Madame Chairwoman and Members of the Subcommittee:

On behalf of the more than 1.2 million members of the Disabled American Veterans (DAV) and its Auxiliary, thank you for inviting our organization to submit testimony for this important oversight hearing. We appreciate the opportunity to offer our views on the Department of Veterans Affairs (VA) implementation plan for the caregiver assistance program and whether it meets Congressional intent embodied in Title I of Public Law (P.L.) 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010.

As this Committee is aware, Title I, which was enacted on May 5, 2010, contains reporting requirements for VA with prescribed timelines to include the following:

1. Not later than 180 days after the date of enactment (November 1, 2010), VA was required to submit a report to the House and Senate Veterans Affairs’ Committees an implementation plan for subsection 1720G(a)(1), as amended by the Act.¹

2. Within 270 days of enactment (January 30, 2011), VA was required to initiate the programs required by (a) and (b) of section 1720G of Title 38, United States Code, as amended.²

3. Not later than two years after the effective date (January 30, 2013), two reports must be submitted to the House and Senate Veterans Affairs’ Committees:
   a. A comprehensive annual evaluation on implementation;³
   b. A report on the feasibility and advisability of expanding the provision of caregiver assistance under section 1720G(a) of title 38, United States Code, to caregivers of veterans seriously injured in the line of duty prior to September 11, 2001.⁴

Unfortunately, VA did not meet timeliness requirements for either submission of an implementation plan or the commencement of assistance and support services for caregivers. The

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¹ P.L. 111-163, Section 101(b)
² P.L. 111-163, Section 101(a)(3)
³ P.L. 111-163, Section 101(c)
⁴ P.L. 111-163, Section 101(d)
annual evaluation report and the report on expansion of caregiver assistance, however, can be submitted at any time prior to January 30, 2013.

While the caregiver assistance program’s date of prescribed implementation could be viewed by some as optimistic, caregivers of severely disabled veterans largely view this timeline as appropriate considering how long they have willingly cared for their loved ones with little to no relief from VA.

On February 28, 2011, VA submitted to the Office of Management and Budget an Interim Final Rule (IFR) to speed the federal rulemaking process to implement, not all, but certain provisions of P.L. 111-163 by early this summer. Madame Chairwoman, the natural tendency for federal agencies in rulemaking is to be close-minded and defensive once they have made a “final” rule determination. Although VA considers the IFR as a good start and has indicated it is open to suggestions as to the scope of the benefit to be provided, DAV is cautiously optimistic the Department will adjust accordingly to Congress’ intent, in light of its initial interpretation contained in the VA’s implementation plan, and the broad concerns raised by that plan.

In this matter, we urge this Subcommittee to ensure that VA exhibits the required good faith and seriously considers post-promulgation comments from the public, including the concerns of our community. Congressional oversight is critical in this particular instance to ensure the IFR is not perceived as and is not allowed to become, an autocratic action.

Before addressing our organization’s evaluation of VA’s implementation plan, DAV wishes to highlight four items that best describe the wide gulf that exists between the intent of Congress and VA in this program.

Assuming VA’s budget request for Sections 101 through 104 of P.L. 111-163 is based on the cost of its caregiver implementation plan, VA requests $65.9 million for Fiscal Year (FY) 2012 and $70.6 million for FY2013. Even by any reasonable estimation of growth in VA’s version of the caregiver assistance program, this funding request falls well short of Congress’ authorized appropriation of $60 million for the first year and $1.542 billion for the subsequent five years. In addition, VA also recently testified the implementation plan would serve only 840 caregivers as opposed to the 3,500 caregivers Congress intended to cover with this legislation.

DAV is concerned that in its zeal, VA has developed a plan that may well abandon most of those caregivers the law was intended to aid and support.

