Veterans' Families, Caregivers, and Survivors Federal Advisory Committee

Recommendations
October 29, 2018

Recommendation 1: That VA lead a national, government-wide interdepartmental effort to identify all federal programs serving Veteran caregivers, families, and survivors and ensure the needs and perspectives of these populations are represented.

Rationale for Recommendation: Presently there is not an organized inventory of VA programs and services for Veteran caregivers, families, and survivors. This effort to identify and include all relevant federal programs (e.g., Federal Recovery Care Coordination Program, Administration for Community Living resources) should focus on expanding services to Veterans' caregivers, families, and survivors, reducing costs related to overlapping and redundant programs (e.g., respite care, wellness programs for caregivers), and identifying and implementing the most cost-effective ways to deliver services. Among the services that should be specifically addressed are respite care, financial assistance, transportation, service navigation (including case management services), and mental health services. For example, agencies such as the National Institutes of Health, Centers for Disease Control, and Administration for Children and Families each share resources related to managing caregiver stress, transportation, among other resources that can be leveraged across agencies and across caregiver populations.

This recommendation can be measured by progress made on the development of this resource inventory. VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 2: That VA centralize efforts to oversee and drive the formation of policy and the implementation and delivery of programs and services supporting Veteran caregivers, families, and survivors.

Rationale for Recommendation: Currently, there is no one office charged with creating and implementing VA's overall strategy towards Veterans' caregivers, families, and survivors. Although there are a number of programs across VA that directly support each of these subgroups (e.g., VA Caregiver Program) there is a need to coordinate efforts across VA to support people attempting to access these resources, to ensure smooth delivery and harmonization of these programs, or to make recommendations regarding long-term coordination of care for Veterans' caregivers, families, and survivors across the VBA, VHA, and NCA. The current structure creates the possibility for families to fall through the cracks of the system and prevents VA from being able to effectively and efficiently support these families or gather data to understand their needs.

We recommend that VA centralize its support of Veteran's caregivers, families, and survivors by engaging in, at a minimum, the following activities:

1. Conducting an audit across the VA system to understand which programs directly support Veteran's caregivers, families, and survivors. The purpose of the audit would be to create an internal inventory of these programs for the benefit of VA staff who might not know they exist, and to create an external central hub where families can navigate these services with ease.

2. Working directly with the leaders of existing programs that support families to make sure they:

a. Have both policy and operational control of their programs
b. Are collecting data that informs our understanding of this population
c. Are effective in serving the Veteran's caregivers, families, and survivors of Veterans
d. Are adequately funded

3. Planning and implementing a national strategy for family support across the entire VA system.

This recommendation can be measured by progress made on each of the recommended activities. VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 3: That VA identify, fund, disseminate, and consistently apply innovations and/or replicable models to address the needs of Veteran caregivers, families, and survivors, in collaboration with non-governmental nonprofit organizations.

Rationale for Recommendation: The newly developed Elizabeth Dole Center of Excellence for Veteran and Caregiver Research, which is dedicated to research to expand the department's capacity to deliver innovative, data-driven and integrated approaches to improve services for Veterans and their caregivers, brings tremendous opportunity to advance research amongst these populations. There is also significant potential for the VA Center for Innovation (VACI), which is currently focused on identifying and replicating successful innovation solutions that have been developed within the VA community. In reviewing the current landscape for innovative or replicable models to address the needs of Veterans' caregivers, families, and survivors, there are a number of notable programs such as programs that extend understanding of PTSD symptoms (e.g., Wounded Warrior Project), effects, and recovery (e.g., Federal Recovery Coordination Program); programs for respite care (e.g., Blue Star Families); telehealth services to include family members; education to combat myths, stigmas, and fatigue among caregivers (e.g., Easter Seals-Military and Veterans Caregiver Services); and peer-to-peer programs (e.g., Tragedy Assistance Program for Survivors).

