needs additional support because he or she provides full-time care to the Veteran, the FRC ensures that the caregiver has information and access to resources and benefits that are available to them as they care for their loved one.

#### *Eight Caregiver Pilot Programs*

Before expansions are made in VA's caregiver programs, it is prudent to evaluate the effectiveness and feasibility of the numerous pilot programs currently underway. VA is currently implementing eight caregiver pilot programs that are testing new methods of support. These programs are located across the country and benefit Veterans of all service eras and their caregivers. The goal of these pilot programs is to explore innovative options for providing education and support services to caregivers as they support and care for the Veteran. Among the key services provided to caregivers are respite care, case management and service coordination, assistance with personal care (bathing and grooming), extended days of respite care, social and emotional support, and home safety evaluations. Education programs teach caregivers how to obtain community resources such as legal assistance, financial support, housing assistance, home delivered meals, and spiritual support. These pilot programs began in 2007 and will end in September 2009. VA will be reviewing the

outcomes of these caregiver pilot programs to determine the advisability and feasibility of nationwide implementation. These eight pilots are summarized below.

1. *Memphis, TN*: Resources for Enhancing Alzheimer's Caregiver Health (REACH VA) is currently piloted in 24 home-based primary care programs across the country in 15 states. This program is specifically for caregivers of Veterans diagnosed with dementia who are enrolled in home-based primary care. REACH VA provides an intervention translated from a similar, evidence-based National Institutes of Health initiative that provides education, support and skills building to help caregivers manage both patient behaviors and their own stress. In October 2008, REACH VA won the Rosalyn Carter Institute Leadership in Caregiving Award.
2. *Gainesville, FL*: Caregivers are taking part in a Transition Assistance Program, which provides skills training, education and supportive problem solving using videophone technology for new stroke patients or patients with stroke-related disabilities and their caregivers. The coordinating site is in Gainesville, while actual pilots are underway at the Stroke Centers of Excellence in Houston, TX and San Juan, PR.
3. *Dayton/Cincinnati, OH*: VISN 10 has established a 24/7 hotline titled, "Caregiver Advocates," who are assigned to coordinate between VA and community providers in home-based primary care programs in Dayton and Cincinnati, OH. Caregiver Advocates assist caregivers in identifying, accessing, and coordinating existing and augmented caregiver resources and providing therapeutic interventions to the caregiver. This pilot also provides additional hours for adult day health care, in-home respite and inpatient respite. This program is designed for caregivers of frail imperiled Veterans at high risk for institutionalization.
4. *Long Beach, CA*: This pilot works with a community coalition to provide interventions that support caregivers for Veterans with TBI, post-traumatic stress disorder (PTSD) and dementia across the State of California using telehealth, web, telephone and video tele-conferencing. Participation in this program is currently limited to Veterans with TBI, PTSD, or dementia. Interventions are provided by the VA Cares Caregiver Center, California Caregiver Resource Centers, the "Powerful Tools" Caregiver Training program, and Stanford University's Internet-based Caregiver Self Management Program.
5. *Albany, NY*: This pilot converted a 3-hour workshop developed by the National Family Caregivers Association, "Communicating Effectively with Health Care Professionals" into a DVD and manual. Face-to-face workshops have been implemented to offer an additional delivery method. If this program proves effective, VA may be able to add this content to the My HealthVet Web site to promote further distribution.
6. *Atlanta, GA*: This pilot uses a model telehealth program adapting "Health Buddy" devices, which are existing technologies used by VA, to provide help and emotional support for caregivers living in remote areas or who cannot leave the Veteran by himself or herself. This program is designed for caregivers of Veterans who are 60 years old or older and who have at least one chronic illness that requires assistance with an activity of daily living or an instrumental activity of daily living. To participate, the caregiver must live with the Veteran.
7. *Miami-Tampa, FL*: Tampa's existing respite program is being expanded to provide 24-hour in-home respite care for temporary relief to caregivers (up to 14 days per calendar year) and emergency respite in local assisted living/medical foster care facilities. The Miami program provides and coordinates comprehensive community-based services, including respite, home companions, adult day care, and use of an emergency response system for high risk Veterans.
8. *VA Pacific Islands Health Care System*: The Medical Foster Home concept is utilized to provide overnight respite for Veterans in areas where no other inpatient respite options are available, particularly in remote and rural service areas. Currently, overnight respite can only be provided at the VA Pacific Islands Health Care System Center for Aging in Honolulu or in contract nursing homes located on Oahu.

#### *Defining Caregivers*

Family structures are changing in all facets of society, and VA is sensitive to the fact that a specific list or a strict definition of family members may not be appropriate for many Veterans. Discretion is needed to ensure that Veterans retain au-



tonomy in designating caregivers who are competent and in whom they are confident. As previously described, spouses often assume caregiver roles, but so do parents, grandparents, siblings, children and others. Many Veterans are able to remain independent in the community because neighbors, friends, and others provide assistance. VA would like to work with the Committee to help form any proposals to ensure adequate arrangements are made to accommodate each Veteran in need of caregiver assistance without creating undue administrative burdens on the system. We believe the definition of caregiver should be broadly defined to encompass a variety of potential caregivers, thus eliminating the need for a discrete list that may inadvertently exclude a candidate (such as a friend, neighbor, or significant other) that meets the Veteran's needs and preferences. Leaving discretion to the Secretary to approve any potential caregiver would ensure this adaptability.

#### *Caregiver Training*

Training is essential for safe and effective caregiver assistance. Training should be designed to provide caregivers with the skills necessary to competently perform necessary personal care services. These needs may vary from patient to patient and VA's caregiver policy must maintain this flexibility to preserve patient care. Under our contracting agreements, home health agencies are required to train and certify family members according to the State's guidelines. Currently, VA works with family members or other attendants before they leave a VA facility and educates them about any issues related to the care of the Veteran's condition. Many of our seriously injured Veterans who would need a caregiver have received treatment in VA's Polytrauma System of Care. Prior to discharge from a Polytrauma Rehabilitation Center, family members may be scheduled to stay with the Veteran in a family training apartment. This allows the family member to experience what the return home will be like for their loved one, while still having rehabilitation staff and nursing staff available to answer questions, address unexpected problems, and provide the emotional support a family may need as they prepare for the next phase of rehabilitation.

#### *Travel Benefits*

An area that some families, caregivers and Veterans have requested additional support is travel reimbursement. Veterans who need caregivers often require assistance when traveling to a VA facility for scheduled care, especially if the Veteran lives in a remote or rural area. VA currently provides travel benefits to attendants of severely injured Veterans who are likely to be most in need of assistance. We appreciate the financial difficulties that families can face when a Veteran is unable to live independently and requires caregiver services. Some family members have had to leave their jobs to care for a loved one, creating further financial strains. VA is currently evaluating the assistance provided to caregivers.

#### *Medical Care and Counseling for Caregivers*

VA is authorized to provide medical care to caregivers on a humanitarian basis in an emergency situation. By law, VA is required to seek reimbursement for hospital care and medical services provided to individuals who are not otherwise eligible for these benefits. This can impose a significant hardship on some caregivers if they have no health insurance or coverage. VA is evaluating the humanitarian care assistance provided to caregivers.

A related issue involves the provision of counseling and mental health services for caregivers. In 2008, Congress expanded VA's authority to provide mental health care and counseling to the Members of the immediate family, the legal guardian of a Veteran, and the individual in whose household such Veteran certifies an intention to live. This care may only be provided as necessary in connection with the treatment of the Veteran. The contracting home health agency often has support systems available. A number of caregiver and family support groups also meet with family members at VA facilities to address caregiver burnout or depression. In so doing, they help address the individual counseling needs of family members that fall beyond VA's existing caregiver authority. VA Vet Centers are also available to provide marital and family counseling as it relates to conditions connected with the Veteran's readjustment to civilian life. Respite care, which I will now address, is also available.

### *Respite Care Programs*

Respite care is an essential complement to caregiver benefits; it temporarily relieves the spouse or other caregiver from the burden of daily care for a chronically ill or disabled Veteran living at home. VA offers a comprehensive respite care program, providing respite in a variety of settings including nursing homes, adult day health care facilities and in the home. To be eligible for respite, a Veteran must be enrolled in VA's health care system, have a chronic condition requiring daily assistance, and have a caregiver who needs respite to maintain the Veteran safely at home. Respite care services are planned in advance to best align caregiver schedule preference with availability of respite in the setting that will meet the Veteran's care needs.

