

RALPH IBSON, SENIOR FELLOW FOR HEALTH POLICY, WOUNDED WARRIOR
PROJECT

TESTIMONY OF
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WOUNDED WARRIOR PROJECT

BEFORE THE

COMMITTEE ON VETERANS AFFAIRS
U.S. SENATE
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Chairman Akaka, Ranking Member Burr, Members of the Committee:

Thank you for inviting Wounded Warrior Project (WWP) to testify about pending legislation, particularly S. 801, a measure that would direct the Department of Veterans Affairs to develop a nationwide, comprehensive wounded warrior family caregiver program, and S. 543, which calls for a pilot program to assess the feasibility of providing such support.

Both bills recognize the extraordinary burdens being shouldered by family caregivers of our nation's latest generation of wounded warriors, and both seek to support these critical stakeholders in the rehabilitative process. Family caregivers, like their wounded warrior, often must adjust to their own "new normal" as they embark on what may be a lifetime of committed care for their veteran. The time has surely come to create a robust, nationwide wounded warrior family caregiver program to address the urgent needs of these family members. The establishment of such a program is Wounded Warrior Project's top legislative priority, and we offer our overwhelming support for S.801.

Wounded Warrior Project knows firsthand the challenges these family members face. We work daily with thousands of our alumni to ensure they become the most successful and well adjusted wounded warriors in the nation's history. Through our nationwide family caregiver outreach and retreat program, Wounded Warrior Project is gathering vital data needed to more appropriately support family caregivers in the rehabilitation of their wounded warriors. This program provides these caregivers much needed respite, counseling, and training. Family caregiver retreats are comprised of participants facing similar challenges based on their unique family roles and experiences. Separate retreats are organized for wives, mothers, and fathers of wounded warriors. Also, we will be holding a caregiver summit in Washington, DC in late June, and we expect that our family caregivers will visit many of you on the Committee. Wounded Warrior Project Supports S. 801.

WWP strongly supports S. 801, "The Family Caregiver Program Act of 2009." This bill reflects a keen understanding of the needs of both severely wounded warriors and the devoted loved ones who selflessly care for them. That understanding is reflected in the establishment of a program

that would fully address the long unmet needs of family caregivers while ensuring the well-being of our most profoundly wounded warriors. Mr. Chairman, we applaud your leadership in taking up this important issue and working with the Ranking Member to craft this strong bill. Not only does S. 801 meet a dire and well-established need, but it builds on an array of services—some of which are already provided at many, but not all, VA facilities. These services are simply not currently integrated in a comprehensive manner to support family caregivers.

The Department of Veterans Affairs (VA) has mounted a number of pilot programs to assist family caregivers, and various elements of the VA system already provide many of the services family caregivers need. Thus, there already exists a strong foundation to take the next logical step and establish a nationwide program of comprehensive support. S. 543, “The Veteran and Servicemember Caregiver Act of 2009,” would provide some of the supports we view as critical to sustain family caregiving. But the measure falls short. It would not provide family caregivers the full range of needed supports (providing simply for study with regard to needed respite and health care), and it is limited in scope to a two-year pilot program to be carried out at not fewer than six facilities. We believe that the time for pilot programs is past.

S. 801, in contrast, proposes just the type of comprehensive solution Wounded Warrior Project recommends and fully supports. Our wounded warriors and those family members who care for them have compelling needs. S. 801 meets those needs head on. We commend the Chairman, the Ranking Member, and all the Committee co-sponsors for introducing this urgently needed legislation.

The Need for Family Caregiver Support.

While many wounded warriors substantially recover from their wounds and are able to live independently, some 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. In-home care by a loved one also affords the wounded warrior greater access to community-based care, a right that has already been affirmed by the Supreme Court in its *Olmstead v. L.C.* decision. Most warriors want to be cared for by their loved ones, if possible, rather than by agency personnel. Most families want the same for their wounded warrior. But the extraordinary demands of caregiving invariably take a toll on family caregivers – physically, psychologically, emotionally, and financially.

Our research makes one thing abundantly clear—very little institutional attention is being paid to family caregivers though they are a vital link in the veteran’s rehabilitation process. The President’s Commission on Care for America’s Returning Wounded Warriors, the Dole/Shalala report, provided powerful data on the nature and magnitude of the problem. Among its findings, the Commission reported that:

- Among OEF/OIF service members surveyed, “33% of active duty, 22% of reserve component and 37% of retired/separated service members report that a family member or close friend relocated for extended periods of time to be with them while they were in the hospital.”

