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**STATEMENT OF
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BEFORE THE
COMMITTEE ON VETERANS' AFFAIRS
UNITED STATES HOUSE OF REPRESENTATIVES
FEBRUARY 6, 2018**

Mr. Chairman and Members of the Committee:

Thank you for inviting DAV (Disabled American Veterans) to testify at this hearing of the House Veterans' Affairs Committee. DAV is a non-profit veterans service organization (VSO) dedicated to a single purpose: empowering veterans to lead high-quality lives with respect and dignity. For many severely ill and injured veterans, leading such lives would be difficult if not impossible to achieve without the love, support and daily sacrifice of their family caregivers, and we appreciate the opportunity to discuss their needs and the Department of Veterans Affairs (VA) caregiver programs.

The Caregivers and Veterans Omnibus Health Services Act of 2010 (P.L. 111-163) required VA to establish a program of comprehensive assistance for family caregivers (Comprehensive Program) of any eligible veteran who has a serious injury, including traumatic brain injury, psychological trauma, or other mental disorder, incurred or aggravated in the line of duty on or after September 11, 2001, and is in need of personal care services. Caregivers participating in the Comprehensive Program can receive certain medical, travel, training, support services, and financial benefits. The law also required VA to establish a program of general caregiver support (General Program) that provides limited services to caregivers of wartime veterans injured prior to September 11, 2001.

In addition, the law required the Secretary to review the program after two years and recommend whether it was feasible and advisable to expand eligibility to severely disabled veterans of earlier eras, such as World War II, the Korean, Vietnam and Gulf Wars. Unfortunately, despite early indications at that time that the program was improving the lives of eligible veterans and caregivers – and mounting evidence since that the program continues to materially support so many veterans and family caregivers – it still remains limited only to post-9/11 veterans.

Mr. Chairman, we are grateful that the Committee is holding today's hearing to examine how to strengthen and modify the existing caregiver program to become more efficient and effective and will offer a number of recommendations to improve it. However, there is no issue more important today than finally correcting the gross

unfairness and inequity that discriminates against veterans ill and injured prior to September 11, 2001, as well as their family caregivers.

How can we look these men and women in the face – some of whom are here with us today – and tell them that their service and sacrifices do not merit equitable access to all caregiver benefits? How can we say that their spouses, parents, siblings, children, and close friends who also sacrifice to be their caregivers, do not deserve the same support as those caring for post-9/11 veterans? There is simply no defensible argument for maintain the arbitrary date placed into law, other than the cold financial calculation of saving money, which transfers the burden of caring for so many severely disabled veterans onto the shoulders of family caregivers, many of whom have carried that heavy responsibility for decades.

Mr. Chairman, today, DAV, along with virtually all of our VSO colleagues, call on this Committee to take bold and decisive actions, similar to what the Senate Veterans' Affairs Committee did last fall, and pass legislation that will end this inequity by extending eligibility for the full array of caregiver benefits and services to veterans from *all eras*.

In addition to those ineligible because they were injured before September 11, 2001, the law as implemented precludes disabled veterans who became severely ill, regardless if that occurred *on or after* that fateful day. As a result, thousands of post-9/11 veterans with catastrophic illnesses, such as those on the Congressionally-mandated Open Burn Pit Registry (P.L. 112-260) or those exposed in 2003 at Qarmat Ali, Iraq to a chemical known to cause lung cancer and respiratory problems. And if the cutoff date were changed but the program remained limited to veterans who suffered *injuries*, it would continue to exclude hundreds of thousands of veterans who suffer from chronic diseases associated with exposure to herbicides like Agent Orange, as well as those who are suffering from Gulf War Illness. Fairness for all veterans requires that the law recognize the hazards of military services by including not just those who suffered wartime *injuries*, but also those who suffer debilitating wartime *illnesses*.

Effectiveness of VA's Caregiver Support Program

For today's hearing, the Committee has indicated its interest in examining the Comprehensive Program for its effectiveness "in serving the highest-need veterans and their caregivers," the reforms needed to successfully expand eligibility including alternative approaches to expansion and opportunities to adopt best practices from other VA programs and benefits without duplicating services, and the public response to the Agency's request for public comment for any changes needed to increase consistency across the Comprehensive Program, as well as ensure it supports those family caregivers of veterans service members most in need. However, to discuss effectiveness of the program, we must first agree on the purpose and goal of the program.

