

Hidden Heroes

America's Military Caregivers

Rajeev Ramchand

Terri Tanielian



Who is caring for
disabled veterans?

What resources are
available to caregivers?

Where are there gaps?



Methods and approach

Phase 1

Literature review

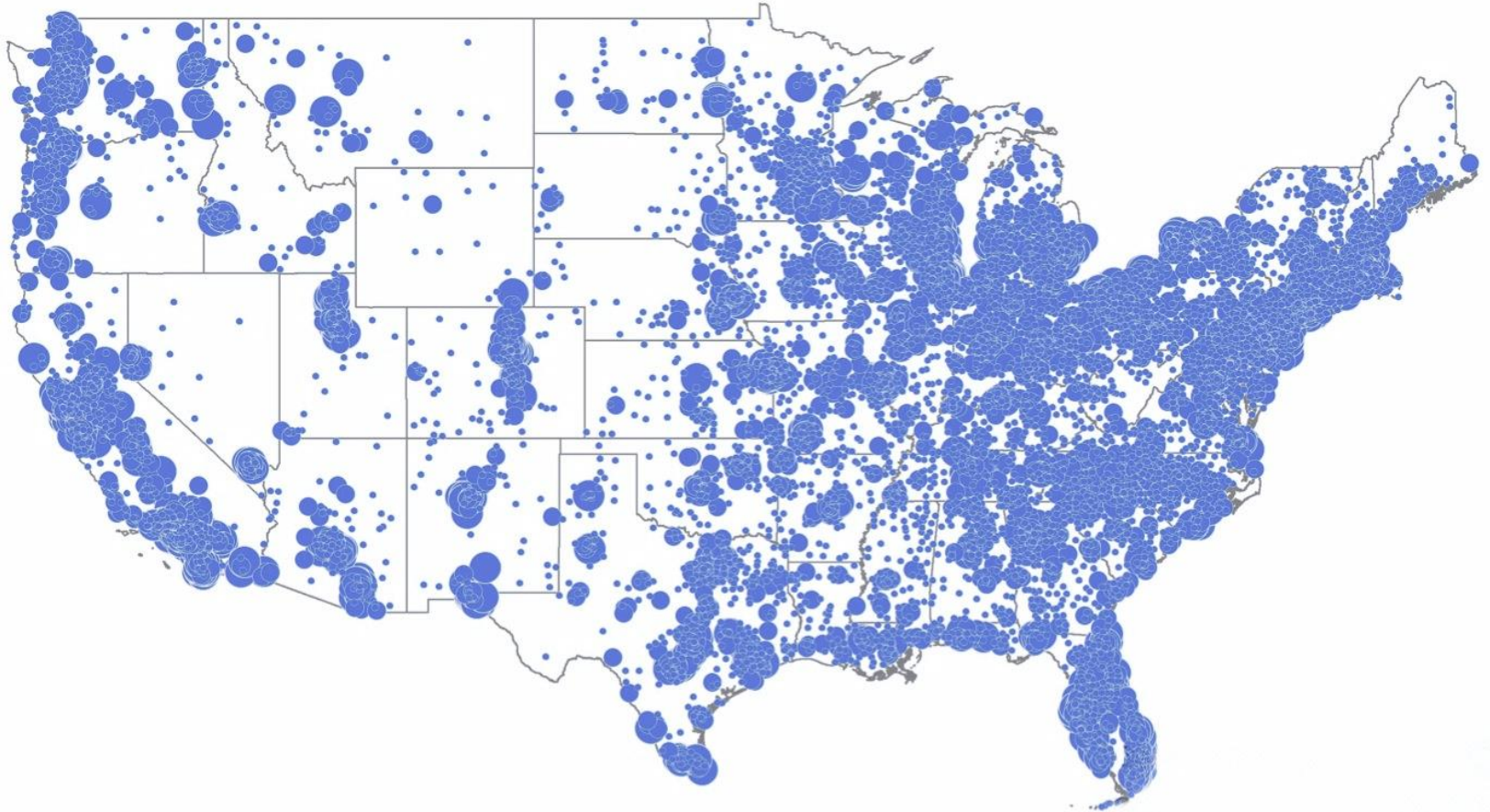
Focus groups/conversations with
military caregivers