- Among OEF/OIF service members surveyed, “21% of active duty, 15% of reserve component, and 24% of retired/separated service members say friends or family gave up a job to be with them or act as their caregiver.”

The Well-Established Burden on Family Caregivers.

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 S. 801.

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.

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, depression, and mortality 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. Studies also suggest that with each incremental increase in assistance with activities of daily living (ADLs), spousal caregivers experience a greater risk for serious illness. Caregivers report poorer levels of perceived health, more chronic illnesses, and poorer immune responses to viral challenges.

Finally, economic issues associated with caregiving cannot be ignored. The literature suggests that informal (unpaid) caregiving is incompatible with full-time employment. 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. Also, while not specifically addressed in the research, a reduction in long-term wages will obviously result in a reduction in future social security benefits.

Wounded Warrior Project works closely with the family caregivers of our wounded warriors and sponsors frequent caregiver retreats. We have learned firsthand that our caregivers experience the same profound challenges so thoroughly documented in the literature.

Let me share just two examples from among the many with whom we work closely. In late 2005, one of our alumni was struck by an Improvised Explosive Device while serving in Iraq. He was permanently and totally blinded, has severe TBI, and is on medications to control seizures and a host of related issues. His wife was forced to leave her teaching job permanently to care for her husband. She is assisted daily by her mother. In the three years she has been a 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 which does not extend to her mother. She was completely unaware of any VA respite care program when we interviewed her. She lives 90 miles from the nearest VA facility.

The mother of one of our alumni lost her job after two months of caring for her son, a severely wounded warrior injured in April, 2003 who requires full-time care. She only has health care

coverage because she is covered by 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 states plainly that her caregiving activities are extremely stressful. She worries about their finances and health care coverage.

The impact on family members such as these of having to care for severely wounded veterans for extended periods of time—and in many cases, for life—can be overwhelming. From the moment one or more family members meet their returning wounded warrior, they come face-to-face with their “new normal.”

From the moment they are injured, the wounded warrior and their family members are forced to make decisions about who will provide routine, daily care. While the decision to care for a loved one—a commitment vital to that wounded warrior's recovery—may come easily, the burden of caregiving itself can take an enormous toll on the family. Family caregivers may be forced to take extended leaves of absence or permanently leave their jobs, losing retirement plans, health care plans, savings plans, and benefits plans in the process. In many cases, the wounded warrior requires personal assistance around the clock and may need specialized, daily care which the family caregiver is neither trained nor emotionally equipped to handle. At present, few family caregivers receive 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.

The High Cost of Doing Nothing.

These family caregivers are, in many cases, the “first responders” to wounded veterans in need. They are often the first ones to detect new challenges to the veteran's rehabilitation and the ones most capable of implementing a positive response to those challenges. Without an appropriate level of support, many of these family caregivers will simply find themselves unable to cope. Over the long-term, such a tragic outcome will ultimately result in an enormous cost to our wounded warriors, their families, and to the health care system which will likely be called upon to care for them.

Setting aside the obligation we owe these warriors and their loved ones, the ultimate cost of failing to address the urgent needs of wounded warrior family caregivers is almost certainly much greater than the cost of establishing a comprehensive wounded warrior family caregiver program for all who need ongoing support. S. 801 clearly recognizes this reality.

There is Currently no Comprehensive, Nationwide Wounded Warrior Family Caregiver Program.

While S. 801 envisions a comprehensive nationwide program, it is important to note that many VA medical centers already provide some of the very services and supports proposed in the bill, including respite care and family education and counseling. But none provide all of these services. Nor do they focus in a comprehensive, coordinated way on family caregivers. Family caregivers need more than piecemeal services and support. They have a profound need for the kind of robust national program proposed in S. 801. Based on the experience of our wounded

warriors, we believe such a program would contribute enormously to the recovery and rehabilitation of severely wounded warriors. Moreover, we believe it would avert what is otherwise likely to be a growing need for long-term institutional care. In short, establishing a comprehensive family caregiver program such as the one envisioned by S. 801 is not only the right thing to do for our wounded warriors, but a fiscally prudent one.