**Eligibility:**

P.L. 111-163 prescribes eligibility criteria that a veteran or servicemember must meet in before support and services can be provided to primary caregivers (their supporting family caregivers) and general caregivers under §1720G. The criteria also provides VA the authority to

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5 United States Senate Committee on Veterans' Affairs, Hearing on the President's Budget, March 2, 2011.
6 Congressional Record, page S2567
consider, “such other matters as the [Department] considers appropriate,” in making eligibility determinations. 7

We believe this last criterion was intended by Congress to give VA the flexibility to act responsibly by ensuring caregivers and veterans who would benefit from this program but are not otherwise considered in the prescribed eligibility criteria, would still be made eligible for primary and family caregiver assistance. However, it appears the Department has ignored this authority took a strict interpretation of the intent of the law—to avoid institutional care placements—to develop and propose a complex and restrictive eligibility criteria that will serve to deny these benefits to thousands of service-disabled veterans.

In its implementation plan, VA indicates a veteran must meet P.L. 111-163 eligibility criteria and all items in the following conditions to be eligible for Primary Caregiver benefits: 8,9

1. Require continuing medical management or be at high risk for personal safety and cannot live independently in the community without caregiver support.
2. Without caregiver support providing personal care services at home in an ongoing manner, would require hospitalization, nursing home, or other institutional care.
3. Require at a minimum six months of continuous and approved caregiver support. 10
4. Receive care at home once caregiver training is complete.
5. Receive ongoing care from a VA Patient Aligned Care Team (PACT) or other VA health care team due to VA’s responsibility, as outlined in the statute, to monitor the well-being of each eligible Veteran receiving personal care services under the program.
6. Services provided by the primary family caregiver will not be simultaneously provided by another entity.

If the veteran or service member is undergoing military medical discharge, an additional criterion must be met:


DAV appreciates VA’s desires for a clear and consistent clinical guideline for VA personnel to apply. Such a guideline could ensure equity in light of the various injuries veterans have sustained from the wars in Iraq and Afghanistan and the subjective nature of eligibility determinations. However, the eligibility criteria outlined in P.L. 111-163 can be considered open to misinterpretation or misapplication. We believe the language in VA’s proposed criteria contains

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7 38 U.S.C. § 1720G(a)(2)(C)(iii) and (b)(2)(C)
9 Additional criteria for veterans/servicemember undergoing military medical discharge: “Meet the clinical eligibility criteria (listed below) based on VA aid and attendance and compensation benefits (based on 38 U.S.C. §1114 and implementing regulations).” Ibid. Page 34.
10 In addition, the fourth requirement listed above that the veteran must need, at a minimum, six months of continuous and approved caregiver support is based on the premise that their family members may be able to utilize 26 weeks of unpaid leave under the Family and Medical Leave Act (FMLA). However, this condition assumes that the family member will not have used any of the 26 weeks at the time this requirement will be applied.
similar qualities that require interpretations and subjective judgments, even as it proposes criteria more restrictive than Congress intended.

In the law, Congress specified an eligible veteran or service member must be, among other deficits, unable to perform one or more activities of daily living (ADL) or be in need of supervision or protection based on symptoms or residuals of neurological or other impairment or injury. VA combined these two discretionary requirements (be at high risk for personal safety and show inability to live independently in the community without caregiver support).

DAV appreciates VA’s desire for a clear and consistent clinical guideline for the purposes of determining eligibility for caregiver assistance under 38 U.S.C. § 1720G. However, using the example of the underlying problem causing the Department’s disability claims backlog to grow, standard application of any guideline is most influenced by proper training and education as it is by avoiding ill-defined words such as “continuing medical management” or “high risk.” In addition, we recommend VA develop retrospective root cause analyses to identify the cause of, and improve upon variability of, eligibility determinations on families denied these services.