Phase 2

National survey of caregivers

Comprehensive environmental
scan

National survey of caregivers

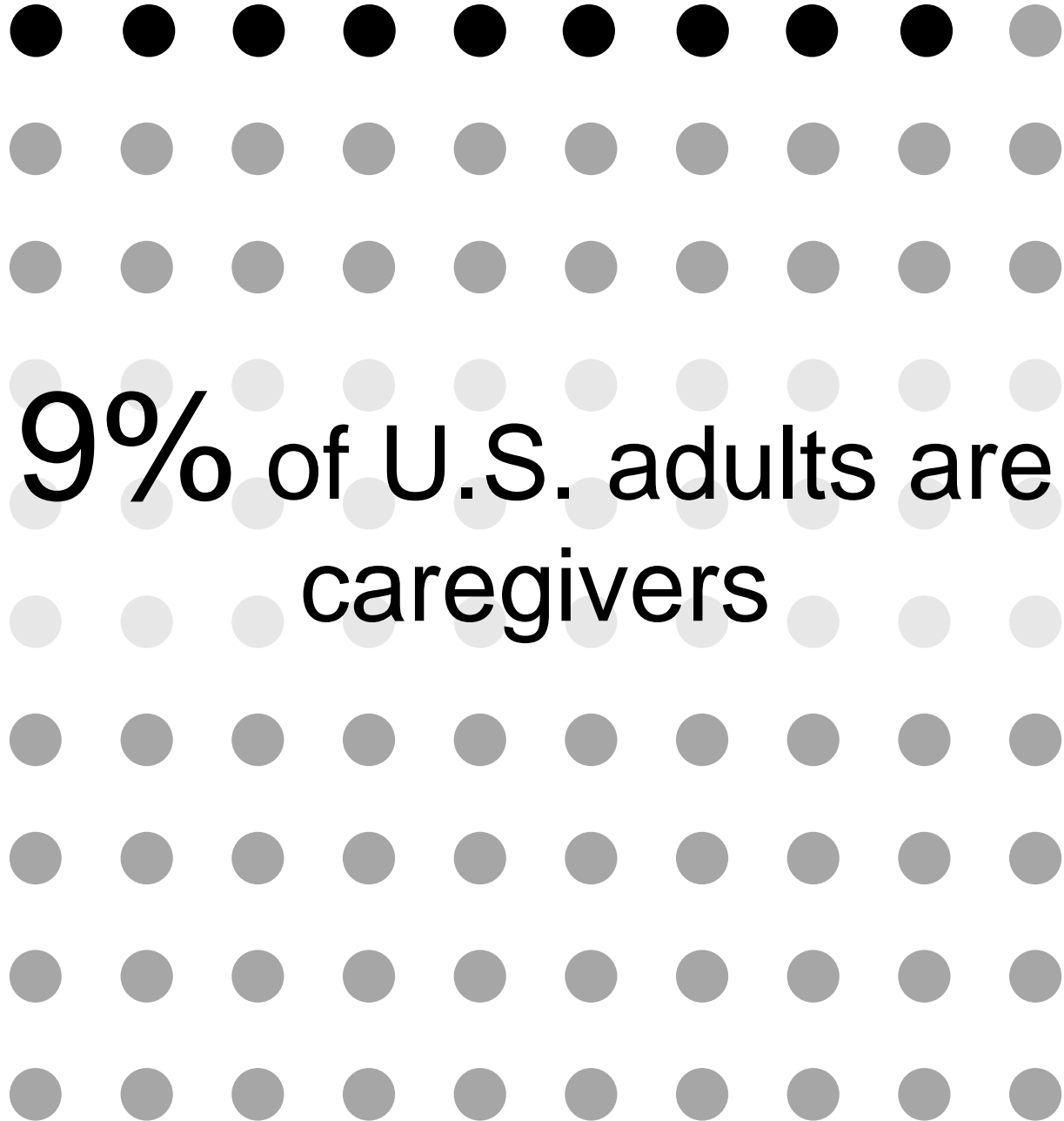


Sample

1,129 military caregivers

1,828 civilian caregivers

1,163 non-caregivers



9% of U.S. adults are caregivers

5.5 million
military caregivers



1.1 million