Given the handful of very limited and inconsistent wounded warrior family caregiver programs and support services now available, families are coping largely on their own. VA testified last year that it provides home health services to veterans in many areas through contract arrangements with some 4,000 home health agencies. But many of the families of our newest generation of wounded warriors consider such services—even if they are available locally—a poor alternative to the care provided by a devoted parent, sibling, spouse, or friend. Local services vary greatly in both quality and quantity. 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 refer them to these same local agencies for possible employment.

Legislation is now urgently needed to avert foreseeable family tragedies through creation of a nationwide, comprehensive wounded warrior family caregiver program such as the one proposed in S. 801. At its core, this legislation would meet a vital need for those seriously wounded warriors who require extensive personal care. This legislation would provide an option not now available to many severely injured veterans whose families cannot meet or sustain their loved ones' caregiving needs.

S.801 Provides the Kind of Comprehensive Support that Family Caregivers Need.

Informed by the experience of our wounded warriors and their families, Wounded Warrior Project enthusiastically supports passage of S. 801. It lays a comprehensive and needed foundation for a VA-administered family caregiver program comprised of three basic elements: training and certification, provision of support services, and a modest monthly allowance. Participation would be predicated on an objective, clinical determination of a veteran's need for extensive daily caregiving, and the family caregivers' capacity to provide the needed assistance.

Under S. 801, an individual who, with the veteran's assent, agrees to serve as the veteran's Primary Personal Care Attendant, and who successfully undergoes training and achieves certification, would be provided the support and services needed to sustain that role. This support and these services would include counseling and needed mental health services; technical support, including access to a Web portal linked to a wide range of nationwide family caregiver support services; 30 days of annual respite care; CHAMPVA health care coverage; and a modest monthly allowance. Other family members can also receive basic family caregiver training, and, upon certification, have access to counseling and technical assistance.

S. 801 provides the full array of support needed by family caregivers while establishing a framework that balances the needs of the wounded warrior and the family caregiver. The legislation provides VA the needed latitude to design and administer the program, but also directs

VA to consult with wounded warriors, family caregivers, VSO's and other pertinent organizations during the design and initial implementation phases.

We anticipate that VA would employ an interdisciplinary process to determine the need for caregiving assistance. Such a process would include an objective assessment of the veteran's need for caregiving assistance in performing such routine activities of daily living as feeding, dressing, bathing and other personal hygiene needs. This assessment and a VA family caregiver recommendation would in no way obligate the family. It would simply provide the veteran and family an additional option where feasible and appropriate.

VA would provide all training and certification at no expense to the service member or designated family caregiver. VA's responsibility to these family caregivers would not end with training and certification. S. 801 sets the framework to provide direct technical support, including information, assistance, and counseling, and to address routine, emergency, and specialized caregiving needs in a timely manner.

To be effective and sustaining, a family caregiver program design must address the intense burden of daily caregiving. S. 801 does so by including such program elements as respite care of not less than 30 days annually, to include 24-hour per day respite, tailored to meet each Primary Personal Care Attendant's needs.

A viable program must also provide a means of protecting the health of a family caregiver who undertakes the weighty commitment of providing ongoing primary care of a wounded warrior. S. 801 meets that important need by making Primary Personal Care Attendants eligible for medical care under the CHAMPVA program.

Finally, cognizant that many family members must forego employment and often relocate to provide care to a loved one, the authors of S. 801 have met a critical need by providing the Primary Personal Care Attendant a modest monthly stipend based on the level of daily care provided. S. 801 would direct VA to establish a schedule of allowances tied to the amount the Department would pay a commercial home health care agency to provide a commensurate level of personal, daily care authorized for that veteran.

We should note that our focus on the importance of family caregiver assistance outlined in Section 3 of S. 801 does not, in any way, indicate a lack of support for the other provisions of S. 801. Section 2 waives charges for humanitarian care provided to family members accompanying certain severely injured veterans receiving care at a VA, VA-contracted, or "fee-basis" facility. Section 4 authorizes VA to pay lodging and subsistence to attendants who travel with a disabled veteran to receive treatment at a VA facility. These additional proposals serve as logical, additional components of a nationwide family caregiver program, and have our full support.

We welcome the opportunity to discuss the elements of S. 801 in more detail, including what some families see as a need for greater flexibility in the bill's oversight provisions. But, above all, we urge the Committee to make enactment of S. 801, "The Family Caregiver Program Act of 2009", a top priority.

Thank you for your interest in this important issue. I'm pleased to address any questions you or other Members of the Committee have at this time.