This recommendation can be measured by the number of innovative and/or replicable models identified, funded, or disseminated. VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 4: That VA develop a system-wide strategy to more comprehensively collect, analyze, disseminate, and utilize data on Veteran caregivers, families, and survivors to improve the delivery of services

Rationale for Recommendation: Data collection and research are of paramount importance to our understanding and continued support of the Veteran family and caregiver population, but the effort to gather information on these families is hindered by several obstacles, including access to the target population itself. For example, right now VA is only collecting data for the very small population of caregivers who are enrolled in VA's Program of Comprehensive Assistance for Family Caregivers. We know from data collected last year as part of the enrollee survey that 2.5 million Veterans indicated they require a caregiver. There is a lack of available data on Veterans' families (particularly longitudinal data) that can be used for research. DOD supports a great deal of data and research on active duty, National Guard, and Reserve families, yet there is an absence of data collection through VA.

Determining critical data points that may be predictive for positive user-experiences and identifying which gaps exist for Veterans' caregivers, families, and/or survivors can have a significant impact on this target audience. Additionally, defining interaction patterns best suited to the critical/predictive "Moments that Matter" will produce the greatest likelihood for matching user expectations and standards for positive customer experiences. Assessing why Veterans, families, and survivors do not utilize VA services can also provide insight on user experience. VA is well-positioned to leverage existing platforms, like the annual VHA enrollee survey, as well as the newly-created Elizabeth Dole Center of Excellence for Veteran & Caregiver Research, to survey this population and gather valuable data that could be utilized to inform long-term research and to develop best practices for supporting this population. It is recommended that VA develop and begin to implement a strategy to integrate Veterans' caregivers, families, and survivors into all relevant data collection processes, including surveys and large-scale research initiatives. We also recommend that VA include, as part of this strategy, efforts to disseminate this data to partners and support organizations that would benefit from the data collected.

This recommendation can be measured by progress made on the data collection, analysis, and dissemination efforts, as well as ways in which the data are utilized (e.g., number of program or policy changes it has informed). VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 5: That VA develop a system-wide strategy to more comprehensively collect, analyze, disseminate, and utilize data related to children and/or dependents of Veterans and the services available to them to improve the delivery of services.

Rationale for Recommendation: Even though the wellbeing of military and Veteran children ranks as a consistently high priority among caregivers and military families, we know too little about the long-term impact and needs of these children. In the 2017 research blueprint, *Improving Support for America's Hidden Heroes*, the RAND Corporation noted that there is no research on the impact of caregiving on military children. Within the VA system, no data are collected on the children or dependents of Veterans, much less the children of Veterans who are also impacted by caregiving. We recommend that VA assess whether there are current initiatives related to supporting children of Veterans and develop a strategy to identify and gather data on these children to help inform the existing literature and research base.

This recommendation can be measured by progress made on the data collection, analysis, and dissemination efforts, as well as ways in which the data are utilized (e.g., number of program or policy changes it has informed). VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 6: That VA (a) conduct a thorough analysis of the need for respite care resources, their availability, and their effectiveness, and (b) offer a range of respite care programs (e.g., Veteran Directed Home and Community Based Services) to improve access to and delivery of respite care by Veteran caregivers and family members.

Rationale for Recommendation: The 2014 RAND Study, *Hidden Heroes: America's Military Caregivers*, found that respite care was a number one need of caregivers taking care of wounded, ill, or injured Veterans. According to the study, there are an estimated 5.5 million military caregivers in the United States. Of these, 1.1 million (19.6 percent) are caring for post-9/11 Veterans. Despite this, respite care utilization remains low among the caregiver population, particularly among post-9/11 caregivers. There are many reasons for this – certain programs that promote the use of respite care (like Veteran-Directed Home and Community Based Services) are only available at certain VA sites, respite programs are not adequately funded to support the number of families who need them, and current models that cater to elderly patients or patients with particular health conditions (e.g. dementia) are not always appropriately structured for younger Veterans or Veterans with mental/behavioral health issues. Specific marginalized populations are currently not supported by the services and resources available through VA. Specifically, extended family members of Veterans are often not eligible to receive benefits or services offered to other, more immediate family members recognized by VA (i.e., Veteran spouses and children). Siblings and parents are often most neglected by services at VA, often only receiving support indirectly as a result of acting in a caregiving role for the Veteran. Improving user experiences based upon the discernment of critical/predictive success factors such as context, accessibility, demographics, individual situations and geography will aid in boosting user experience for Veterans' families, caregivers, and survivors.