Adult day health care is available for use in providing respite services as well as for caregiver support and education, such as instruction on managing challenging behaviors in Alzheimer's patients. To qualify for adult day health care, a Veteran must be enrolled and otherwise require nursing home care. Adult day health care is currently provided at 21 VA medical centers by VA staff and at 120 VA medical centers through contracts with community providers.

In many areas, there are simply no providers with whom VA can contract for home respite. VA has two pilot programs underway to expand home respite services. VA Voluntary Services (VAVS) is establishing and operating a community-based home respite program to benefit Veterans and their primary caregivers. Any Veteran eligible for respite care can participate in this program, which is being implemented at 12 VA medical centers. This program is volunteer-oriented and provides full-time caregivers a needed break. VA recently added a "buddy" component that matches Veteran volunteers with OEF/OIF Veterans, creating a relationship, bond and support system to expand services outside the home environment. Volunteers are trained using materials provided by the Senior Companion Program. More than 60 Service Organizations have been briefed about the program, and VA is soliciting potential volunteers. Volunteer availability is the only limitation on the potential for this program. The second pilot is a caregiver assistance program that is underway at two VA medical centers to provide 24-hour in-home respite care.

VA recently adopted an innovative program to aid Veterans and their families with an option for long-term care. The medical foster home program identifies persons in the community who are willing to open their homes and care for Veterans who need daily assistance and are no longer able to remain safely in their own home, but do not want to move into a nursing home. VA calls this program, "Support at Home—Where Heroes Meet Angels."

Both Volunteer Home Respite and Medical Foster Home work out very well for the family, the Veteran, and the community, particularly in rural areas. Concerned citizens often express an interest in helping Veterans, but they live too far away from a VA facility to participate easily. These programs offer them a chance to serve Veterans in their city or town by either visiting the home of the Veteran or opening their own home to the Veteran. VA trains all individuals who participate.

VA provides caregiver support services for the families of Veterans receiving VA home-based primary care and hospice care. Veterans receiving home-based primary care typically have chronic, disabling diseases, and the burden of care often falls on the Veteran's family. Home-based primary care provides home care to over 19,000 of our most frail Veterans every day, and provides caregiver education and training on the care needs of the Veteran. VA recently adopted a new quality indicator, which helps us determine the level of strain and fatigue on our family caregivers. By the end of 2008, VA assessed the caregivers of 73 percent of these Veterans in Home Based Primary Care, and offered guidance or support to 93 percent of those identified with caregiver strain. Home Based Primary Care currently operates at 132 VA Medical Centers, and 22 of these are in designated rural settings. To further expand the reach of this program to serve rural Veterans, we awarded funds in May 2009 to start Home Based Primary Care satellites in 25 rural community-based outpatient clinics and 14 Indian Health Service facilities with funding support from VA's Office of Rural Health.

### *Caregiver Programs for the Future*

While VA's caregiver programs address an immediate need, we recognize some Veterans, particularly young Veterans, will need care for the rest of their lives. VA is building the systemic infrastructure now that will support them and other Veterans into the future while allowing us to adapt to their changing needs. While we do not yet know what new advances await us in health care, VA remains committed to leading the medical community and establishing the benchmark by which all

caregiver programs will be measured, as we have with our electronic health record and mental health services.

VA sees an ideal caregiver program as one that leaves broad discretion to the Veteran and the Department concerning who can be named a caregiver. Similarly, caregiver services would not be limited by whether the Veteran's condition is physiological, psychological, neurological or other. It most often would involve an intermediary responsible for supervising and ensuring accountability of care between the Veteran and that caregiver to prevent conflicts of interests or strained relations between the Veteran and their health care provider based upon difficulties or issues between the Veteran and their caregiver. While caregiving is an essential complement of health care management, caregivers are selected because of the pre-existing relationship and trust they have with Veterans. Health care providers maintain their relationships on a professional level and develop trust through compassion and experience. By retaining an intermediary, VA preserves both relationships and forestalls any choice a Veteran may feel compelled to make between his or her caregiver and health care provider.

Training and qualification for certification of caregivers should remain the responsibility of others, such as home health care agencies, which already have the expertise and knowledge on how best to prepare caregivers for their duties.

VA's array of caregiver programs would remain in effect to meet the individualized needs of Veterans and to preserve their independence for as long as is safe and possible. Elderly Veterans require different support mechanisms than Veterans with quadriplegia or a similar condition, and these Veterans have different needs than those with TBI; maintaining programs tailored for different populations ensures VA offers optimal care to all Veterans. These offerings must continue to be coordinated across the Department, principally with the Veterans Benefits Administration and its Aid and Attendance or Housebound benefits. VA envisions a model of a three-tiered system that will strengthen and support Veterans across their lifetime. At the broadest tier of this system, home-based support programs are currently provided to allow Veterans to retain as much independence as possible. Second, those requiring additional support and supervision can find these services in an assisted living, medical foster home, or community residential care environment. In providing these services, VA can assist Veterans in finding an appropriate residence and provide oversight, but it lacks the authority to pay for or provide this service. Finally, VA also will continue to offer community living centers and community nursing homes to those with even greater needs.

#### *Conclusion*

Mr. Chairman, caregivers fulfill a vital role in providing quality and necessary health care to Veterans with complex needs. Our current programs are striving to meet the needs of both caregivers and Veterans, and we will make every effort to enhance our programs and strengthen our collaborations with others, such as DoD or the administration on Aging. This statement provides some general principles which VA believes an effective caregiver program must include. VHA representatives are available to discuss this matter further with you and your staff. Thank you again for the opportunity to testify. My colleagues and I are prepared to answer your questions.

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**Prepared Statement of Edwin L. Walker, Acting Assistant  
Secretary for Aging, Administration on Aging,  
U.S. Department of Health and Human Services**

Chairman Michaud, Congressman Brown, distinguished Members of the Committee: Thank you for this opportunity to discuss the needs of family caregivers of veterans. I want to commend you for recognizing the important role caregivers play in the lives of those for whom they care. We honor their heroism by supporting them and their loved ones when they return home.

For more than forty years, the U.S. Administration on Aging (AoA) has served as the effective and visible advocate for older Americans at the Federal level. AoA provides national leadership, funding, oversight and technical support to a national aging network and is charged under the Older Americans Act to develop a comprehensive and coordinated system of home and community-based services for older people and their family caregivers.

The aging network consists of 56 State Units on Aging; 629 Area Agencies on Aging; 246 Tribal organizations; over 20,000 community services provider organiza-

tions and thousands of volunteers. The aging network reaches into every community and plays a key role in delivering consumer-centered services and supports to some of the most vulnerable Members of society. What is more, funding for State and community-based services is significantly leveraged, with funding from sources other than the Older Americans Act to triple the amounts provided by AoA.

Through strategic partnering with other Federal agencies and national organizations, AoA has positioned the aging network as the leading provider of home and community-based long-term care services to vulnerable Americans and their caregivers.

My testimony today will highlight AoA and the national aging network experiences in addressing the complex needs of caregivers through our national Family Caregiver Support Program (Caregiver Program). This program was the first Federal program to formally recognize the importance of supporting family caregivers on a sustained basis. I will highlight examples of some of the innovative approaches used by our aging network to serve caregivers as well as new opportunities we have to better meet the needs of caregivers, including AoA's recent collaboration with the Department of Veterans Affairs (VA) to establish a Veteran Directed Home and Community-Based Services Program (VD-HCBS).

### **Caregivers: Who are they? What do they sacrifice?**

Informal caregiving is the foundation of America's long-term care system. Each day, in every State and community, family members, friends and neighbors provide extraordinary levels of assistance to persons of all ages with chronic illnesses and disabilities. Caregivers manage tasks ranging from assisting with basic personal care and homemaking to carrying out more complex health-related interventions like medication administration and wound care.

The needs of family caregivers are complex and ever changing. Whether caring for a child with disabilities, an aging parent with dementia or a veteran returning from active duty with polytrauma or less severe injuries, caregivers face often rapidly changing situations and needs. As a result, caregivers must be able to depend on a system that understands their needs and responds to them with a comprehensive, consumer-centered and flexible array of programs and services.

Caregivers may be found in every community. They come from every walk of life. They are male and female, young and old, and may or may not possess adequate financial resources to meet their own daily needs or the needs of those for whom they care.

