



## **Caregiver and Veteran Experience: Respite Care Needs and Actionable Solutions to Improve Federal and Community Programs**

[Military Officers Association of America](#) (MOAA) and [Quality of Life Foundation](#) (QoLF) roundtable events offer collaborative forums for governmental and non-governmental leaders and experts to work toward a common goal of improving the overall health and well-being of our nation's military and veteran communities. The following is a list of the top unmet needs and actionable solutions gathered from an Oct. 24, 2023, roundtable discussion on *The Caregiver and Veteran Experience with Respite Care*. Agencies and individuals are encouraged to use this information in their respective areas of influence to improve respite care programs and services for our nation's caregivers and veterans.

### **Unmet Needs:**

#### **1. Trust and Confidence in the Veterans Health Administration (VHA)**

- Some caregivers and their veterans are skeptical of VHA's ability to meet their needs and fear the system will reduce or eliminate benefits or access to health care should they seek respite care.
- Some caregivers and veterans are averse to VHA or contracted providers coming into their home.

#### **2. Access Options in Rural Areas**

- Many rural caregivers face a limited availability of services and providers.
- Technology literacy issues and equipment/broadband access limitations may impede the use of telehealth services.
- Limited access to the [Veteran Directed Care Program](#) (VDC)<sup>1</sup> may prevent a veteran from establishing a budget for personal care services and accessing help with activities of daily living.

#### **3. Outreach, Education, and Training**

- There is a notable absence of collaboration, cooperation, and communication of programs and services among and between federal agencies and the community.
- Caregivers and veterans receive insufficient education regarding available respite care options through federal agencies and the community.
- VA medical center staff have inadequate training and knowledge of the respite care options in VHA, Medicare/Medicaid, and in the community.

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<sup>1</sup> [https://www.va.gov/GERIATRICAL/pages/Veteran-Directed\\_Care.asp](https://www.va.gov/GERIATRICAL/pages/Veteran-Directed_Care.asp)

#### **4. VHA Program Eligibility and Access**

- VHA respite programs are difficult to navigate and lack standardization in applying eligibility standards and delivering services across the system.
- The absence of standardization of respite care services creates disparities in quality and availability of options across the Veterans Integrated Services Network.
- Coordination of VHA respite care lacks flexibility to meet emergent needs of caregivers or for managing family life, especially for families with minor children.
- Caregivers and veterans have no primary advocate or single care coordinator to help navigate VHA and more quickly access care options.

#### **5. VHA Respite Care Funding**

- The VDC Program and staff have insufficient funding.
- VHA is unable to serve the rapidly growing population of veterans who will need respite or other home- and community-based and long-term care services without additional funding or interventions from outside of VA.
- VHA has a limited number of specialized facilities or staff to provide skilled nursing services to veterans with spinal cord injuries, bowel and bladder conditions, or other complex medical ailments.
- VA has a limited number of VHA residential care facilities to meet demand.

#### **6. Respite Care Providers and Provider Accountability**

- The nation faces a shortage of home and community-based services and skilled nursing providers.
- There are notable complaints from caregivers and veterans about providers who are no-shows or do not meet contract hours authorized for care.
- VHA does not hold contractors to account for failing to fulfill contractual hours and obligations.

#### **7. Personal Financial Considerations**

- Caregivers and veterans have significant out-of-pocket expenses for respite care services not subsidized through a federal agency or the community.
- Caregivers and veterans have limited options for respite care services that are accessible, available, and affordable in the community.

#### **8. Respite Care Program Usage**

- There is a limited understanding of caregiver and veteran usage of respite care services across VHA.
- Rigorous study on caregiver usage of respite care services across federal agencies and in the community — who and where care is provided — should be performed.

## 9. Caregiving and Child Care Responsibilities

- Assistance is needed in coordinating respite care and balancing child care responsibilities in the home.
- There is a limited understanding of the impact of the veteran's care and the respite needs of caregivers with children living in the household.

## 10. Synchronization of Benefits and Services Among Federal and Community Programs

- Respite care benefits and services vary greatly across the federal government.
- Continuity and quality of care are impacted when there are disruptions in services because there is an absence of collaboration, cooperation, and communication among the federal agencies.
- Federal agencies and community providers are limited in their knowledge of respite resources and how to plug into these services to augment their programs.