We recommend that VA conduct a thorough assessment of the type and utilization rates of respite opportunities available to caregivers and families through the VA system. It is also extremely important that VA expand availability and funding for Veteran-Directed Home and Community Based Services, which allows Veterans and caregivers to make hiring decisions regarding the Veteran's care. Finding a respite provider that both the caregiver and Veteran trust is essential to ensuring that respite care is used, and often the caregiver and Veteran are best equipped to find and engage with a provider who understands their needs. Furthermore, providing options for respite and supportive care will empower Veterans, caregivers, and their families to make essential decisions about the delivery of care to their Veteran. Expanding the Veteran-Directed Home and Community Based Services program to all VA sites, and ensuring adequate funding for the program, will allow all eligible caregivers and Veterans the opportunity to engage with respite care services on their own terms, regardless of location.

This recommendation can be measured by the number of Veteran caregivers and family members accessing respite care services. VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 7: That VA develop an enterprise-wide strategic plan to raise awareness to ensure that VA systems and professionals are defining the importance and role of caregiving and communicating sensitively and effectively with all persons serving in the role of caregiver, family member, and survivor for Veterans.

Rationale for Recommendation: Veterans' caregivers, families, and survivors interact with multiple professionals and providers throughout experiences with clinical care, support services, and home-based services. VA anticipates well over 150,000 Veterans of all eras may be eligible for the Caregiver program when the changes made by the VA Mission Act of 2018 are fully implemented. To effectively prepare for this vast increase in caregivers interacting with VA programs, it will be essential to not only strengthen recruitment and retention efforts, but also identify training opportunities to improve Veteran and caregiver experiences with VA professionals (e.g., Elizabeth Dole Foundation's Campaign for Inclusive Care).

Veterans' caregivers can be defined broadly: a family member, friend or acquaintance who provides a broad range of care and assistance, though stigma is sometimes associated with the caregiver title. The Program of Comprehensive Assistance for Family Caregivers allows up to two (Primary and Secondary Caregiver) per Veteran. Many interventions and resources focus on a single caregiver model, often the Veteran's spouse. However, neither Veteran nor caregiver exists in a vacuum, and their behavior and challenges often affect the entire family. Primary caregivers are often spouses, parents, siblings or friends. Those primary caregivers are critical but are only one piece of the caregiver model. Secondary caregivers are individuals who support and are emotionally invested in the Veteran's health and recovery. Secondary caregivers could be the Veteran's parents, spouse, siblings, children or close friends. There is not a one-size-fits-all archetype to support persons serving in the role of a caregiver. Therefore, its is recommended that the VA not only increase awareness of the roles of Veteran caregivers, but also develop a holistic model of Veterans' caregiver, families, and survivors support to address the unique challenges they face.

This recommendation can be measured by the number of individuals touched by the enterprise wide strategic plan, as well as through change in Veteran and caregiver satisfaction reports of communication with VA systems and professionals. VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 8: That VA develop training materials and resources for VA's interdisciplinary teams to (a) identify Veteran caregivers, (b) integrate Veteran caregivers into the assessment and delivery of care and social services, and (c) identify and address the unique mental health and physical needs of Veterans' caregivers, family members (including children), and survivors.