It is estimated that 44.4 million Americans provide care for adult family members and friends or other loved ones. The Family Caregiver Alliance in San Francisco, California estimates these caregivers provide in excess of 37 billion hours of care per year.

The economic value of unpaid caregiving in 2007 was estimated to be about \$375 billion, up from \$350 billion in 2006.<sup>1</sup> This is what it would cost if that care had to be replaced with paid services. This amount equals more than the total of medical and long-term care spending in 2006.

We are seeing growing numbers of caregivers "sandwiched" between two generations of individuals needing care: young children and aging family members. They often experience difficulty balancing work schedules with the demands of caring for their loved ones. As a result, many caregivers leave the workforce or struggle with what amounts to two full time jobs: their formal employment—essential for income and health care coverage—and caring for their loved one.

We also are seeing younger individuals caring for parents, grandparents or siblings, and growing numbers of family caregivers working to keep disabled adult family members out of institutions and in their homes and communities. Another growing segment of the caregiver population includes grandparents or other relatives of children, with or without disabilities, taking on full-time parenting responsibilities for the second or third time in their lives because the child's parents are unable or unwilling to do so, or because they are serving our country in distant lands.

And, not surprisingly, with our military actively engaged in Iraq and Afghanistan, we are seeing an increased emphasis on supporting the families of military personnel who are returning from combat with traumatic brain injuries and other serious, chronic or debilitating conditions.

<sup>1</sup>Gibson M.J., & Houser, A.N. *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*. Washington, D.C.: AARP Public Policy Institute: 2008 November, Insight on the Issues #13.

In recent years, numerous studies have emerged exploring the complexities of caregiving. These studies have examined the health impacts of caregiving, the status and challenges of rural caregivers, cultural differences among caregivers and the challenges faced by those who balance work, family and caregiving responsibilities.<sup>11</sup>

Caregivers also fill multiple roles within the context of their caregiving situation. Caregivers are often both nurse and home health aide, paralegal and financial advisor, as well as devoted family member. They often perform highly skilled or specialized medical tasks such as tube feeding, wound care, and medication management and administration.

Caregivers themselves have many needs that often go unaddressed or are ignored altogether. Research has shown the stress associated with caregiving exacts a significant toll on the emotional, physical and financial well-being of many caregivers. Caregivers often report declines in their own health and functional ability as a result of the care they provide. Caregivers experience high rates of depression, stress and other mental health issues. Financially, the impact of caregiving can be significant. One study found that caregiving for a parent significantly increases the caregiver's chances of living in poverty in later life.

Despite the negative impacts of caregiving, there is a bright side as well. Many caregivers report deriving great satisfaction from caregiving and from having the opportunity to fulfill what they see as an essential familial obligation to a loved one or friend. In fact, past surveys of recipients of aging network caregiver support services showed that nearly two-thirds of caregivers felt a sense of accomplishment as a result of the care they were providing.

Regardless of their background, living situation, or level of training, family caregivers represent the best society has to offer. And, while caregiving is an experience affecting all races, ethnicities, lifestyles, and income levels, on a deeply personal and individual level, it has become an essential component of the national dialog surrounding our Nation's health and long-term care system.

### **The National Family Caregiver Support Program**

The AoA National Family Caregiver Support Program (Caregiver Program) serves as a platform for the aging network to focus specifically on the needs of family caregivers by integrating those needs with the provision of other home and community-based services, including State-funded caregiver programs. The unprecedented caregiver support infrastructure established by the Caregiver Program created a multifaceted system of services for caregivers, including:

- Information about available services;
- Assistance to caregivers in gaining access to services;
- Individual counseling, organization of support groups and caregiver training;
- Respite care; and
- Other supplemental services.

Amendments to the Caregiver Program in 2006 permitted caregivers of persons with Alzheimer's disease or related dementias of any age to be served and lowered the age of grandparents and relative caregivers raising children from 60 to 55. These two modifications allowed the aging network to expand the scope of its reach to include a broader cross section of service recipients.

The Caregiver Program has allowed AoA and the aging network to acknowledge the central role of caregivers in our health and long-term care delivery systems. National survey data of our service recipients tell us that nearly 73 percent of caregivers assist the care recipients with very basic life activities such as bathing, dressing and eating.

Caregivers must have access to services and supports designed to safeguard their health and emotional well-being while offering protections against some of the financial burdens often associated with caregiving. To that end, AoA, through its partnership with the Centers for Medicare and Medicaid Services, has established highly visible Aging and Disability Resource Centers (ADRCs) in 46 States and territories and in more than 200 communities nationwide, with plans to have ADRCs functioning in every State by 2010. For caregivers, ADRCs are a trusted source for reliable information on the range of programs and supports available to them.

The aging network has many examples that highlight its creativity, flexibility and innovation in serving older consumers, persons with disabilities and their caregivers.

<sup>11</sup> For more information on the varied needs of caregivers and to view and download a variety of research reports pertaining to caregivers, please visit the National Alliance for Caregiving's Web site at: <http://www.caregiving.org/>.

For example, in Connecticut a pilot consumer-directed cash and counseling option is being developed in the South Central region of the State with funds from our Caregiver Program and the statewide Respite Care Program. This option helps consumers at risk of nursing home placement but who are not yet eligible for Medicaid to remain in their own homes.

In Texas, the Area Agency on Aging of Central Texas has partnered with Scott & White Memorial Hospital to establish two innovative programs for caregivers. The first organizes and connects caregivers with volunteer support teams who assist them with practical and emotional support. The second provides the evidence-based Resources for Enhancing Alzheimer's Caregiver Health (REACH) intervention. This approach assesses the needs and risk factors of caregivers, matching them with services and supports to reduce their risks and enhance well-being.

The Caregiver Program has allowed AoA and the aging network the opportunity to:

- Infuse the principles of consumer direction into existing service delivery systems;
- Address the unique challenges associated with serving caregivers in both urban and rural settings;
- Provide a broad range of services, including respite, for diverse age groups, including grandparents and other relatives raising grandchildren; and
- Ensure that programs serve consumers in culturally competent ways.

#### **Caregiver Program Accomplishments**

The aging network has had a significant impact in the lives of caregivers and in supporting the work they do. Through the Caregiver Program, we annually touch the lives of more than 1 million people—caregivers, families seeking assistance, grandparents and other relatives raising grandchildren.

We know that through the Caregiver Program, the aging network is having a positive impact on the lives of those we serve. More than 81 percent of caregivers interviewed for the most recent National Survey told us that the Caregiver Program enabled them to care for their loved ones longer, thereby avoiding costlier and more restrictive placement in an institutional setting. Seventy-five percent of caregivers indicated that services helped to reduce some of the stresses they felt and nearly 46 percent of caregivers said respite was the service found to be most helpful, thus underscoring the importance of caregivers taking time away from their situation to rest and recuperate.

#### **The AoA/VA Collaboration**

The Department of Veterans Affairs and the Administration on Aging have long recognized the many concerns in serving our respective populations. Addressing the needs of family caregivers is essential for helping individuals remain in their homes and communities; and the knowledge that both younger veterans and older adults want to be in charge of their own lives to direct their own service needs.

AoA and VA recognize the importance of caregivers' service to their loved ones. Together we have a shared commitment to meeting the needs of consumers and their families, on their terms and according to their needs and preferences. The aging network recognizes the importance of partnering with the VA at the local level to meet the needs of veterans. In Maine, for example, Area Agencies on Aging (AAA) coordinate services and benefits for veterans in collaboration with the Veterans Homes throughout the State, the Togus VA Medical Center and the Department of Veterans Affairs. Coordination is done via the ADRCs, the Partners in Caring State-funded respite program, the State Health Insurance Assistance Program, and our Family Caregiver Program.

Additionally, some of the AAAs have veterans' advocates who come to their agency on a scheduled basis to meet with veterans and their caregivers. Community information staff at AAAs obtain and distribute updated information regarding veterans' benefits. Finally, some of the AAAs have adult day programs at which veterans participate.

AoA and VA are jointly funding the Community Living Program and the "Veterans Directed Home and Community-Based Services Program." Through this program, veterans of all ages are being served to direct and purchase their long-term services and supports through the aging network. For its role, the aging network assesses the needs of veterans and caregivers; develops care plans; supports veterans through the provider selection process; arranges for Financial Management Services; and, most importantly, develops a professional relationship with the vet-

erans to ensure they receive the services as planned to meet their needs, and make changes where necessary.