post-9/11 military caregivers



Describing Caregivers



Post-9/11 caregivers

Younger

Post-9/11 caregivers

Younger

More likely to be a spouse,
friend, or parent

Post-9/11 caregivers

Younger

More likely to be a spouse,
friend, or parent

**Less likely to have
a support network**

Post-9/11 caregivers

Younger

More likely to be a spouse,
friend, or parent

Less likely to have
a support network

More likely to be employed

Describing Care Recipients



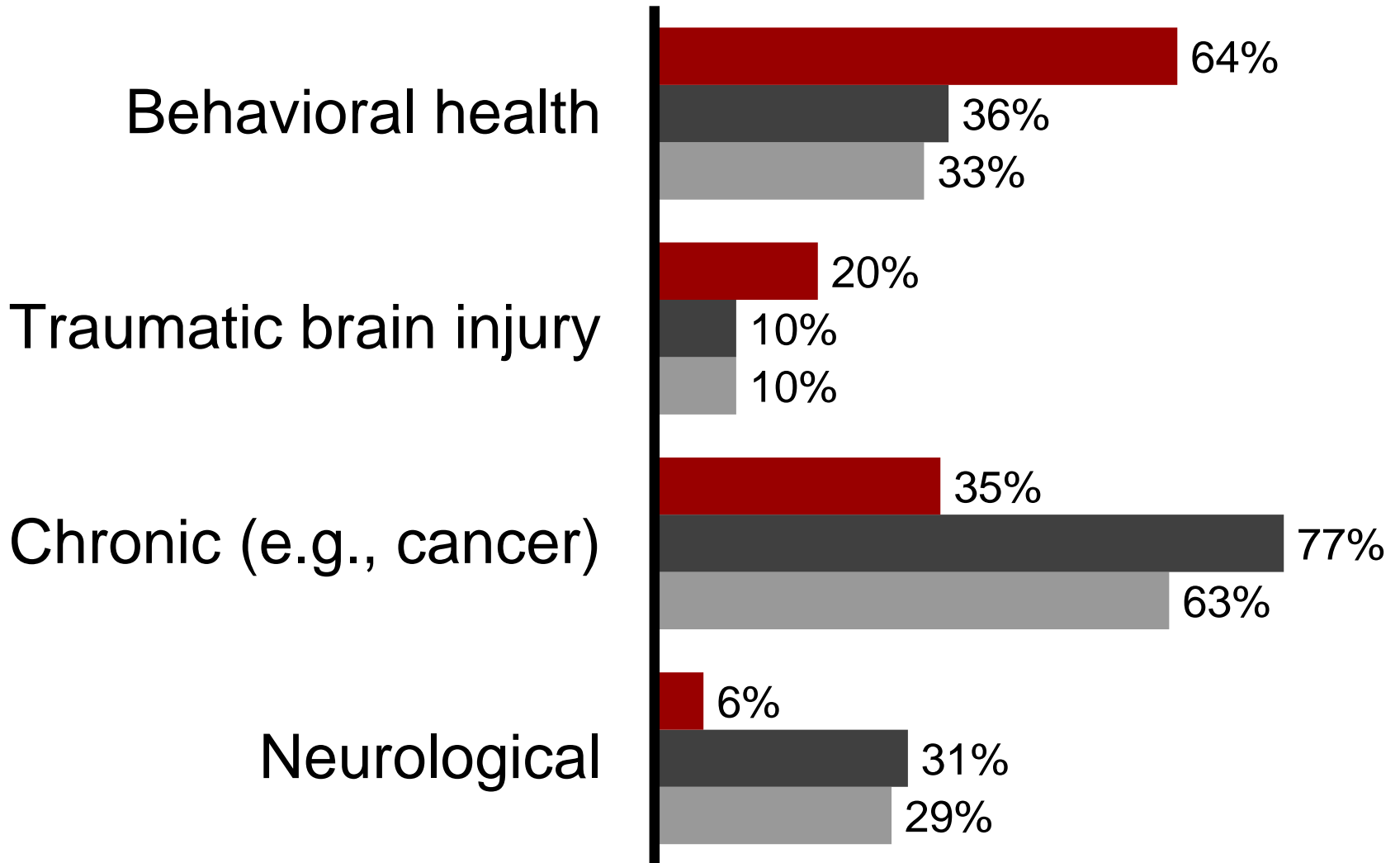
Post-9/11 care recipients

More likely to have
a behavioral health problem

■ Post-9/11

■ Pre-9/11

■ Civilian