When the legislation was being debated in Congress, the President's Commission on Care for America's Returning Wounded Warriors found that 21 percent of active duty, 15 percent of reserves, and 24 percent of retired or separated service members who served in Iraq or Afghanistan had friends or family members give up a job to be with them as their caregiver. In doing so, they had to give up their health insurance and spend their savings at a time when they chose to stay home and selflessly care for the veteran. Congress recognized that even without a job or health insurance, and in very stressful situations, family caregivers worked to fulfill the nation's obligation to care for its wounded warriors at great personal cost. Both the VA Comprehensive and General Program, collectively referred to as the Caregiver Support Program, were created to mitigate this situation.

Last June, DAV released a comprehensive report on veteran caregivers entitled "America's Unsung Heroes" (www.dav.org/wp-content/uploads/Caregivers_Report.pdf) in order to document the challenges and needs of veteran caregivers of all eras. The report contained a qualitative online survey conducted by DAV, which received 1,833 validated responses from veterans and caregivers. The results of the survey offer a deeper look at the hurdles all veteran caregivers face, as well as the supports they receive and need to help care for their loved ones. This report provides a clearer picture of the lives of veterans' caregivers to help guide critical public policy changes in the coming years. We include findings of this report pertinent to the work of this Committee for this hearing.

In speaking to the effectiveness of the Comprehensive Program, the survey DAV offered veterans and caregivers participating in the program the opportunity to provide their perspective. The comments included below exemplify the views we received of the effectiveness and value of the Comprehensive Program:

Caregiver, Spouse, 38, teenage children

We depend on the Caregiver Program more than you can imagine. I miss doing what I love (my career) but I love my husband and my children, so it can be such a struggle some days. I have found that the older the children get the more strenuous it is at home as well, due to the typical "teenage" stuff, but it affects my husband and myself. My husband depends on me in so many ways that there are days when I am just so exhausted, but I continue on because I know he needs me. We need so much support so we can continue to better ourselves, our spouses, and our families as a whole.

Caregiver, Spouse, 39, teenage children

I am currently participating in the Caregiver program through the VA. I have been extremely thankful for this program because of the education provider gave me coping skills and helped me learn to achieve stability in our family that was most certainly not there before.

Veteran, 37, spouse is caregiver

If we are speaking of quality of life, it would be quite the contrast from living in fear and disparity, to living in hope and security. Even the most responsible and capable person can be reduced to a hopeless and destitute in the wake of traumatic events and experiences. Having a familiar face, who is educated in the fields in need, to help bring a positive daily expectation of life is my most precious commodity today. Recovery is possible, but I cannot fathom moving forward without the help provided by my spouse with the assistance of the caregiver program.

Mr. Chairman, these are the real life results of the current program indicating it is working as intended. But there is always room for improvement, which is why DAV has advocated from the program's inception to integrate a research component. Studies performed with the VA Caregiver Support Program could help find answers such as how to effectively support family caregivers of severely ill and injured veterans in a cost-effective manner and could better inform program managers, policy makers and the public.

To this end, VA should be commended for embarking on a research initiative and funding the VA Caregiver Support Program Partnered Evaluation Center in April 2014. This three-year collaborative partnership project was to evaluate the short-term impacts of the Comprehensive Program and the General Program along four aims: 1) assessing the program's impact on the health and well-being of veterans by examining health care encounters expected to be sensitive to caregiver support (potentially avoidable utilization); 2) assessing the impact of the both the Comprehensive and General Program on the health and well-being of family caregivers; 3) understanding how caregivers use and value components of both programs, and; 4) gain a preliminary understanding of the relationship between the cost of Caregiver Support Programs and their value to caregivers.

VA was able to compare a small number of caregivers enrolled and not enrolled in the Comprehensive Program and found that caregivers in the Comprehensive program felt more confident in their caregiving, were more aware of resources to help in their caregiving role and felt more confident in supporting their veteran.

According to VA, the short-term impact of program participation includes an increase in utilization of VA primary, mental health, and specialty care, and long-term services and supports. However, the cause of increased utilization remains unclear as well as whether it will lead to better health outcomes and thus fewer health care costs in the long term.