With regard to the additional criteria for veterans or servicemembers undergoing military medical discharge, it appears VA intended this additional criterion to be in line with the special compensation for severely injured military servicemembers under Section 603(a) of P.L. 111-84, the National Defense Authorization Act for Fiscal Year 2010 (NDAA).11

However, the purpose of this special compensation benefit is for both the Department of Defense (DOD) and VA to ensure the seamless transition of care of all service members retiring for medical disability. This NDAA provision would recognize that family members are making life-altering sacrifices in order to care for service members at home. The provision would cap the amount of special compensation at the amount authorized for aid and attendance compensation for veterans under section 1114(r)(2) of title 38, United States Code. By aligning the NDAA authority with the authority to provide aid and attendance compensation for veterans under section 1114 of title 38, United States Code, the conferees expected to close gaps in coverage and care for catastrophically injured service members transitioning from DOD to VA.12

If VA has concerns with aligning the eligibility criteria for caregiver assistance under 38 U.S.C. § 1720G to the special monthly compensation rates, we suggest VA look to the eligibility criteria for the special compensation under 37 U.S.C. § 439 (b). Since this DOD special compensation is primarily a financial benefit, we believe it is more appropriate to remove VA’s proposed eligibility that references 38 U.S.C. § 1114 and address its alignment concerns under the stipend provisions of P.L. 111-163.

We have testified many times and written in *The Independent Budget* our concerns with respect to transition of active duty service members to civilian veteran status. Numerous reports have revealed great weaknesses between VA and DOD in effectively promoting a seamless transition even in cases where the individuals concerned are severely wounded and in need of an array of health and benefits services from both agencies. In this implementation plan, VA may

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11 37 U.S.C. § 439
have failed to coordinate its decisions with DOD with respect to severely injured active duty and veterans. Lack of coordination will exacerbate the existing gaps in transition and could result in caregiver support services being unnecessarily duplicated or unavailable across both systems at the detriment of the quality of care and rehabilitation of the individuals concerned. As VA reviews its implementation plan for caregiver support services as a result of strong Congressional oversight and involvement of this community, we urge VA to work closely with DOD counterparts in fashioning change.

**Stipend:**

Due to the number of concerns DAV has identified about the potential caregiver stipend, we believe a closer inspection is needed to determine if this benefit as proposed by VA is both appropriate and valid in light of Congress’s intent.

First, the amount of personal caregiver services that will be required of a caregiver may include skilled nursing care (wound care, bowel and bladder care, tracheostomy or ostomy care, etc.), physical and occupational therapy, home health aide care and homemaker duties. As amended by P.L. 111-163, title 38, United States Code, § 1720G(a)(3)(C)(ii)(V), recognizes this potential and states the stipend be, “not less than the monthly amount a commercial home health care entity would pay an individual in the geographic area of the eligible veteran to provide equivalent personal care services to the eligible veteran.” (Emphasis added.)

However, VA proposes to take the intended minimum monthly stipend amount and convert it to the maximum amount payable. The Department proposes to base the stipend payment on the Department of Labor’s Bureau of Labor Statistics (BLS) wage rate for a home health aide, with no other option. In doing so, VA may not fully recognize all the personal care services a primary caregiver will provide.

Second and subsequent to the previously mentioned proposal, VA incorporates an especially grievous proposal that sets a bar caregivers must overcome but is not recognized by the stipend benefit despite VA’s statement that, “[t]he stipend is an acknowledgement of the sacrifices that families are making to care for seriously injured eligible Veterans.” This situation is evident in two forms:

1. VA proposes that in order for the caregiver to be eligible for the monthly stipend, the caregiver must be able to provide personal care services that include any additional care requirements prescribed by the PACT or veteran’s primary care team—that is, other personal care services such as skilled nursing care that a home health aide would not or could not otherwise provide. Yet, VA proposes to limit the stipend amount to that paid to a home health aide; and

2. In another set of requirements VA’s implementation plan includes a standardized veteran/caregiver assessment tool (Appendix B) that will be used to evaluate and validate

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14 Ibid. Page 13
caregiver competence, which is required for the primary caregiver to begin receiving the stipend and other benefits.  Part of the assessment tool includes whether the caregiver furnished needed Instrumental Activities of Daily Living (IADL). In calculating the hours of work that VA estimates a primary caregiver will need to provide required personal care services, it appears that no weight is given to the hours of care needed to perform IADLs in calculating the monthly stipend.

Third, DAV is also concerned about the calculation of hours of care VA estimates a primary caregiver will need to perform the required personal care services.