The program began in February 2009 with funding for 20 States, ten of which provide VD–HCBS. To date 70 veterans are being served in Michigan and New Jersey and we are already beginning to see the results. In Michigan, for example, a 74 year old veteran living in an assisted living facility was referred to the newly established VD–HCBS program at the AAA. Because of that program, the veteran was able to move out of the facility and into his own apartment where he has hired a personal aide who works for him for 40 hours per week, providing the supports he needs to remain independent in the community. Staff report that he is doing well.

By building on the capacities and infrastructure of the aging network, the VA is already helping to ensure a coordinated and consumer-centered approach to serving the needs of veterans and their caregivers.

### **Conclusion**

It has often been said that caring for an older person is a family business. The same can be said for caring for a returning veteran. No one knows better how to care for someone than their loved one and those receiving the care are the better for it. Caring for the caregivers must be a national focus and a top priority as our Nation moves ahead.

As AoA and the VA move forward in their collaborative efforts to serve the complex needs of veterans and their caregivers, the aging network stands ready to put its years of experience honoring and serving older persons to work serving those brave men and women who have served our country so honorably.

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### **Prepared Statement of Noel Koch, Deputy Under Secretary of Defense, Office of Transition Policy and Care Coordination, U.S. Department of Defense**

Mr. Chairman, I am pleased to be with you today to discuss the efforts of the Department of Defense in support of our wounded, ill and injured service personnel, their families and the needs of family caregivers. The Department of Defense (DoD) and Department of Veterans Affairs (VA) continue to work together to address these needs through the partnership we formed 2 years ago with the establishment of the DoD/VA Senior Oversight Committee.

While all of our wounded, ill or injured servicemembers will eventually become veterans, some may be able to return to active duty following their recovery, and may choose to do so. In the meantime, their recovery may require the assistance of a family member as a full or part-time caregiver. These caregivers endure distinct losses of their own and have needs specific to their situation. DoD and VA are working on ways to alleviate those losses and assist with those needs.

The President's Commission on Care for America's Returning Wounded Warriors and the National Defense Authorization Act for 2008 (NDAA 2008) required our departments to provide a single point of contact for recovering servicemembers and their families, along with a recovery plan, to assist them along the continuum of care from recovery and rehabilitation, and from there either back to active duty or reintegration into civilian life.

The DoD Recovery Care Coordinator (RCC) and the DoD/VA Federal Recovery Care Coordinator (FRC) work with the recovering servicemember and his or her family to assess their needs and identify resources needed to support them. If the family caregiver requires additional support as a result of having to provide full-time care to the servicemember and is therefore precluded from earning an outside income, the RCC or FRC will assure that they are guided to the resources and benefits available to them.

A recovery plan is created in conjunction with the RCC or FRC, the servicemember, his or her family, and members of the clinical and non-clinical recovery team. The plan identifies goals, actionable steps to achieve the goals, and points of contact for each step toward reaching the goal. Effectively, the plan is a roadmap guiding the recovering servicemember and the family along the process or recovery, rehabilitation, and reintegration. It may include information to assist the family member serving as the primary caregiver in receiving compensation, financial assistance, job placement services, support with child care, counseling, respite services, and other benefits and services available from Federal, State, and local governments, as well as our non-profit partners.

In response to the NDAA 2008 requirement to improve policy on care management and transition of our recovering servicemembers, our DoD Instruction on the Recovery Coordination Program is in coordination and is slated for approval by 15 July 2009. This policy establishes uniform guidelines and procedures for our Military Service Wounded Warrior Programs and assigns responsibilities for implementation of the Recovery Coordination Program.

In addition to the Recovery Plan and the Recovery Care Coordinators, there are a number of other resources available to our recovering servicemembers and their families through a variety of Web sites and publications. These include, but are not limited to, the following:

**The National Resource Directory (NRD):** This is a successful tri-agency initiative comprising DoD, VA, and the Department of Labor. It is an online resource linking servicemembers, care providers and family caregivers to information on more than 11,000 Federal, State and local support services. The NRD facilitates searches by State, as different states provide different resources and benefits.

**The Family Handbook:** This DoD publication provides caregivers information about the recovery process, and includes such advice as why and how the caregivers themselves should attend to their own health and well-being as they go about helping their family member. It also shows them how to track information that is key to the recovery of the servicemember.

**The Compensation and Benefits Handbook:** This book includes a section dedicated exclusively to caregivers. It provides community options such as transportation services, respite care, financial assistance, and counseling resources.

**Military One Source:** A 24/7 year round call center and Web site for active duty Members and families.

Our Recovery Coordinators, recovery teams and providers, as well as our servicemembers and their families all make use of these offerings. A recent poll of our Recovery Coordinators and providers indicated over 90 percent utilization of these resources as they develop and execute their recovery plans.

The Center for Naval Analysis (CNA) has completed a study of family caregivers confirming that mothers and spouses on an average spend more than a year, and in severe cases, longer, providing physical and emotional support to recovering servicemembers. Based partly on the findings, DoD proposed legislation for 2010 which would provide special monthly compensation to catastrophically wounded servicemembers. The amount of the compensation, intended to be used to compensate designated family caregivers, would be based on the monthly income of a private sector home health care professional, and that would continue until the servicemember transitions through DoD and into the Department of Veterans Affairs.

As a result of NDAA 2008, DoD currently provides respite services to those caring for seriously ill or injured active duty servicemembers. Primary caregivers are given a reprieve from their responsibilities for up to 8 hours a day, 5 days a week.

In addition to this respite care benefit, there is a separate respite care provision provided under the Extended Care Health Option (ECHO), which provides a more limited break for caregivers. ECHO beneficiaries are eligible for a maximum of 16 hours of respite care in any calendar month in which they also receive ECHO-authorized benefits apart from the ECHO Home Health Care Benefit.

These programs notwithstanding, much remains to be done. As you know, there are several legislative proposals under consideration that further address the needs of family caregivers. Both DoD and VA are aware of the need for further research into how better to support our family caregivers, and this is under discussion in the Department.

Mr. Chairman, we are reminded daily of our obligation to our servicemembers and their families, and particularly to the wounded, ill and injured, and those who bear the greatest burden of caring for them. We are committed to providing the support they need to help ensure a successful transition through recovery and rehabilitation and back to active duty or reintegration into their communities.

We appreciate the opportunity to come before you today to discuss a subject which the Secretary of Defense has said repeatedly is a Departmental priority second only to the wars in which we are engaged. I will be happy to try to answer your questions.

Thank you.

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

Mr. Chairman and Members of the Subcommittee:

On behalf of the more than 1.3 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 by the Subcommittee on Health. We appreciate the opportunity to offer our views on meeting the needs of family caregivers of disabled veterans.

Informal caregivers play a critical role in facilitating recovery and maintaining the veteran's independence and quality of life while residing in their community, and are an important component in the delivery of health care by the Department of Veterans Affairs (VA). These family members, relatives, or friends are motivated by empathy and love, but the very touchstones that have defined their lives—careers, love relationships, friendships, and their own personal goals and dreams—have been sacrificed, and they face a daunting lifelong duty as caregivers. Research has found that all too often the role of informal caregiver exacts a tremendous toll on that caregiver's health and well-being. Family caregiving has been associated with increased levels of isolation, depression and anxiety, higher use of prescription medications, compromised immune function, poorer self-reported physical health, and increased mortality. Research also suggests that caregiver support services can help to reduce adverse health outcomes arising from caregiving responsibilities and can improve overall health status.

Despite these documented physical and psychological hardships and knowledge of effective interventions against caregiver burden, family caregivers of disabled veterans receive little support from VA, compromising their ability to provide care to their loved one. Accordingly, the delegates to our most recent National Convention, held in Las Vegas, Nevada, August 9–12, 2008, approved a resolution calling for legislation that would provide comprehensive supportive services, including but not limited to financial support, health and homemaker services, respite, education and training and other necessary relief, to immediate family member caregivers of veterans severely injured, wounded or ill from military service.

**Established VA Programs**

Based on existing statutory and regulatory provisions,<sup>1</sup> VA currently administers a number of services that support some informal caregivers. These programs are primarily within VA's long-term care program and include: adult day health care (ADHC); homemaker and home health aide (H/HHA); home-based primary care (HBPC); care coordination/home telehealth (CCHT); respite care; case management and coordination; transportation services; hospice; and general caregiver education and support services.