Rationale for Recommendation: Health care providers working with Veterans' caregivers should conduct initial and subsequent follow-up assessments of the caregivers' needs, alongside the Veterans' own needs, to ensure that the caregiver and care recipient are both adequately supported. Providers should be knowledgeable about the effects of caregiving on recovery outcomes for Veterans and should integrate caregivers in the Veteran's treatment to ensure optimal recovery outcomes. Civilian sector providers often lack cultural competency of the military culture and of understanding post-deployment effects on child development, failing to ask screening questions such as military status. Such providers also need training on the potential for, and identification of, secondary traumatic stress among parents who have Veteran children that may have served in combat. This population, which is often neglected in research and excluded from support programs, can experience significant physical and emotional impacts from caregiving for their Veteran sons and daughters that can contribute to secondary traumatic stress. Civilian health care providers should be informed on other related challenges Veterans face including reintegration challenges, impact of physical injuries, and behaviors associated with PTSD. Any additional training would help provide support to parents who serve as caregivers to their Veteran children. It is also important that home health care clinicians are prepared and trained to direct Veterans and their family members and/or caregivers to the appropriate benefits and services available to them to meet their unique care needs. While some of this work is underway with VA's Campaign for Inclusive Care with USAA and Elizabeth Dole Foundation, it is recommended that VA advance this work by ensuring caregiver integration is the standard of care.

This recommendation can be measured by the number of interdisciplinary teams that receive related materials or resources, and how these resources impact their delivery of care and services. VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 9: That VA (a) integrate the Veteran-designated family member and/or caregiver into all relevant discussions on health record modernization, and (b) include an official designation identifying a Veteran-designated family member and/or caregiver as part of a Veteran's health record.

Rationale for Recommendation: VA has made tremendous strides in the past few years to modernize their IT system and address security and interoperability challenges. The newly created Office of Electronic Health Record Modernization has been tasked with phasing out the old, cumbersome legacy system to the new Cerner system, which will allow better data sharing with the Department of Defense. The changes being made are even more important as VA works to streamline Veteran access to community care through the VA MISSION Act, expand telehealth initiatives, and implement the Choose Home program. For these changes to be successful, however, VA must engage with users of the system – Veterans and their caregivers. One of the consistent challenges reported by caregivers is ensuring that their Veteran's records are up to date and properly recorded in the VA system. Caregivers struggle to ensure that VA records are shared with community providers, that records from community providers are fed back into the VA system, that community providers are reimbursed in a reasonable timeframe, and within the VA network itself, that the various departments have access to a clear and full picture of Veterans' health records. Caregivers offer a unique perspective as users of the system that bridge the gap between VA and community providers, and VA and the Veteran patient. We recommend a two-pronged solution: a) VA integrate the caregiver perspective into all relevant health record modernization discussions, including having a caregiver representative on the EHRM Councils and incorporating caregiver input

into the implementation of the VA MISSION Act and other relevant VA initiatives, and b) VA adopt the following items to integrate into its record-keeping strategy:

- That the name of the family caregiver be recorded as part of the intake process
- That the family caregiver is included as part of the care team developing the Veteran's treatment plan, and that they are notified of any major changes or decisions to that plan that affect the care they will provide
- That the family caregiver is notified when his or her loved one is discharged from the hospital or medical facility
- That the primary care team provide verbal and written instructions for the family caregiver detailing the care responsibilities they will have to fulfill at home

Based on the provisions of the CARE Act, these measures will help ensure that the caregiver is made an official part of the Veteran's health record and recognizes them as a vital part of the care team, giving the caregivers rights as outlined in legislation. This would provide a balance between Veteran's security and privacy while also giving the Veteran's caregiver the ability to access and coordinate services as part of the Veteran's care team.

This recommendation can be measured by assessing the ways in which caregivers have been integrated in discussions on health record modernization, and by identifying the number of family members or caregivers included in Veteran health records. VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 10: That VA review and standardize the VHA clinical appeals process to be more transparent and to better integrate Veteran caregiver and family input as a means of processing appeals.