VA also deemed it necessary in 2017 to extend VA-CARES with a long-term evaluation project. This project will examine the effect of the Comprehensive Program on a veteran's total health care costs at three years, conduct a formative evaluation of

the application process to identify areas and approaches for improving consistency across VA, and examine potential changes in the level of stress of caregivers participating in the Comprehensive Program. DAV eagerly awaits the deliverables of this project in 2019.

Such commitment by VA recognizes the Caregiver Support Program embodies the most sweeping national support program for family caregivers. We urge Congress to support VA's efforts to leverage this first and only national program of its kind to better inform policy makers and other health care systems considering supporting family caregivers across the nation.

Understanding caregivers' burdens and needs can help identify those most at risk for health and mental health effects and support them appropriately. Effectively supporting caregivers can delay placing veterans in more costly care settings such as emergency rooms and nursing homes. It is imperative that Congress require and fund a military and veteran caregiver research strategic plan to monitor the health and well-being of family caregivers and the recipients of their love and support; to study current and innovative interventions, their availability, accessibility, and use in supporting family caregivers; and study military and veteran caregivers from a public health perspective.

Needed Reforms in the Comprehensive Program, VA

As has been reported, the need for comprehensive caregiver support services by family caregivers of severely injured veterans was greater than anticipated by Congress and the Administration when the Comprehensive Program experienced significantly higher than expected demand in the years following implementation. With insufficient resources and funding, and higher than expected demand, additional challenges emerged in the timely processing of applications, consistency in applying the eligibility criteria, lack of program staffing in central office and the field, inadequate Information Technology (IT) support, and other issues.

We applaud VA's efforts to address each of these challenges, to include amending regulations of existing programs such as ensuring service members undergoing medical discharge with a qualifying primary or secondary family caregiver is able to apply for the Comprehensive Program¹ and has access to VA's Home Improvements and Structural Alterations (HISA) Benefits Program,² improving veterans and family caregiver experiences with State Home adult day health care programs,³ and to ensure family caregivers would be able to maintain eligibility on behalf of a veteran in the VA Veteran-Owned Small Business Verification Program.

To improve Comprehensive Program operations, VA amended existing regulations in January 2015 to ensure veterans are notified in writing should a family caregiver request to no longer be the caregiver, extending from 30 to 45 days the time the family caregiver has to complete all required training, and a change in the stipend

¹ 79 Federal Register 59562, October 2, 2014.

² 78 Federal Register 69614, November 20, 2013.

³ 80 Federal Register 34793, June 17, 2015.

calculation to ensure that primary family caregivers do not experience unexpected decreases in stipend amounts from year to year.⁴ VA also continues to work on stabilizing the current IT supporting the VA caregiver support program and identifying and implementing a more permanent solution.

Since the interim final regulations⁵ for the Comprehensive Program were made final in January 2015, DAV had been strongly advocating that more consistent guidance be issued to the field governing local program operations including changing how VA historically treated family caregivers, clearer staffing responsibilities, consistent application of eligibility rules and discharge procedures for the Comprehensive Program, and greater transparency of calculating tier assignments. VA finally issued a program directive in June 2017.⁶

This long overdue directive was distributed far and wide in the midst of a temporary suspension initiated in April⁷ of discharging or revoking caregivers out the Comprehensive Program and to conduct an internal review to evaluate the consistency of the program nationwide. We commend VA for the suspension and for conducting its review with input from stakeholders, including caregivers across the country, DAV and other VSOs. Upon its completion, VA reinstated full operation of the program in July⁸ making significant changes to the program to affect policy and execution moving forward. This change includes mandatory VA staff training of the new directive, standardizing program information, a Frequently Asked Questions webpage for the program and a document outlining the roles, responsibilities and requirements for Caregiver Support Coordinators, family caregivers and veterans participating in the Comprehensive Program.

Communications. Based on DAV's long-standing concerns regarding appropriate and meaningful communication with veterans and family caregivers in the Comprehensive Program, we are particularly interested in VA's recent changes to its communications with stakeholders, including a standard discharge letter to provide, in plain language, the reasons for discharging participants from the Comprehensive Program.