Such services are part of VA's goal to provide veterans care in the least restrictive settings. In doing so however, VA has not adequately addressed the concerns of this Subcommittee as well as those of the veteran community. VA has recently reported large year-to-year increases in long-term care activity, but VA's data conventions for reporting this workload, which assists VA's ability to manage this program's patient population, are problematic for the purposes of oversight and may misstate that activity.<sup>2</sup> We applaud VA leadership in reinforcing the elimination of local restrictions, which limit access to such services as a cost-saving measure; however, we continue to receive reports that service-connected disabled veterans and their family caregivers are not receiving the services they need through these alternative programs.

The DAV is aware of barriers that exist when veterans and their families attempt to access other VA services. A recurring theme from our Members includes the lack of knowledge about what services are available, significant variability in availability of services from one VA facility to the next; residing outside a VA facility's geographic service area, difficulty honoring the veteran's preferences to have family provide care rather than strangers, the lack of resources in rural areas; and, lack of flexibility in existing VA programs that do not fit the needs of the family caregiver.

For example, VA's HBPC is a group effort between the veteran, family, caregiver, VA, and community. The HBPC team, which generally consists of a physician, registered nurse, licensed practical nurse, dietician, occupational or physical therapist, and social worker, serves as a primary link between a VA medical center and veterans and their informal caregivers who could benefit from home visits. The goals

<sup>1</sup> 38 U.S.C. §§ 1782(a), 1782(b), 1712A(b); 38 C.F.R. § 17.38.

<sup>2</sup> GAO-09-145 (<http://www.gao.gov/new.items/d09145.pdf>).

of the HBPC team are to assist veterans and their family caregivers to limit the effects of chronic illness and maintain or restore them to the highest level of health and well-being so they may remain at home for as long as possible. Once it is determined that a veteran qualifies for the HBPC program, the HBPC team provides skilled nursing care, patient education, limited rehabilitation, nutritional counseling, social services, caregiver support, medication management education, and wound care. However, HBPC services are provided to veterans in a limited geographic area that is in close proximity to a VA medical center, a VA outpatient clinic, or a satellite office. Moreover, if a service is not provided by the HBPC team, a referral may be made to other community resources such as mobile meals, homemaker services, or community home care agencies. Again, such community resources are limited in rural and highly rural areas where nearly three million veterans (40 percent) of VA's enrolled veteran population resides.

For VA's respite care benefit, a significant majority of veterans do not avail themselves of such services due to lack of knowledge of such a benefit or the services are simply not available in that community. The majority of in-home respite care is purchased by VA from community agencies that may not provide weekend or overnight respite services. Furthermore, trust and privacy remain significant barriers when an individual who is to provide in-home respite, homemaker and home health programs, is perceived as a stranger. For VA's homemaker/home health aide program, low utilization can be attributed to the limited hours of services made available by a VA facility to each veteran and family. There is also low utilization of VA's ADHC benefit due to limited availability in the community as well as the lack of age-appropriate settings in some cases. Other barriers to access include limited flexibility in VA policy for lodging and transportation (including special modes of transportation) for disabled veterans who require the assistance of their caregivers when traveling to and from VA appointments, and unmet demand for assistance with instrumental activities of daily living (IADLs) and supplementary services. Similar barriers also exist in accessing caregiver support in an individual or group setting.

In situations where a veteran will require long-term or lifetime care or assistance in the requirements of daily living, VA indicated it provides counseling and training to family members and other caregivers who are capable and willing to take on this responsibility. VA has pointed out that training for family members is addressed when it is clinically necessary and appropriate through local arrangements with community home health care agencies and providers that train the family member, and, if hired, supervise the care they give to the veteran. Such an arrangement puts these agencies in the position of being responsible for assuming the liability coverage of the family caregiver and ensuring that the quality of the care veterans receive meets the standards that are required. Unfortunately, to our knowledge VA has not provided Congress or the veteran community data to describe the breadth and depth of these arrangements. It is our understanding these arrangements are passive by nature where a veteran or the informal caregiver must self-identify as wanting to be trained, certified, and paid before VA will refer them to the local community agency.

Furthermore, there is no guarantee under these arrangements that the family caregiver will be employed, and if hired, the agency may require the veteran's family caregiver to provide caregiver services to other veterans or civilian clients. There is no assurance that as an employee of a community agency, family caregivers will receive the specialized training to care for polytrauma and other combat-related disabilities. Equally important, we question whether caregiver support services will be provided as an employee in a workforce that is known to have high worker turnover.<sup>3</sup> Without sufficient information to address these basic concerns, the DAV is wary about this course of action by VA to provide training for family caregivers of severely disabled veterans.

Mr. Chairman, when we think of long-term care, we generally assume it is reserved for the oldest veterans, near the end of life. Today, however, we confront a new population of veterans with different demographics, a different culture, expectations, and need specialized forms of long-term care—a population that will need comfort and care for decades. As part of VA's medical care benefits package, the Department's long-term care program was created primarily to meet the needs of *aging* veterans, not the newest generation and the needs of their family caregiver. The DAV is greatly concerned that VA's long-term care program, which has failed to keep pace with innovative trends outside the Department in caring for aging veterans, appears poised to do so with this new population of younger severely disabled

<sup>3</sup>Institute of Medicine, "Retooling for an Aging America: Building the Health Care Workforce." 2008.

veterans and their family caregivers who are increasingly being treated as incidental to, rather than as a key Member of, VA's interdisciplinary treatment team and patient-centered care.

We acknowledge health care is population based and VA services are driven by the needs of the population it serves. As this Subcommittee is aware, for fiscal year (FY) 2010, VA expects to treat nearly 6.1 million patients, of whom 419,256, or 7 percent, are Operations Enduring and Iraqi Freedom (OEF/OIF) veterans. Some of them suffer severe polytraumatic injuries and traumatic brain injuries (TBI) as a consequence of combat in Iraq and Afghanistan. Most of the severely injured OEF/OIF veterans will be able to return to their families or will be moved to an appropriate therapeutic residential care setting—but with the expectation that family members will serve as lifelong caregivers and personal attendants to help them adjust and make up for the dramatic loss of physical, mental, and/or emotional capacities as a result of their war injuries.

Although they share similar challenges with family caregivers of aging veterans with chronic disabilities and acute care needs, immediate families of severely injured OEF/OIF veterans face other daunting challenges. The spouse of a severely injured veteran is likely to be young, have dependent children, and reside in a rural area where access to support services of any kind can be limited. They are also more likely to be dependent on State programs and Medicaid, with great variability from State to State.<sup>4</sup> Complicating matters is the increasing number of the severely injured are from reserve components (primarily Army and Marine) and National Guard units. It is likely that the families of these troops have never lived on military bases and do not have access to the available social support services and networks connected with active duty military life. Spouses of the injured often must give up their own employment and employment benefits (or withdraw from school in many cases) to care for, attend to, and advocate for their injured veterans. They often fall victim to bureaucratic mishaps in the shifting responsibility of conflicting government pay and compensation systems (military pay, military disability pay, military retirement pay, VA compensation). Also, they rely on this much-needed subsistence in the absence of other personal income in an era when two-income families are the norm.

In discussion with VA officials, including facility executives and clinicians who are caring for some of these injured veterans, it has become apparent to DAV and others in our community that VA still needs to adapt its existing long-term care programs to better meet the individualized needs of a truly special and unique population. We believe VA's existing programs will not be satisfactory or sufficient in the long run. In that regard, VA needs to address barriers to existing programs that support family caregivers. VA must also have a clear and measurable plan to establish a menu of age-appropriate services tailored to meet the different needs of this new patient population as well as the aging veteran population and their family caregivers. These services must be available and provided when and where they are needed. While the numbers of veterans sustaining these catastrophic injuries are small, their needs are extraordinary and will need to be met over a much longer timeline. While today they are under the close supervision of the Department of Defense and its health agencies, their family members, and VA, as years go by, VA will become a more crucial part of their care and social support system, and in many cases may need to provide for their permanent living arrangements in an age-appropriate therapeutic environment.

### VA Initiatives

There are a series of ongoing initiatives listed below that may have a positive impact on VA's policies and programs for caregiver support; however, the DAV is concerned about the incremental and fragmented approach to this issue. We are hopeful that with this Subcommittee's commitment to strong oversight, a more focused effort will yield a thoughtful synthesis to address the pressing need for a robust caregiver support program.