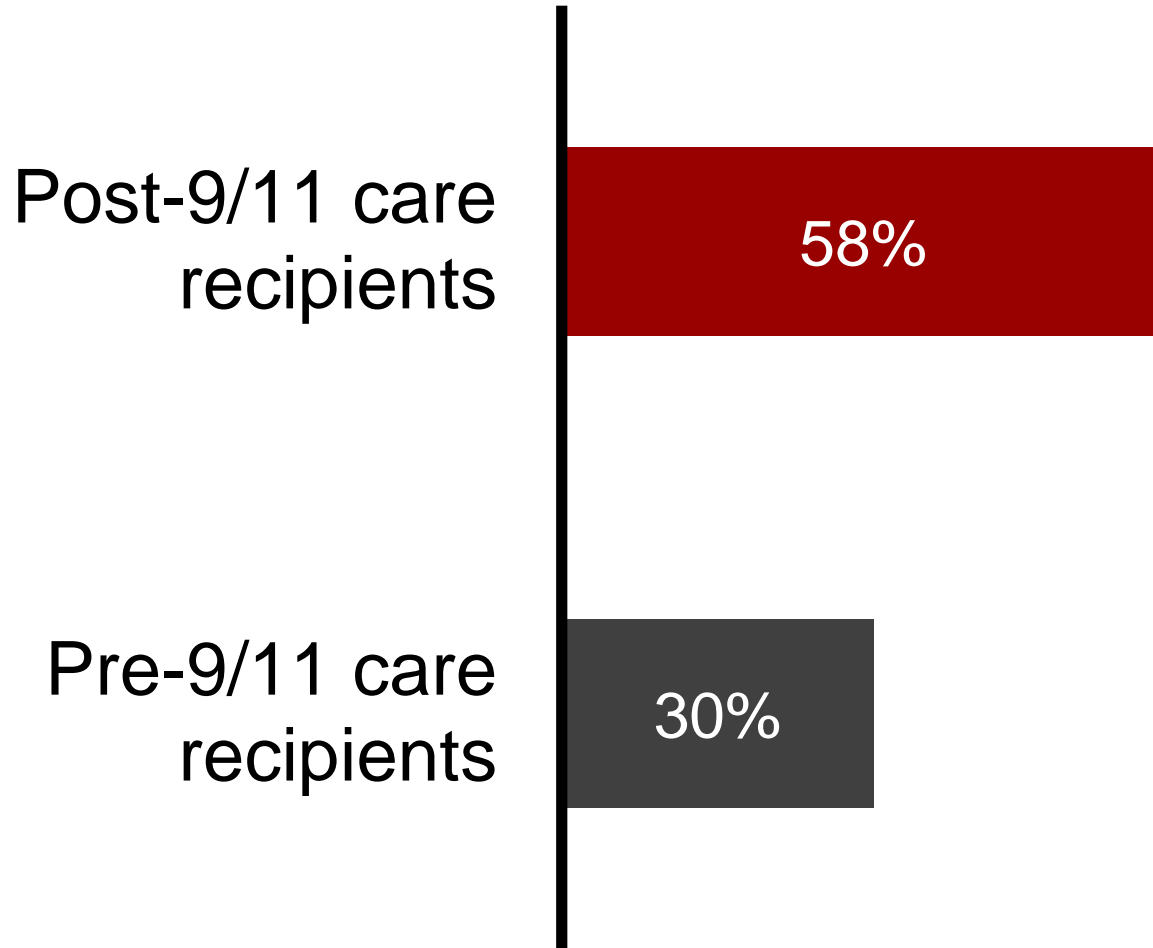


Post-9/11 care recipients

More likely to have
a behavioral health problem

More likely to have
a disability rating

% of care recipients with a disability rating



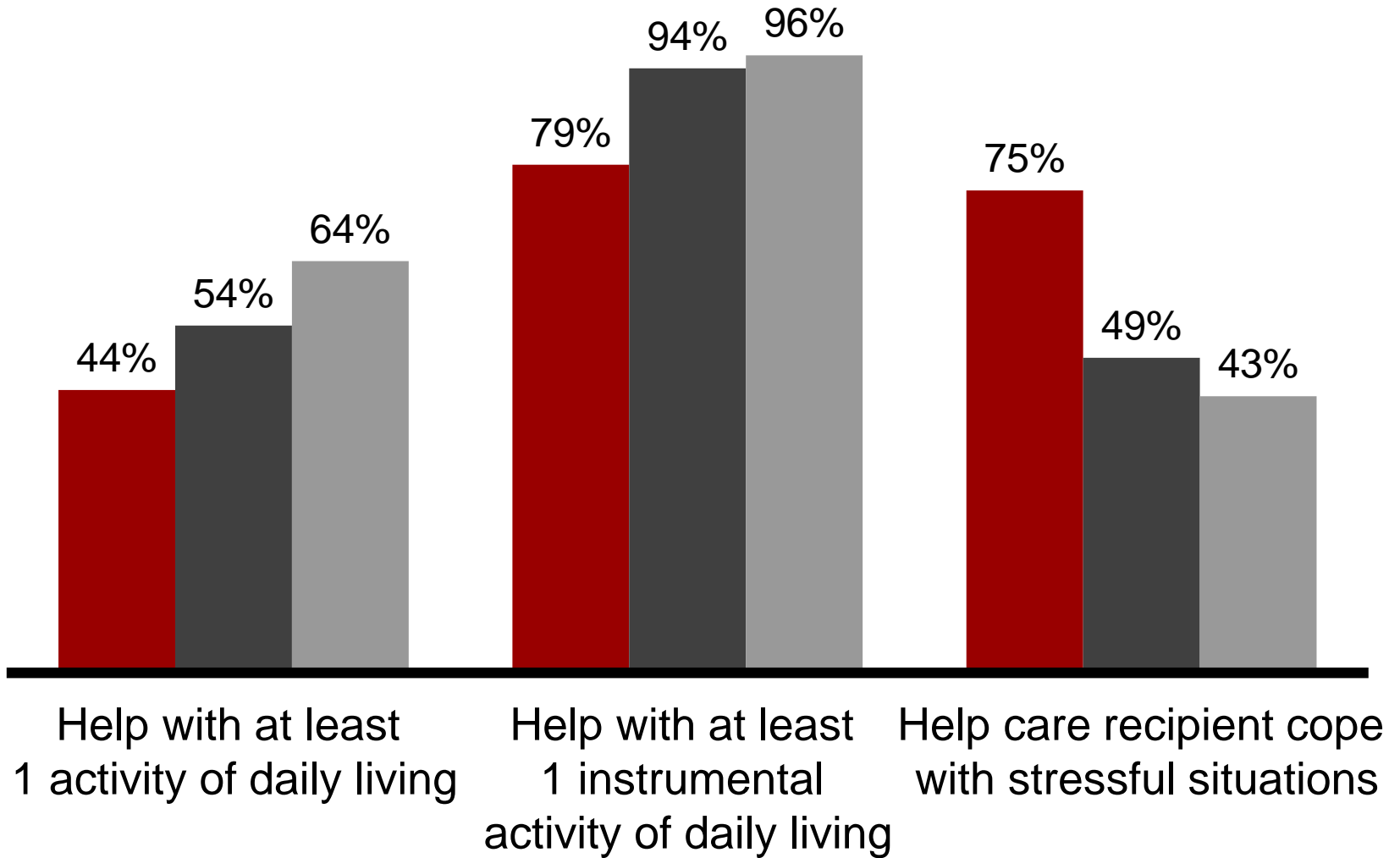
Caregiving Duties



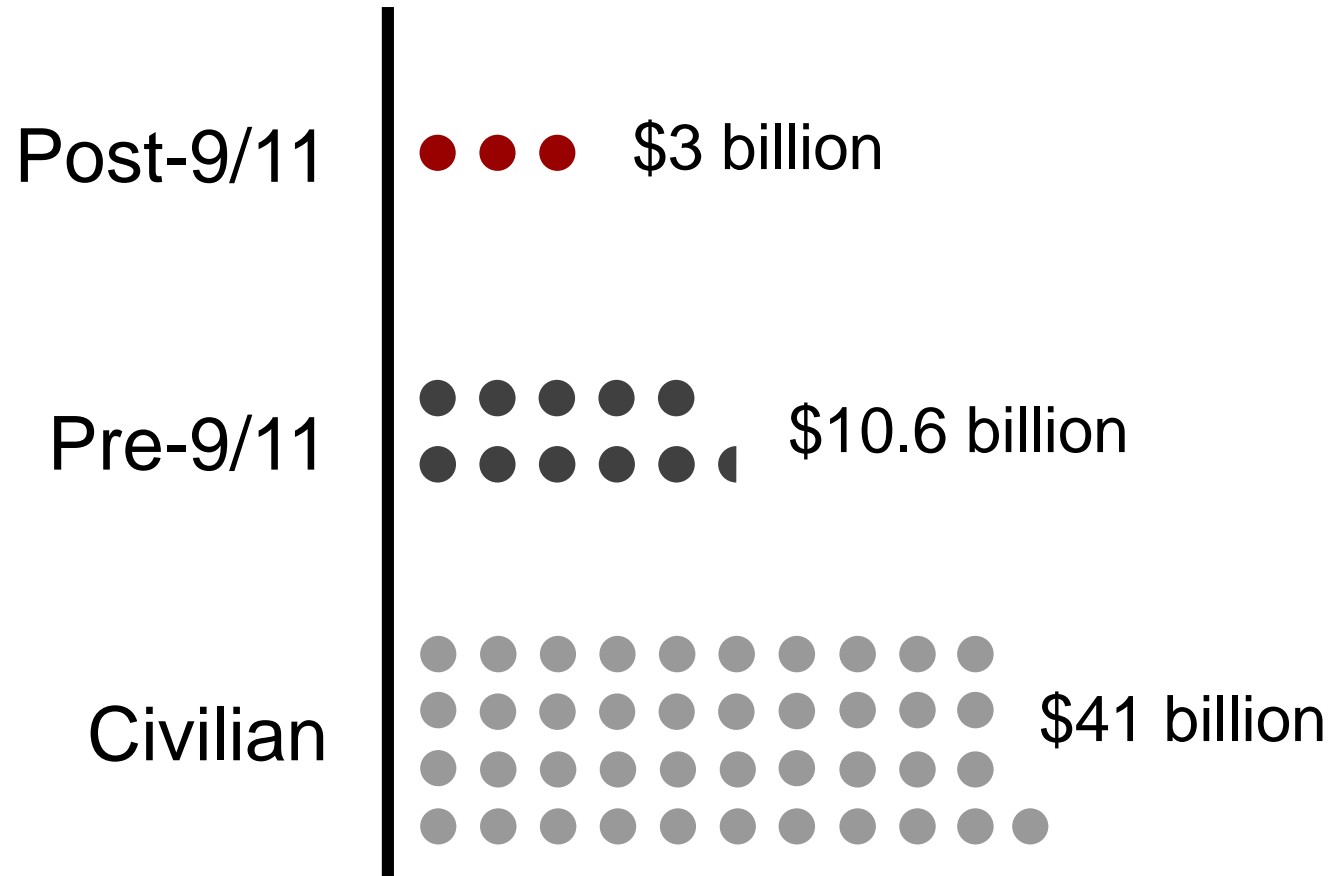
■ Post-9/11