We recommend VA improve and standardize its Comprehensive Program decision letter. To ensure veterans and caregivers understand the reasons and bases of the decision, the letter should contain, at the minimum:

- Identification of the issues decided;
- A summary of the evidence considered (to ensure completeness of medical evidence);
- A summary of applicable laws and regulations;
- Identification of findings favorable to the applicant;

⁴ 80 Federal Register 1357, January 9, 2015.

⁵ 76 Federal Register 26148, 26148

⁶ Veterans Health Administration Directive 1152, Caregiver Support Program, June 14, 2017.

⁷ VA Press Release, "VA Announces Internal Review of Caregiver Program," April 17, 2017.

⁸ VA Press Release, "VA Caregiver Support Program Resumes Full Operations," July 28, 2017

- In the case of a denial, identification of elements not satisfied leading to the denial;
- An explanation of how to obtain or access evidence used in making the decision; and
- Identification of the criteria that must be satisfied for a favorable decision.

With these basic elements included in VA's communication articulated with reasonable clarity, veterans and caregivers would be able to make a more informed decision to agree with or appeal the decision. This is particularly important because of certain limitations of the current clinical appeals process.

DAV identified early on the need for an independent mechanism through which: (1) a caregiver can appeal a clinical decision; (2) the decision can be carefully reviewed *de novo*; and (3) an unwarranted decision can be reversed, altered, or sent back to the clinical team with instructions to reassess or consider additional factors.

In this vein, we also applaud this Committee's work to address other issues in the Comprehensive Program in 2016 when it passed H.R. 3989, the Support Our Military Caregivers Act, which was intended to establish an expedited external review process for cases in which the veteran or family caregiver disagreed with VA's decision. Accordingly, DAV supported H.R. 3989.

Respite Care. When DAV survey participants were asked about the importance of respite care, nearly 60 percent indicated it is important or very important; however, only a small minority (seven percent) receives respite care, of which only three percent believe they are receiving enough respite, while the vast majority (93 percent) are not receiving any respite whatsoever.

The DAV survey found that approximately one of every three veterans with family caregivers also had children living at home; 20 percent had children younger than 18 living with them. As expected, this was principally the case for post-9/11 veterans where 67 percent had children at home, including just over a third of the post-9/11 households (34.3 percent) who had children under 12 years old. However, having children in the same household impacts respite care delivery to the caregiver, particularly if agencies are utilized and do not provide child care while caring for the veteran. That is, the caregiver is unable to truly experience respite if their caregiving responsibilities shift from the veteran to the children. Caregivers may not also be using this critical benefit due to unavailability of service in their community and because they are concerned about entrusting the health and well-being for their veteran to a complete stranger.

It is imperative VA identify local barriers to receiving respite care in the most convenient setting for the caregiver and veteran. We fully support VA's current efforts to use every means available, such as innovating an existing program, the Veteran Directed Home and Community Based Services (VD-HCBS) to address this unmet need.

Stipend. Stipend funds under the Comprehensive Program are determined primarily using Activities of Daily Living⁹ and Instrumental Activities of Daily Living¹⁰ to assess the caregiver's burden, which may not give adequate weight to caregivers of veterans with behavioral health issues, including those with severe post-traumatic stress disorder or traumatic brain injuries. These veterans may be able to handle daily tasks, but need constant supervision and support to ensure that they are not threats to themselves or others and require more assistance with managing the administrative tasks of daily living.

In addition, the condition of some severely injured veterans improves and declines over time, yet VA national policy is silent on how to mitigate the effect of tier reductions and subsequent stipend reduction. With tier reductions having the greatest potential for adverse effect, VA should revise the immediacy of the effective date for tier reductions/stipend reduction to lessen the financial impact on veterans and caregivers.

We note that if revocation of the designation of primary caregiver is due to improvement in the veteran's condition, death, or permanent institutionalization, the family caregiver will continue to receive caregiver benefits for 90 days. We recommend VA apply this procedure of continuing the stipend rate for 90 days prior to reduction.