**Caregiver Assistance:** The more widely recognized initiative VA has undertaken that reflects the Department's commitment to providing family caregivers the sup-

<sup>4</sup>United States Agency for Health care Research and Quality, 2007 National Health care Quality & Disparities Reports, Rockville, MD, 2008. Also, Jim Garamone, U.S. Military Recruiting Demographics," American Forces Press Service, November 23, 2005; David S. Riggs, "Difficulties in Family Reintegration Following Military Deployments," *Healing the Scars of War* (New York: Institute for Disaster Mental Health, 11 Apr. 2008); U.S. Department of Defense, Population Representation in the Military Services. (Washington: Office of the Under Secretary of Defense, Personnel and Readiness, 2006) ([www.defenselink.mil/prhome/PopRep\\_FY06](http://www.defenselink.mil/prhome/PopRep_FY06)).

port and services they need is the December 2007 announcement that it would provide nearly \$4.7 million for caregiver assistance pilot programs.<sup>5</sup> These pilot programs are to expand and improve health care education and provide needed training and resources for caregivers who assist disabled and aging veterans in their homes. Oversight and assessment for adoption into existing VA programs of these eight pilot programs are the responsibility of the VA interdisciplinary Caregiver Advisory Board (CAB). Also, the CAB is to identify system-wide core caregiver needs, develop initial recommendations for VA caregiver support services; and develop a national VA caregiver assistance program. As these pilot programs sunset at the end of this fiscal year, we look forward to early adoption of services that have been found effective, and we are hopeful the CAB report will provide useful information that may guide and shape VA's caregiver support services.

**VA Advisory Committee on OEF/OIF Veterans and Families:** In April 2007, VA established this 17-person Committee which is responsible for reviewing VA services and benefits, advising the VA Secretary on health care, benefits, and family support issues, and making recommendations for tailoring VA services and benefits to meet the needs of OEF/OIF veterans and their families. The DAV appreciates the insight and advocacy of the Committee's interim report. We look forward to its final report and recommendations on issues affecting families, including dependents and survivors.

**Brain Injury Family Caregiver Panel:** Pursuant to section 744(a)(2) of P.L. 109-364, the Veterans Traumatic Brain Injury Family Caregiver Panel was established in 2007. The 15-member panel was created by the DoD to operate under a Defense Health Board as a Subcommittee to advise and specifically provide DoD and VA with independent advice and recommendations on the development of training curricula to be utilized by the above mentioned family members on techniques, strategies, and skills for care and assistance for such individuals with TBI. The panel was convened on several occasions, to include a recent townhall meeting to discuss matters related to the development of this curriculum and to hear from the public about the issue.

**Assisted Living:** We are encouraged by VA's shift in its position to seek authority from Congress to provide assisted living. Then-VA Secretary Principi's transmittal letter conveyed with the 1999 Assisted Living Pilot Program (ALPP) report to Congress stated that VA was not seeking authority to provide assisted living services, believing this is primarily a housing function. In its most recent budget request, VA acknowledges that the findings<sup>6</sup> should be useful both in VA and nationwide in guiding the growth and development of assisted living programs and in designing an optimal system of residential care services for disabled veterans. Although it is not clear what this new posture is based on or if VA will seek legislative authority, the DAV applauds Congress for passing P.L. 110-181, the FY 2008 National Defense Authorization Act, which requires VA, in collaboration with the Defense and Veterans Brain Injury Center of the Department of Defense, to conduct a 5-year ALPP with special consideration for veterans residing in rural areas and veterans suffering from TBI.

**Volunteer Respite:** In February 2008, VA began working on establishing twelve pilot sites for the OEF/OIF Caregiver Support Program Initiative, in which the VA Voluntary Service recruits and trains volunteers to provide a few hours of respite care a week for family caregivers of veterans who live in their community. This promising new initiative provides in-home and casual respite in a preferred setting by age-appropriate volunteers in areas where such services is not available, particularly in more rural areas.

**Homeless:** VA intends on using the authority mandated in P.L. 110-387, the Veterans' Mental Health and Other Care Improvements Act of 2008, and authority provided in other legislation to establish pilot programs with community-based non-profit and cooperating agencies to provide supportive services specifically designed to prevent homelessness. These pilots will also be coordinated with programs of other relevant agencies to encompass both rural and urban sites with the goal of preventing homelessness and maintaining housing stability for the veteran's family.

**Mental Health:** Vet Centers, operated by VA's Readjustment Counseling Service, provide nonmedical readjustment counseling that includes individual and group counseling, marital and family counseling for military-related issues, bereavement counseling, military sexual trauma counseling and referral, community outreach

<sup>5</sup>(1) Memphis (Tenn.) and Palo Alto (Calif.) VA medical centers; (2) Gainesville (Fla.) VAMC; (3) VA Health care System of Ohio; (4) VA Desert Pacific Network and the VA Sierra Nevada Health care System; (5) Albany (N.Y.) VAMC; (6) Atlanta (Ga.) VAMC; (7) Tampa (Fla.) VAMC and Miami VA Health care System; (8) VA Pacific Islands Health Care System.

<sup>6</sup>*The Gerontologist*. 47 (3), 365-377.

and education, substance abuse assessments, medical referral, assistance with VA benefits, employment counseling, guidance and referral and information and referral to community resources. This includes psychological counseling for traumatic military-related experiences and family counseling when needed for the veteran's readjustment. VA has established teams in approximately 100 facilities to address the mental health needs of returning veterans. These teams work with Vet Centers to conduct outreach in the community and "in-reach" to facilitate identifying mental health conditions in primary care, educating veterans and family members about mental health conditions, and providing services in an environment specific to new veterans.

**Hospice and Bereavement:** VA researchers have developed a new VA palliative care quality measure that currently is being tested nationwide. Using telephone interviews of family members of veterans who had received hospice care from a VA facility, the FATE (Family Assessment of Treatment at End of Life) survey was created to identify aspects of end-of-life care in the VA system not otherwise assessed and also identifies issues unique to veterans. Such a system-wide strategy to assess the quality of end-of-life care for veterans will allow VA to define and compare the quality of end-of-life care at each facility and to identify opportunities for improvement at the facility and regional levels. This will help VA identify and disseminate successful processes and structures of care throughout VA that will honor the preferences of the veteran and family.

**Department of Health and Human Services (HHS):** In September 2008, HHS announced it would provide VA with over \$19 million to provide consumer-directed home and community-based services to veterans regardless of age (designed to reach people who are not eligible for Medicaid). Administered by HHS' Administration on Aging (AoA) in collaboration with the Veterans Health Administration (VHA), \$10.5 million is being provided by HHS through AoA, and \$5.7 million by the states. VA estimates purchasing at least \$3 million in veteran-directed home and community-based services across 10 states<sup>7</sup> for older veterans and for recently returned veterans with long-term care needs to divert those at risk from nursing home placement. The program features a consumer directed model of care by providing veterans more control over their long-term care, including the ability to determine the types of services they receive and the manner in which they receive them, including the option of hiring their own care workers.

### Overarching Concerns

**Eligibility for VA Caregiver Support:** To its credit, VA has acknowledged<sup>8</sup> that the Department needs to provide more support to family caregivers caring for veterans. While the DAV is hopeful these initiatives will be used to create system changes within VA to meet the needs of informal caregivers, VA's institutionalized perspective that the informal caregiver is incidental to the lifelong care of a severely disabled veteran remains one of our chief concerns. Under current law, 38 United States Code § 1782, VA provides counseling, training, and mental health services to members of the veteran's immediate family, the veteran's legal guardian, and to the individual whose household the veteran certifies as intention to live. In accordance with this law, these services are only provided for: 1) veterans receiving treatment for a service-connected disability if the services are necessary in connection with that treatment, and 2) veterans receiving treatment for other than a service-connected disability if the services are necessary in connection with the treatment, the services were initiated during the veteran's hospitalization, and the continued provision of the services on an outpatient basis is essential to permit the discharge of the veteran from the hospital. Services covered under this authority are certainly part of the support services family caregivers need, but fall far short of a comprehensive package the DAV believes would be sufficient. Moreover, VA's current authority is silent on providing prolonged support services for family caregivers beyond acute or sub-acute treatment and rehabilitation of the veteran.