VA states that nothing in § 1720G, as added by section 101 of P.L. 111-163, shall be construed to create “an employment relationship between VA and an individual in receipt of assistance or support,” to include primary family caregivers. However, VA’s implementation plan uses a 40-hour work week as a standard and proposes a maximum 40 hours of care without consideration for the time needed to provide personal care services during evenings, weekends, or holidays. This restriction is proposed despite VA’s eligibility requirement that a veteran must need “continuous and approved personal care services.”

Fourth, according to VA, behavior points from the Patient Behavior Scale assessment will be subtracted from the ADL points from the Katz ADL Scale. Combined results of these scales are given a numeric value to determine the level of the stipend payment:

- VA’s implementation plan assumes behavior points are equal to ADL points without explanation or validating evidence to support this assumption.
- VA’s implementation plan lacks explanation of how the combination of ADL and behavior points relate to the amount of hours-of-care needed.
- VA’s implementation plan does not conform to Section 101, P.L. 111-163, where IADL is not specified as a tool to be used in the evaluation and calculation of stipend amounts.

**Assessment Instruments:**

Determining the type of ADL and IADL care that a patient needs permits a clear idea of whether or not living at home with care is an option. Further, recognizing a person’s functioning level as it relates to ADL and IADL is the first step in developing a care plan (or making a referral for care) to provide the appropriate type and level of assistance. This is also recognized in Appendix B (page 56), the Veteran/Caregiver Assessment Tool, which evaluates both ADL and IADL limitations.

VA’s implementation plan proposes to use the Katz Index of Independence in Activities of Daily Living, a patient behavior scale to determine the levels of the caregiver stipend payable. The Katz Index uses a dichotomous rating (0 = independent; 2 = dependent) for each activity; Alternatively, VA proposes a trichotomous rating (1 = high dependence; 2 = medium dependence; 3 = low dependence). These three levels of dependency are ill-defined and will

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16 Ibid. Page 56.
most certainly lead to wide variations in scoring among health care providers, and will fail to meet VA’s stated goal for a clear and consistent guideline.

We recommend VA consider a rating scale with each item assigned points according to a defined decision rule (e.g., 0 = no help needed; 1 = uses a device; 2 = needs human assistance; 3 = completely dependent). Alternatively, the Lawton IADL scale developed by Lawton and Brody in 1969 assesses the more complex ADLs necessary for independent living in the community where competence in skills such as shopping, cooking, and managing finances are necessary tasks. VA could consider using the trichotomous rating used in the Lawton IADL instrument (1 = unable; 2 = needs assistance; 3 = independent). In any case, VA provides no evidence about the validity of using other than the dichotomous rating of a patient as either dependent or independent for an ADL in conjunction with the Katz Index.

DAV is also concerned VA’s implementation plan does not propose to use an IADL instrument to assess the personal care needs a veteran or servicemember may require, which the primary caregiver will undoubtedly perform. Katz developed another scale for instrumental activities of daily living such as heavy housework, shopping, managing finances and telephoning but it is not referenced in the implementation plan.

Of equal concern is the lack of information in VA’s implementation plan on whether the proposed Patient Behavioral Scale is a valid instrument in determining veterans’ needs and amounts of personal care services that primary caregivers must provide.

Madame Chairwoman, DAV would like to highlight a missing yet critically important component in VA’s implementation plan – any instrument to assess the personal care needs of a veteran or service member suffering from neurological or cognitive impairment due to traumatic brain injury (TBI).

Although impairment in cognitive function is a recognized concern in P.L. 111-163 (§ 1720G(a)(2)), VA did not propose to assess veterans’ or service members’ executive functions (planning, organizing, problem solving, sequencing, self-monitoring and controlling behavior). Deficits in executive functions may be devastating to someone's ability to cope with everyday life, work, and relationships. Executive functions are assumed to be located in the frontal lobes of a human brain. These are particularly vulnerable to damage after TBI because they sit on bony projections in the skull, and thus are at greater risk of injury and damage. Although the Katz ADL Index is sensitive to changes in declining health status, it is limited in its ability to measure small increments of improvements seen in the rehabilitation of patients.