Rationale for Recommendation: Veteran caregivers assist with nearly all aspects of the care and treatment of their Veterans, and appealing a clinical decision is no exception. Currently, VA facilities have the authority to develop their own clinical appeals process, under the guidance of VHA Directive 1041. The current appeals process in the Program of Comprehensive Assistance for Family Caregivers for Veterans and their caregivers is not consistent and does not provide an independent arbiter to review the clinical determination for reduction in tier level or revocation from the program. Veterans and caregivers who disagree with the clinical determination must appeal through the Patient Advocate, the VA Medical Director and finally the VISN, which often results in varied and inconsistent interpretation and application of policy across VHA. The clinical appeals do not rise beyond the VISN level, unlike appeals within VBA, which can rise to a national board of appeals. These processes give rise to serious issues for the caregivers and Veterans filing their appeals.

There is a lack of standardization and clarity of the appeals process itself – each facility can choose how or what to review to make their determination, within the confines of the VHA Directive, making it difficult for the caregiver or Veteran to know what to provide for review. Caregivers report that, in some cases, the appeal review boards do not interview the Veteran, the caregiver, or any of the primary care team to make an assessment on the appeal, instead relying solely on the Veteran's records, which may be hard to navigate and can lack appropriate context, especially in determining the need for a caregiver. The opportunity for an Independent Arbiter to review determinations provides the Veteran and the caregiver a fair and consistent view of their case independent of VA providers, clinical eligibility team, primary care team, caregiver support coordinator, Medical Directors and VISNs who may be biased by localized interpretations of national policy, as seen in other VHA service lines such as prosthetics. Caregivers and Veterans should be able to rely on a clear and standard appeals process to mediate clinical concerns, and caregivers should be brought into the appeals

process as the part of the care team that has the most day-to-day contact with the Veteran. It is recommended that VA engage MSOs, MSOs, and Caregiver support organizations in this process.

This recommendation can be measured by assessing the extent to which the VHA clinical appeals process was reviewed and/or standardized. VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 11: That VA create a 90-day adjustment period for stipend payment amounts when a tier level is lowered for Veterans and their caregivers participating in the Program of Comprehensive Assistance for Family Caregivers.

Rationale for Recommendation: There is a substantial financial burden placed on Veterans and their caregivers when a tier level reduction occurs in the Program of Comprehensive Assistance for Family Caregivers. These Veterans and caregivers have come to rely on the stipend as part of their income. The financial implications of a tier level reduction and subsequent lowered stipend amount are applied the day the caregiver and Veteran are notified of the tier reduction. There is no time for the Veteran and the caregiver to find or create options for replacing the income to their household. If a revocation occurs, the stipend amount continues for 90 days to allow the Veteran and caregiver to adjust financially. It is recommended that VA create a similar adjustment period when tier reductions or lowered stipends occur to allow for the same financial adjustment for the Veteran and caregiver.

This recommendation can be made by assessing the progress toward the creation and implementation of a 90-day adjustment period. VA will provide an update to the Committee on progress toward this recommendation within one year.

Recommendation 12: That VA establish a clinical indication for Veteran caregivers of the most catastrophically wounded/injured participating in the Program of Comprehensive Assistance through the Veteran's primary care team to lessen the need for reassessment.

Rationale for Recommendation: Our most catastrophically injured Veterans and their caregivers are often subject to reevaluation of their status in the Program of Comprehensive Assistance for Family Caregivers when it is obvious that the medical care needed, and care provided by the family caregiver, has not changed and is not likely to change over the course of six months. A Veteran who is rated "permanent and total" by one VA entity should not have such ratings disregarded or questioned by another VA agency. The internal system can easily verify level of disability without encumbering the Veteran with annual reevaluations which are unnecessary and, in some cases, create a burden on caregivers of our most catastrophically wounded. To address this need, it is recommended that VA establish a clinical indication and process for labeling Veterans and caregivers with this designation to avoid the 90 day and annual reevaluations. The expected outcome would be reduced burden on Veterans and caregivers of the most catastrophically injured.

This recommendation can be measured by assessing the progress toward establishing and implementing the clinical indication. VA will provide an update to the Committee on progress toward this recommendation within one year.