■ Pre-9/11

■ Civilian



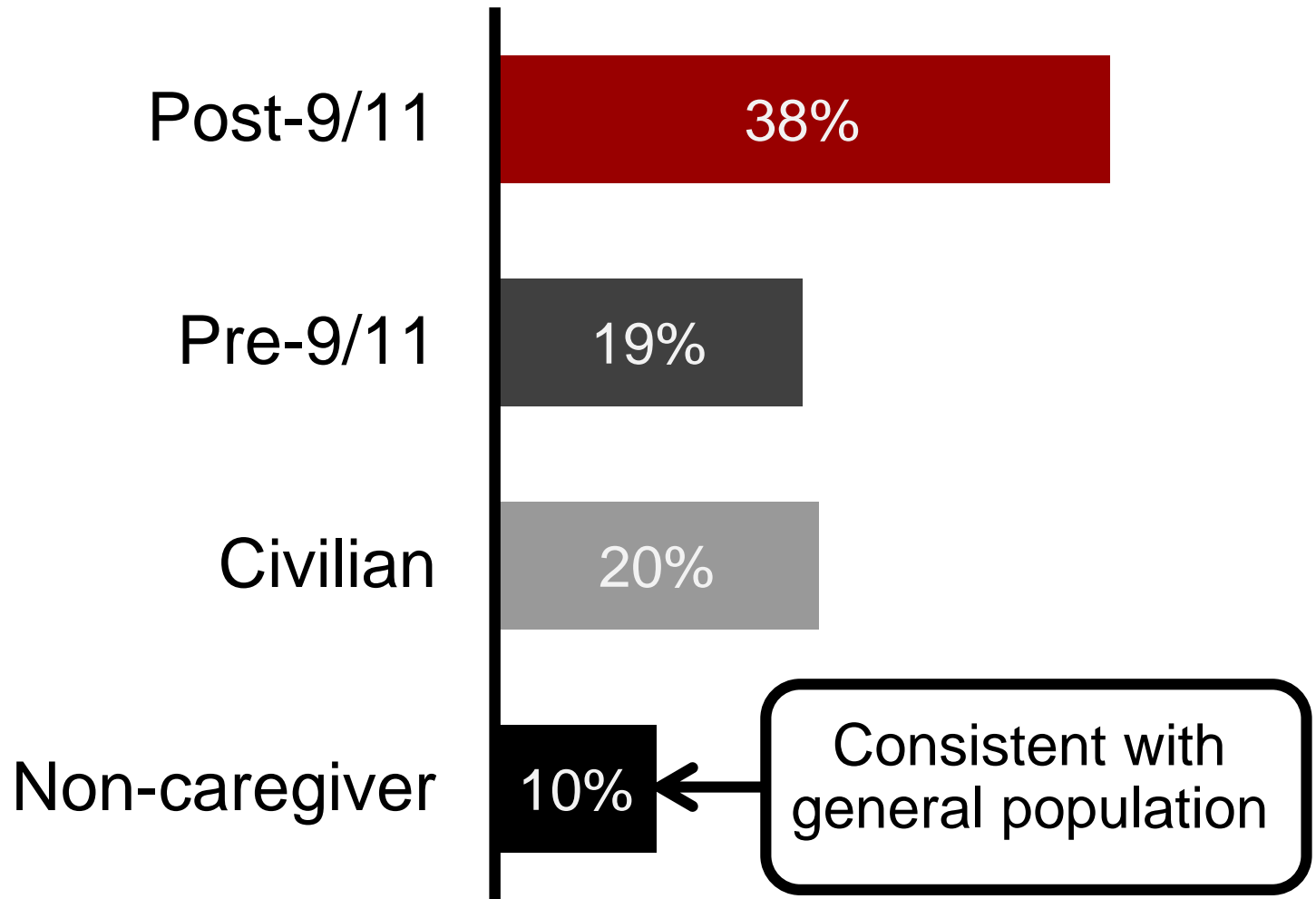
Annual public value of caregiving



Burden of Caregiving



% of caregivers meeting criteria for probable depression



Confirmed
predictors of
major depression
among post-9/11
caregivers

Demographics (race/ethnicity, sex, age, marital status)