It is not clear from VA’s implementation plan whether the proposed Katz Scale or the Patient Behavioral scale will be used to assess cognitive, neurological impairment, and other residuals of TBI. Notwithstanding there is no assessment instrument proposed for veterans suffering from TBI, we appreciate VA’s not intimating the use of the Global Assessment of Functioning (GAF) Scale as a proxy. GAF scores are used in conjunction with a multiaxial evaluation of a psychological disorder, whereas severe TBI can result in not only psychological, but physical, cognitive, and psychosocial impairments and functional disabilities.
For example, damage to the frontal lobes is often associated with good recovery of motor, sensory, and linguistic functions as seen on neuropsychological testing. Thus, the person with frontal lobe or executive functioning damage may appear normal in testing, or in the context of a highly structured and routine environment. On the other hand, executive dysfunction can cause many problems despite good recovery in the aforementioned areas, and debilitating complications can be seen with managing cognitive, social and communicative functioning, and behaviors. It can result in difficulty in executive functions such as attending, planning, organizing, learning, problem-solving, and reasoning in the unstructured reality of life tasks even though these individuals may show good performance on highly structured neuropsychological tests.

Research has generally supported hierarchical arrangement of functional skills by demonstrating IADLs are affected earlier in the course of cognitive impairment, whereas ADLs are preserved until relatively late. There is robust discussion on subdividing IADLs or higher level functional skills to reflect relevant underlying cognitive abilities. In essence, there is a need to establish a tool or series of tools that has a proven ability to link domains of daily function to particular domains of cognitive function. This would improve VA’s ability to make meaningful predictions about which specific functional impairment might result from specific cognitive impairment.

There are three general approaches to measuring everyday function: Self-report, Informant report and Performance based measuring. Self-report has been shown to be problematic in individuals with cognitive impairment. Performance based measuring is argued to be the most valid and reliable method of assessing functional abilities of patients with cognitive impairment, but a caveat must be stressed. That is, all reasonable effort must be made to ensure the measurement is not administered under artificial conditions in which the individual is “prompted” to engage in a task and provided all the materials he or she requires in completing the task.

Critics cite performance based measuring as time consuming and requires extensive equipment, thus making it impractical for routine use. More practical would be the use of the caregiver or similar individual—who knows the patient best—as a proxy rater.

This measure also authorizes a significant new array of respite services that were intended to be provided in a flexible and helpful way to caregivers of severely wounded veterans. To date, we note VA’s significant delay in broadening the benefit authorized in the law. Also, the Government Accountability Office and other independent reviewers have cited a series of weaknesses in VA existing respite program. We hope and urge that VA include early implementation of a strong but flexible respite program for those so much in need.

Conclusion:

18 Kemp et al., 2002; Richardson, Nadler and Malloy, 1995; Tomaszewski et al., 2005
19 Sclan and Reisber, 1992; Suurmeijer et al., 1994)
20 Debettignies, Mahurin, and Pirossolo, 1990; Seltzer et al., 2001
Madame Chairwoman, 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. They 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 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.

Along with other veterans service organizations, DAV has been working for years with the Administration and VA to address these lapses. DAV is concerned that VA’s implementation plan will not result in actions rooted in Congress’ intent in passing P.L. 111-163. We are keenly aware of VA’s ability to do what is right by veterans and their caregivers. VA recently issued a news release on the topic, “Resources for Enhancing Alzheimer's Caregivers Health (REACH) VA.” REACH VA is an initiative translated from a VA randomized control trial. The clinical trial showed significant improvement in caregiver burden, depression, health/self-care, social support, and management of patient behaviors. The goal of REACH VA is to implement nationally an effective intervention to decrease stress among caregivers who typically provide the majority of care for those with dementia, on average 16-20 hours per day, and improve the management of patient behaviors throughout the VHA system.

VA is indeed capable of administering a caregiver assistance program envisioned by caregivers of disabled veterans, the veteran community, and Congress. In time, we will know if VA has listened to the concerns, considered them, and adjusted its position when the IFR is published as a final regulation.

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