We believe there are significant gaps in VA's existing medical benefits package, and clarity is needed in VA's priority and responsibility to provide the support necessary that would allow family caregivers of severely disabled veterans to remain in their vital role. The DAV understands caregiver support services falls under VA's long-term care program; however, we urge Congress to address the unequal eligibility for long-term services that impacts eligibility of family caregivers for services,

<sup>7</sup>Arkansas, Connecticut, Florida, Massachusetts, Michigan, New Jersey, New York, Texas, Virginia, and Washington.

<sup>8</sup>U.S. Senate Committee on Veterans' Affairs hearing, "Pending Health-Related Legislation," April 22, 2009.

and for VA to abandon its one-size-fits-all approach in long-term care which is not patient centric, and limits the use of and access to such care.

**Caregiving is a Public Health Concern:** There is also a growing movement in the United States to address the needs of informal caregivers as a public health concern by looking at population-based public health outcomes of caregivers to promote healthy living rather than life without disease.

The Institute of Medicine designates the general functions of public health as assessment, policy, and assurance. Having a solid evidence base is necessary to inform policies, programs, and interventions. The National Long Term Care Survey (NLTCS) is funded through a Cooperative Agreement (2 U01 AG0007198) between the National Institute on Aging (NIA) and Duke University. It is a longitudinal survey designed to study changes in the health and functional status of older Americans (aged 65+). It also tracks health expenditures, Medicare service use, and the availability of personal, family, and community resources for caregiving. A supplementary caregiver survey was added to obtain information on the health and functional status of people who take care of the 65 and older population in a home environment.

The NLTCS in combination with the caregiver supplement to the NLTCS can be used to examine such things as how many hours of help they provide with ADLs and IADLs for chronically disabled elders receive weekly, and what number and percentage of those hours are provided by informal caregivers. It can also be further broken down by primary and secondary caregivers and by relationship, (e.g., spouse, son, daughter, friend, etc.) as compared to paid workers. This enables policy researchers to measure the time burden of providing informal care on caregivers (especially primary caregivers) in relation to the severity of disability and other care recipient characteristics. The relationship between weekly time burden of informal care and self-reported indicators of caregiver stress can then be analyzed. Further analyses could be carried out with respect to relationships among time burden of informal care, self-reported caregiver stress, use/non-use of formal services, and funding sources for formal services (public/private). Finally, the NLTCS/ICS contains numerous questions regarding the primary informal caregiver's perception of the need or lack of formal services and the reason why these services are not being used if they are perceived as needed (e.g., lack of affordability, lack of local availability, etc.). This enables policymakers to estimate (using various different criteria) the potential size and characteristics of the target population for public policy interventions to assist caregivers. As part of the *Independent Budget* (IB), the DAV believes VA should conduct a baseline national survey of caregivers of veterans. Considering the demographics of the enrolled and user population of the VA health care system, attention to caregivers has with reason been drawn to the needs of the aging veteran, but that group represents only one segment—although a large one—of those who receive and provide care; however, the survey should include a special emphasis on caregivers of OEF/OIF veterans. In addition, since caregiving is a life-span experience, this survey should be conducted in regular intervals.

Because health outcomes and quality of life of veterans with severe injuries and chronic disability also affect the family, a patient and family centered perspective is essential for quality improvement in redesigning long-term care. We believe policy makers must view family caregivers of severely injured servicemembers as a resource rather than as an unrecognized cost-avoidance tool. In programs where caregivers are assessed, they can be acknowledged and valued by practitioners as part of the health care team. Caregiver assessment can identify family members most at risk for health and mental health effects and determine if she or he is eligible for additional support. Effectively supporting caregivers can result in delayed placement of more costly nursing home care.<sup>9</sup>

Assessment is a critical step in determining appropriate support services. Caregiver assessment is a systematic process of gathering information to describe a caregiving situation. It identifies the particular problems, needs, resources, and strengths of the family caregiver and approaches issues from the caregiver's perspective and culture to help the caregiver maintain his or her health and well-being.<sup>10</sup>

The National Consensus Development Conference for Caregiver Assessment brought together widely recognized leaders in health and long-term care, with a variety of perspectives and expertise, to advance policy and practice on behalf of family and informal caregivers. The Family Caregiver Alliance's (FCA) National Center

<sup>9</sup>Mittelman, M. S., et al. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *JAMA* 276(21), 1725–1731.

<sup>10</sup>*Journal of Social Work Education*, Vol. 44, No. 3 (Fall 2008); Supplement. *American Journal of Nursing* 108(9), 38–39 (2008).

on Caregiving designed and convened this conference, held September 7–9, 2005, in San Francisco. The conference generated a report<sup>11</sup> on the fundamental principles and guidelines to advance caregiver assessment nationally and in each State, and to serve as a catalyst for change at Federal, State and local levels. As part of the IB, the DAV believes VA should conduct caregiver assessments that meet the principles outlined in the conference report. Furthermore, such assessments should be readily available to researchers for evaluation and analysis to guide VA policy and programs.

### **Conclusion**

The DAV is concerned that in the immediate and foreseeable future, caregiving support services will likely continue to be developed and provided in piecemeal fashion hampered by existing barriers without Congressional action. Such an approach carries inherent risk and pitfalls against which severely injured veterans and their family caregivers must unfairly struggle. In a May 9, 2007, hearing before this Subcommittee on the State of VA's long-term care program, we testified that the present State of that program is now lagging behind its rich history as an early leader in caring for aging veterans and their caregivers, and is in danger of falling behind non-VA health care systems.<sup>12</sup> There is a striking contrast when comparing VA's current caregiver support to existing national policies designed to support caregivers such as the AoA Alzheimer's Disease Demonstration Grants to States (ADDGS) program, the Family and Medical Leave Act, and the Cash and Counseling (consumer directed care) program. We applaud AoA for granting \$19 million to VA to provide health care consumer direction in choosing their home and community-based services, which we hope is a symbol of a progressive movement in VA's long-term care program. In this vein, we urge VA and Congress to address the barriers outlined in this testimony. We also recommend VA adopt a more robust and statistically valid survey such as the NTLCS than that it has used in the past to guide the creation and assess the effectiveness of a standardized and comprehensive package of support services for caregivers.

Mr. Chairman, in the absence of family caregivers, an even greater burden of direct care would fall to VA at significantly higher cost to the government and reduced quality of life for these veterans who have sacrificed so much. If VA is to continue to provide care to veterans in the least restrictive settings, it must improve current services and adopt new effective evidence-based interventions to ensure family caregivers do not remain untrained, unpaid, unappreciated, undervalued, and exhausted by their duties.

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<sup>11</sup> Family Caregiver Alliance. Caregiver assessment: principles, guidelines and strategies for change. Report from a national consensus development conference. Volume I. San Francisco (CA): Family Caregiver Alliance; 2006 Apr. 43 p. Retrieval from: [http://www.caregiver.org/caregiver/jsp/content/pdfs/v1\\_consensus.pdf](http://www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf).

<sup>12</sup> <http://www.veterans.house.gov/hearings/hearing.aspx?NewsID=24>.

**POST-HEARING QUESTIONS AND RESPONSES FOR THE RECORD**

Committee on Veterans' Affairs  
 Subcommittee on Health  
 Washington, DC.  
 June 10, 2009

Honorable Eric K. Shinseki  
 Secretary  
 U.S. Department of Veterans Affairs  
 810 Vermont Avenue, NW  
 Washington, DC 20240

Dear Secretary Shinseki:

Thank you for the testimony of Dr. Madhulika Agarwal, Chief Patient Care Services Officer of the Veterans Health Administration at the U.S. House of Representatives Committee on Veterans' Affairs Subcommittee on Health Oversight Hearing on "Meeting the Needs of Family Caregivers of Veterans" that took place on June 4, 2009.

Please provide answers to the following questions by July 22, 2009, to Jeff Burdette, Legislative Assistant to the Subcommittee on Health.