Needed Reforms in Comprehensive Program, Congress

In contrast to VA's Comprehensive Program, DoD's Special Compensation for Assistance with Activities of Daily Living (SCAADL) program covers injuries as well as illnesses. The program helps offset the lost income of the primary caregiver who provides nonmedical care, support and assistance for service members with catastrophic injury or illness, but does not provide health insurance, respite care, counseling, training or other benefits that accrue to caregivers under PCAFC. Program participants transitioning from military to VA benefits may be unprepared to deal with the significant differences in these programs.

In addition, VA is authorized to provide counseling, training and mental health services to members of the veteran's immediate family, the veteran's legal guardian and to the individual in whose household the veteran certifies as intending 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 a nonservice-connected disability if the services are necessary in connection with the treatment, the services began during the veteran's hospitalization, and the continued provision of the services on an outpatient basis is essential for discharging the veteran from the hospital. Such restrictions in law and resulting policies may perpetuate the treatment of family caregivers as incidental to the care of veterans rather than as the primary recipient of such caregiver supports.

⁹ Basic and fundamental functions of daily living (ADLs) such as bathing, toileting, dressing, grooming, getting in and out of bed or chair, walking, climbing stairs, and eating.

¹⁰ Functions necessary to live independently in the community such as shopping, housekeeping, managing money and medication, preparing meals, communicating with others, and driving or using public transportation.

Needed Reforms in General Program

Severely ill and injured veterans of all war eras want the option to live at home with appropriate supports for them and their family caregiver. VA's efforts to provide long-term care in home- and community-based settings will reduce the need for nursing home admissions and preventable hospitalizations. However, like many home- and community-based services that could support veterans and family caregivers, Government Accountability Office (GAO) reports have consistently described gaps in access and availability of these critical services.

VA should be commended for finally issuing a unified policy for providing long-term services and supports to include support services for caregivers of severely ill and injured veterans who are not eligible for the Comprehensive Program. VA offers a relatively robust and innovative set of home- and community-based services that support both the veteran and their family caregivers. The unified policy issued in October 2016 is a strong step towards addressing the long-standing issue of access and availability.

To execute this policy, VA must grow total spending for home- and community-based services. While there have been tremendous strides increasing spending on home- and community-based services as a ratio of total long-term services and supports spending—nearly doubling from 16 percent in FY 2010 to 31 percent in FY 2015, with commensurate decreases in the proportion of total long-term services and supports spending on nursing home care, going from 84 percent to 69 percent, VA must continue this effort if it is to provide appropriate supports for severely ill and injured veterans and their family caregivers and see the cost saving associated with such spending.^{11,12,13}

Home Based Primary Care. Veterans and family caregivers would benefit from VA's Home Based Primary Care (HBPC) program, which has been shown to reduce total VA and Medicare costs by 12 percent. VA must continue to expand access to this program and make it available at all VA facilities.

Veterans-Directed Home & Community Based Services. Because of the eligibility restriction to the Comprehensive Program, the statutory requirement acknowledges VA must collaborate with other entities that support caregivers. DAV has also advocated for VA to take full advantage of Public Law 111-163, which states "the Secretary shall collaborate with the Assistant Secretary for Aging of the Department of Health and Human Services in order to provide caregivers access to aging and disability resource centers under the Administration on Aging of the Department of Health and Human Services."

¹¹ "Toward a Model Long-Term Services and Supports System: State Policy Elements." H. Stephen Kaye, PhD, John Williamson, PhD, *The Gerontologist*, Volume 54, Issue 5, 1 October 2014, Pages 754–761. <https://doi.org/10.1093/geront/gnu013>; H. Stephen Kaye, "Gradual Rebalancing of Medicaid Long-Term Services and Supports Saves Money and Serves More People, Statistical Model Shows," *Health Affairs*, June 2012, <http://content.healthaffairs.org/content/31/6/1195>.

¹² Kali Thomas and Vincent Mor, "Providing More Home-Delivered Meals Is One Way to Keep Older Adults with Low Care Needs out of Nursing Homes," *Health Affairs*, October 2013, <http://content.healthaffairs.org/content/32/10/1796.full>

¹³ Carol V. Irvin et al., *Money Follows the Person 2014 Annual Evaluation Report*, Mathematica Policy Research, Washington, D.C., <https://www.mathematica-mpr.com/our-publicationsand-findings/publications/money-follows-the-person-2014-annual-evaluation-report>.