### Actionable Solutions:

1. **Create a “Pathway to Advocacy” through legislation like the [Veteran Caregiver Application and Appeals Reform \(CARE\) Act of 2023](#)<sup>2</sup> for veteran service organizations (VSOs) and non-profit organizations operating in the veteran and caregiver sphere to advocate for that population within VHA.**
  - This pathway would provide a standardized process for stakeholder organizations to operate on behalf of veterans and caregivers to assist them with navigating VHA programs.
  - Advocates would be able to provide regular feedback to federal agencies and providers.
2. **Develop and implement a program of Federal Respite Care Liaisons (FRCL) to assist caregivers with navigating all programs that are available for respite care inter- and intra- federal agencies.**
  - Create a Federal Respite Care Liaison (FRCL) to guide caregivers through all respite programs available throughout the federal government, modeled on the [Federal Recovery Coordination Program](#) (FRCP)<sup>3</sup>, in their original intent, to coordinate all respite care options and help select the most beneficial programs for the veteran and caregiver.
  - Install FRCLs at all VAMCs and at all [Program of All-Inclusive Care for the Elderly](#) (PACE)<sup>4</sup> offices and Area Agencies on Aging offices (state agencies for the elderly).

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<sup>2</sup> <https://www.congress.gov/bill/118th-congress/senate-bill/1792/text?s=1&r=2&q=%7B%22search%22%3A%22Veteran+Caregiver+Application+and+Appeals+Reform+%28CARE%29+Act+of+2023%22%7D>

<sup>3</sup> <https://www.gao.gov/assets/gao-11-572t.pdf>

<sup>4</sup> <https://www.npaonline.org/find-a-pace-program>

- Introduce care coordination initiatives that include respite care planning for caregivers with the FRCL.
- 3. Educate caregivers, providers, and the public on what respite care is, what options are available, and where/how to find respite.**
    - Create a national education campaign on how to self-identify as a caregiver; how to identify that one needs respite; or to identify that one has a caregiver, and the caregiver may need respite (potential PSA).
    - Develop training for medical providers, social workers, and clergy, both inside and outside the VA, to help them identify caregivers and their need for respite, as well as options for respite services that exist through the different federal agencies.
    - Implement a respite care referral process for providers to refer caregivers for respite, both inter- and intra-agency.
  - 4. Expand options and personnel to provide respite care.**
    - Increase availability of VDC offered by VA and ensure facilities have the necessary personnel and funding to provide respite care for their serviced areas.
    - Educate staff that some families would rather use family members for respite and allow them to do so through VDC, if an option.
    - Solicit more respite care providers in rural areas for all federal programs.
    - Educate staff that some families have to navigate child care and respite care simultaneously; create programs allowing caregivers to establish care through both at the same time so caregivers may take respite.
  - 5. Make respite programs easier to identify and use by developing integrated systems that help facilitate collaboration, cooperation, and communication between agencies.**
    - Create, maintain, and advertise a directory of respite care options among federal, state, and local agencies in each community, with the program qualifications for participation in each program and a direct contact person being the local FRCL.
    - Provide funding for states and counties to develop options for respite care through grants.
    - Enhance support for caregivers by broadening partnerships and wrap-around services to facilitate access to respite care.
    - Establish a timely, patient-centered health care exchange of information between federal agencies and care providers that includes respite care services needed and supplied, and by whom.
  - 6. Create better accountability practices for providers.**
    - Develop an electronic timecard system for caregivers to track and verify requested vs. fulfilled hours in real time to communicate with authorizing agencies.

- Allow VSOs and stakeholder non-profits to provide regular feedback to federal agencies and providers about respite care in particular areas.
- Solicit feedback on respite through Community Health Needs Assessments and other initiatives to engage with providers, beneficiaries, federal agencies, and the community.

**7. Enhance peer support for caregivers seeking respite.**

- Launch peer mentorship programs to provide guidance and support for caregivers navigating respite care services and resources offered by agencies and community providers.
- Establish a caregiver Battle Buddy Program to coach caregivers and veterans to use respite care.

**8. Study caregiver usage of respite care services across federal agencies and in the community.**

- Identify why caregivers do and do not use respite care.
- Identify costs and benefits of respite care usage for all stakeholders.