1. What is the VA's response to testimony provided by Jill Kagan on the administrative barriers to veterans and their family caregivers accessing respite care? I would also like the VA to provide a written summary of the copayment policy for the range of respite care provided by the VA and the rationale for this copayment policy. In addition, please share the total copayment amount collected in each of FY 2003 to FY 2008
2. Dr. Agarwal's testimony states that temporary lodging for caregiver accompanying a veteran to a VA health care facility is provided on a first-come first-serve basis and that the VA Fisher house program served 5,949 families in 2008. Does VA track how many caregivers who would like to utilize this service are turned away due to demand?
3. The eight caregiver pilot programs mentioned in Dr. Agarwal's testimony will conclude this fall and VA will review the effectiveness of these programs. What is VA's timetable for determining whether these programs were effective and deserving of broader implementation?
4. In Dr. Agarwal's testimony, she stated that respite care services are planned in advance. How far in advance must the caregiver arrange for the provision of respite care? What options does VA offer a caregiver in need of immediate service?
5. Please elaborate on the new medical foster program. How does VA reach out to communities to identify participants? To this point, has VA been successful in finding volunteers for the program?
6. Please outline the relationship between the Department of Defense's Recovery Care Coordinators and VA's Federal Recovery Coordinators. How do they work together to ensure a seamless transition from DoD to VA for the servicemember and their caregiver?

Thank you again for taking the time to answer these questions. The Committee looks forward to receiving your answers by July 22, 2009.

Sincerely,

MICHAEL H. MICHAUD  
*Chairman*

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**Questions for the Record Hon. Michael H. Michaud, Chairman,  
 Subcommittee on Health, House Committee on Veterans' Affairs,  
 June 4, 2009, Meeting the Needs of Family Caregivers of Veterans**

**Question 1:** What is VA's response to testimony provided by Jill Kagan on the administrative barriers to Veterans and their family caregivers accessing respite care? I would also like VA to provide a written summary of the copayment policy for the range of respite care provided by VA and the rationale for this copayment policy. In addition, please share the total copayment amount collected in each year of FY 2003 to FY 2008.

**Response:** Ms. Kagan provided a useful review of barriers to respite care in the Department of Veterans Affairs (VA) and community sectors. VA agrees that addi-



tional steps need to be taken to enhance the Department's respite care program, particularly in home and community based care (H&CBC) settings. VA is studying a number of policy changes that will reduce the barriers to H&CBC respite services, including greater collaboration with the administration on Aging's National Respite Care Program. These changes will be reflected in a new policy handbook specifically addressing respite care at home and in the community to be published this fiscal year.

Co-payments for extended care services, including respite care, are mandated by 38 USC 1710B. Veterans are exempt from extended care copayments for compensable service-connected care. All other Veterans with incomes greater than the maximum VA pension rate for a single Veteran are liable for a copayment. Co-payments for extended care services are outlined at 38 CFR 17.111. The institutional respite care copayment is a maximum of \$97.00 per day. This is a sliding scale copayment, based on income, assets, dependents and allowable expenses. The \$97.00 maximum is the same as the nursing home copayment maximum, and is appropriate since most institutional respite care is provided in nursing home beds. The \$97.00 amount reflects the Medicare copayment level for nursing home care in 2003, which is still the current rate.

The copayment amount for H&CBC or non-institutional respite care is \$15.00 per day. Veterans are also exempt from this copayment for compensable service-connected care. The \$15.00 amount reflects the co-payment amount for basic outpatient visits. VA recognizes that State respite care programs have voluntary copayment structures.

The data below displays total respite care collections, by setting, for fiscal year (FY) 2006—FY 2008:

*Respite Care Collections:*

*FY 2006*

Institutional Care: \$32,464.00

Non-Institutional Care: \$384.00

*FY 2007*

Institutional Care: \$65,347.00

Non-Institutional Care: \$898.00

*FY 2008*

Institutional Care: \$65,309.00

Non-Institutional Care: \$6,495.00\*

\*Note: Increase reflects growth in average census (118 in FY 2006 to 417 in FY 2008) and expanded co-pay collections efforts.

**Question 2:** Dr. Agarwal's testimony states that temporary lodging for a caregiver accompanying a Veteran to a VA health care facility is provided on a first-come, first-serve basis and that the VA Fisher House program served 5,949 families in 2008. Does VA track how many caregivers would like to utilize this service are turned away due to demand?

**Response:** Caregivers and families who cannot be accommodated in a Fisher House are referred for accommodations in the community at no cost to them or at a discount cost. VA tracks the number of caregivers and families referred for accommodations in the community on a monthly basis. In FY 2008, 3,078 families were referred for accommodations in the community. VA continues to explore options for these services and is pleased that the Fisher House Foundation is now building larger 20 bedroom homes to accommodate more families. In addition to the existing 13 VA Fisher Houses, seven others are under construction with expected completion dates in 2010.

**Question 3:** The eight caregiver pilot programs mentioned in Dr. Agarwal's testimony will conclude this fall and VA will review the effectiveness of these programs. What is VA's timetable for determining whether these programs were effective and deserving of broader implementation?

**Response:** VHA's Patient Care Services Caregiver Advisory Board (PCSCAB) will review the effectiveness of the eight caregiver pilot programs and determine whether these programs should be expanded for the first quarter of 2010. The PCSCAB is expected to complete its review of these programs and make recommendations by November 30, 2009. VA will prepare a final report of the caregiver pilot programs and submit it to Congress by December 31, 2009.

**Question 4:** In Dr. Argarwal's testimony, she stated that respite care services are planned in advance. How far in advance must the caregiver arrange for the provision of respite care? What options does VA offer a caregiver in need of immediate service?

**Response:** Respite care services in VA's community living centers (CLC) are generally scheduled 30 to 90 days in advance to allow staff to assess patient needs, assure funding and services are available. CLC-based respite care programs also have flexibility to address urgent or emergency respite-care needs. In addition, most VA medical centers offer immediate respite services in home, community-based settings and in community nursing homes.

**Question 5:** Please elaborate on the new medical foster program. How does VA reach out to communities to identify participants? To this point, has VA been successful in finding volunteers for the program?

**Response:** The medical foster home (MFH) expansion initiative, Support at Home—Where Heroes Meet Angels, began through supplemental funding provided to 33 sites in May 2008. MFH creates an alternative to nursing home for long-term care. MFH is a unique partnership of adult foster home and a VA interdisciplinary home care team providing long-term care in a personal home for Veterans who meet a nursing home level of care.

As of May 31, 2009, VA has 22 operational sites identifying Veterans who are appropriate for and interested in MFH, and is finding suitable caregivers and homes. VA has placed 487 Veterans in MFHs since the program began in 2000 as a pilot in Little Rock, Arkansas.

VA seeks and identifies MFH caregivers in the communities. The MFH caregivers open their homes to Veterans voluntarily; they do receive compensation from the Veteran for room, board, and daily supervision and personal assistance they provide to the Veteran. VA reaches out to the communities to identify able and dedicated caregivers through a variety of mechanisms, including discussing the program with Veteran's organizations and the community. VA also uses local media outlets including community newspapers and television. Other referrals may come from the individuals themselves or from other VA and non-VA personnel.

**Question 6:** Please outline the relationship between the Department of Defense's Recovery Care Coordinators (RCC) and VA's Federal Recovery Coordinators (FRC). How do they work together to ensure a seamless transition from DoD to VA for the servicemembers and their caregiver?

**Response:** Both programs provide care coordination for qualifying servicemembers and Veterans. Recovery care coordination (RCC) is a Department of Defense (DoD) program with oversight residing in the Transition Policy and Care Coordination Office. It works with servicemembers who:

- Have a serious injury or illness;
- Are unlikely to return to duty within a time specified by each servicemember's Military Department; and
- May be medically separated from the military.

The Federal Recovery Coordination program (FRCP) is a joint program of the DoD and VA with its administrative home at VA. It is designed to provide oversight and coordination for those servicemembers who:

- Have a severe/catastrophic injury or illness;
- Are highly unlikely to return to duty; and
- Will most likely be medically separated from the military.

Both programs develop customized recovery plans; FRCP uses the Federal individual recovery plan (FIRP), and RCC uses the comprehensive recovery plan (CRP). The recovery plans are based on the servicemember or Veterans goals, with input from their family or caregiver, and Members of the multidisciplinary team. These plans monitor and track the services, benefits and resources needed to accomplish the identified goals. The number and types of goals relate to the individual's medical problems, the stage of recovery, and the holistic needs of the client and family. The recovery coordinators work across all agencies with a variety of case managers, providers, and other individuals to make sure the goals are reached.

FRCs and RCCs are frequently co-located at military treatment facilities. They work together to ensure the right benefits and care are provided at the right time for servicemembers and Veterans enrolled in the programs. Both Departments will continue to work together to ensure that the needs of our servicemembers and Veterans are met in a timely, effective and compassionate manner.