The VD-HCBS is administered through a partnership with Health and Human Services Administration for Community Living (ACL) and has proven to be a program that can meet the needs of some of VA's most vulnerable populations, including many who would likely be placed in nursing homes without this option.

Through VD-HCBS, the veteran has the opportunity to manage a monthly budget based on functional and clinical need, hire family members or friends to provide personal care services in the home, and purchase goods and services that will allow him or her to remain in the home. We will hold Secretary Shulkin accountable for his commitment, made during his nomination hearing in February 2017, to expand access to the VD-HCBS program, to make it available at every VA medical center within the next three years.

A recent analysis of VD-HCBS participants' health care use in FY 2015 before and after enrolling in this program found 29 percent reduction in inpatient days of care, 11 percent reduction in emergency room visits and 14 percent reduction in other than home- and community based services. While not conclusive, it suggests clear potential of reducing health care costs.

However, this program, like many home- and community-based programs supporting veterans in their home, relies on provider agreements. VA currently has a temporary Choice Provider Agreement authority, which it is using to the greatest extent possible with the number of veterans served increasing 37 percent to 1,751 in fiscal year (FY) 2016. In FY 2016, 81 VD-HCBS providers have entered into VA Choice Provider Agreements with VAMCs and 30 new VD-HCBS providers have been approved to deliver VD-HCBS services to veterans, which has expanded access for veterans in over 130 rural and highly rural counties.

Provider Agreement Authority. To help VA provide these and many other cost effective home- and community-based services programs, Congress must enact legislation granting VA permanent authority to enter into provider agreements with community providers.

In addition, VA and Congressional oversight is necessary to continue implementing effective strategies based on measuring veteran and family caregiver needs for increased access to home- and community-based services, creating an appropriate balance with nursing home care, and ensuring veterans are able to stay in their own homes, with appropriate supports for them and their family caregiver for as long as possible.

DAV recommends VA monitor and publicly report progress of individual facilities and regional networks toward meeting performance measures that focus on rebalancing long-term care, which includes increasing the availability and access to home- and community-based services. VA should focus first on expanding HBPC and VD-HCBS, while leveraging opportunities under the Veterans Choice Program.

Need to Expand Eligibility to Comprehensive Caregiver Support Program

Mr. Chairman, as discussed above, the most critical reform to the program is expanding eligibility to veterans from all eras. Research has shown that family caregivers delay, avoid, and, in certain situations, can actually help transition disabled veterans out of, expensive nursing homes. Allowing severely disabled veterans to remain in their homes longer is economically smart and will more efficiently use VA and taxpayer funds.

As this Committee is aware, their Senate counterparts approved S. 2193, the Caring for Our Veterans Act of 2017, which includes provisions to improve and phase-in expanded eligibility for the Comprehensive Program for family caregivers. According to CBO, stage one of the expansion under this bill to eligible veterans who were injured during service on or before May 7, 1975, would carry an average cost per participant of \$30,000 in 2020. Stage two of the expansion to remaining eligible veterans—those injured during service after May 7, 1975, and before September 11, 2001, with an average cost per participant of \$29,000 in 2022.

The annual cost estimated by the Congressional Budget Office for each veteran severely ill and injured before September 11, 2001, to participate in the Comprehensive Program is about \$30,000 compared to the federal cost of nursing home care of over \$60,000 in State Veterans Homes (matched by equal or greater state funding), \$100,000 in community nursing homes, and about \$400,000 in VA nursing homes.

To those who are concerned about the cost of doing the right thing for all severely disabled veterans and their family caregivers, we cannot now turn our back on the obligation to care for those who fought to defend our way of life. The cost of veterans benefits and services is a true cost of war and must be treated as such. It is an obligation this nation must shoulder and share by supporting disabled veterans and their family caregivers.

After a lifetime of caregiving for Gulf, Vietnam, Korean and World War II veterans, many family caregivers are aging and their ability to continue in their role is declining. With bipartisan support in the Senate, and growing support in the House, now is the time to finally provide fairness to caregivers of veterans from all eras.

Mr. Chairman, we call on this Committee to expand eligibility for VA's comprehensive caregiver support program to veterans severely ill and injured from all eras and their family caregivers.

This concludes my testimony and I would happy to respond to any questions that you may have.