Education level

Type of disability

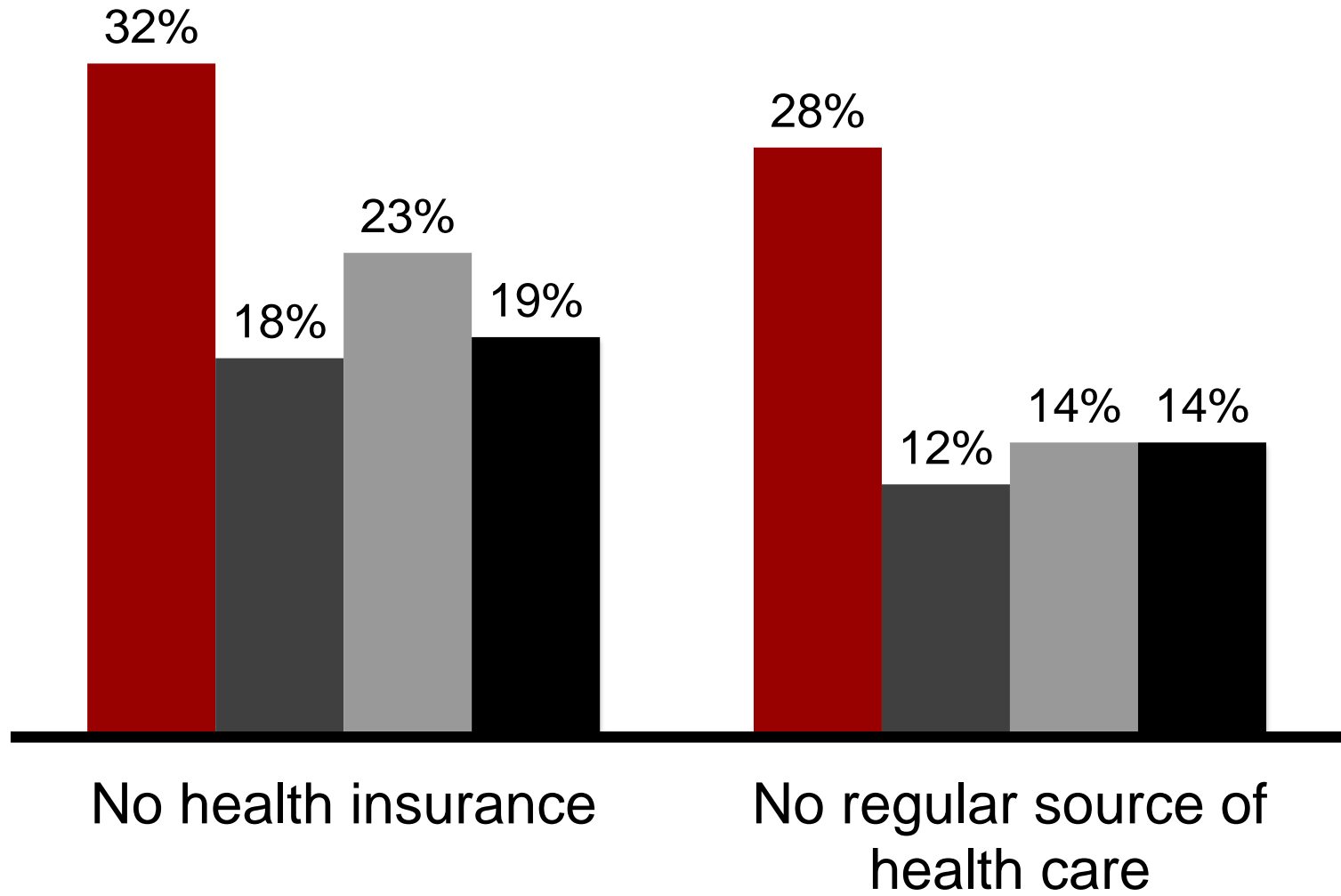
Household income/characteristics

Relationship to care recipient

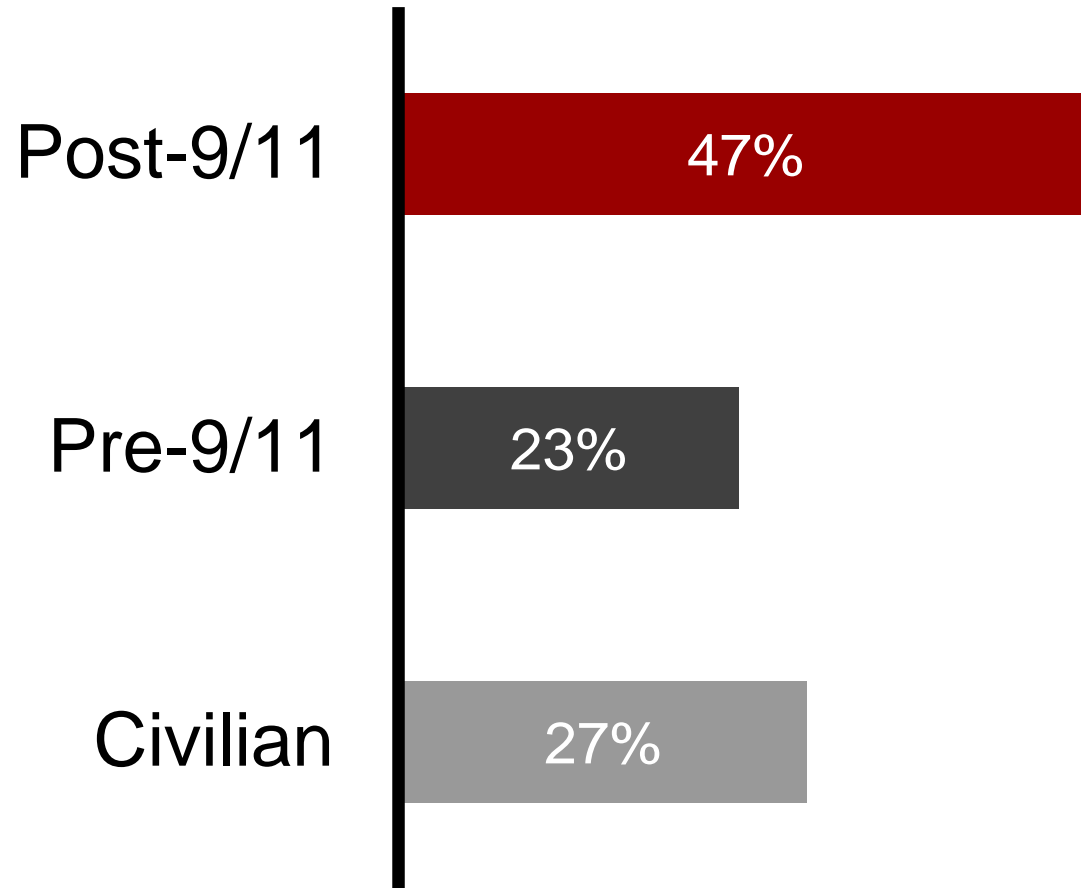
Time spent caregiving

Helping care recipient cope with stressful situations

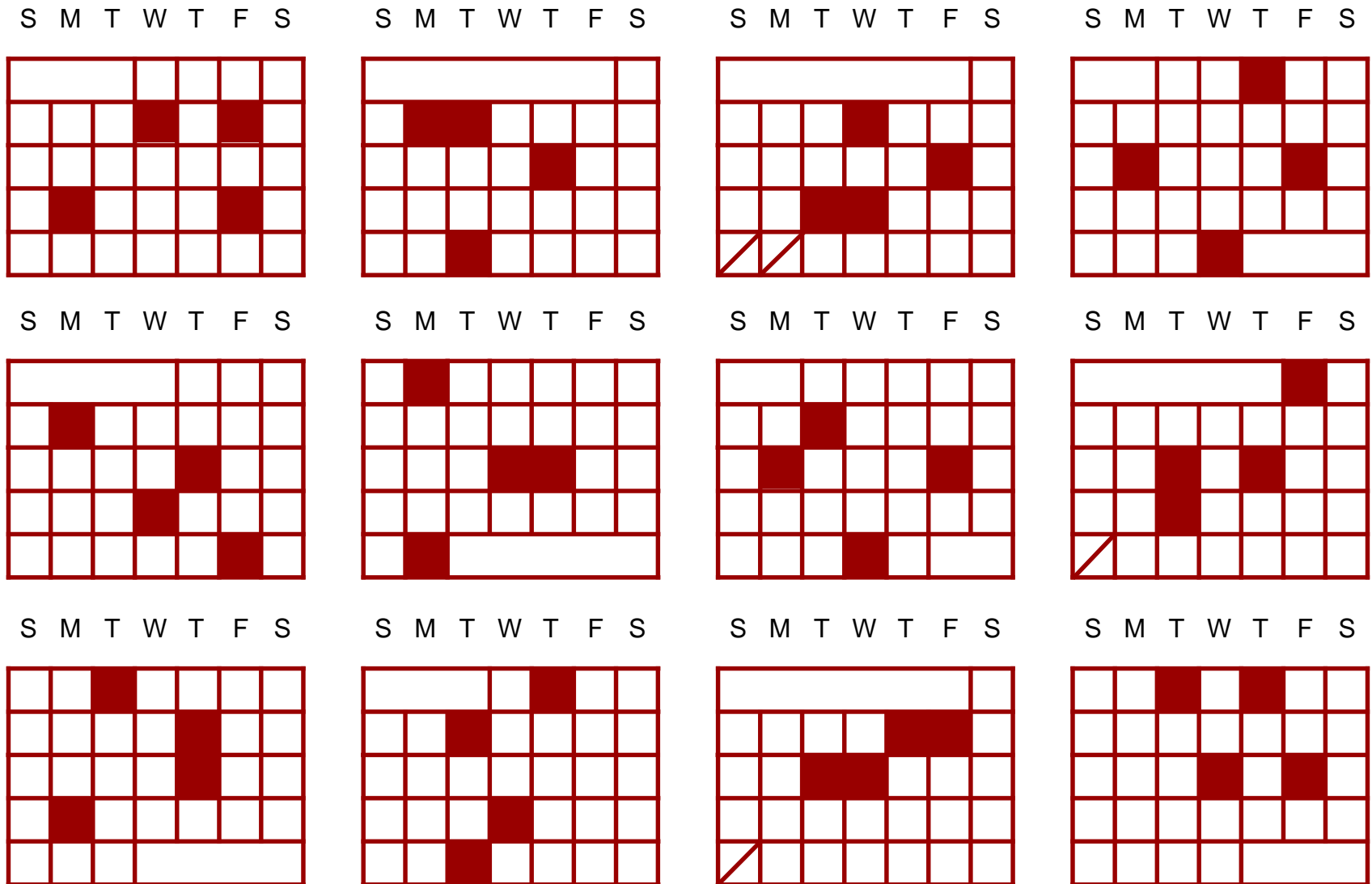
■ Post-9/11 ■ Pre-9/11 ■ Civilian ■ Non-caregiver



% of caregivers reporting work schedule adjustments



\$5.9 billion per year in lost productivity



Resources for Caregivers



Methods and approach

Phase 1

Literature review

Focus groups/conversations with
military caregivers

Phase 2

National survey of caregivers

Comprehensive environmental
scan

Web searches

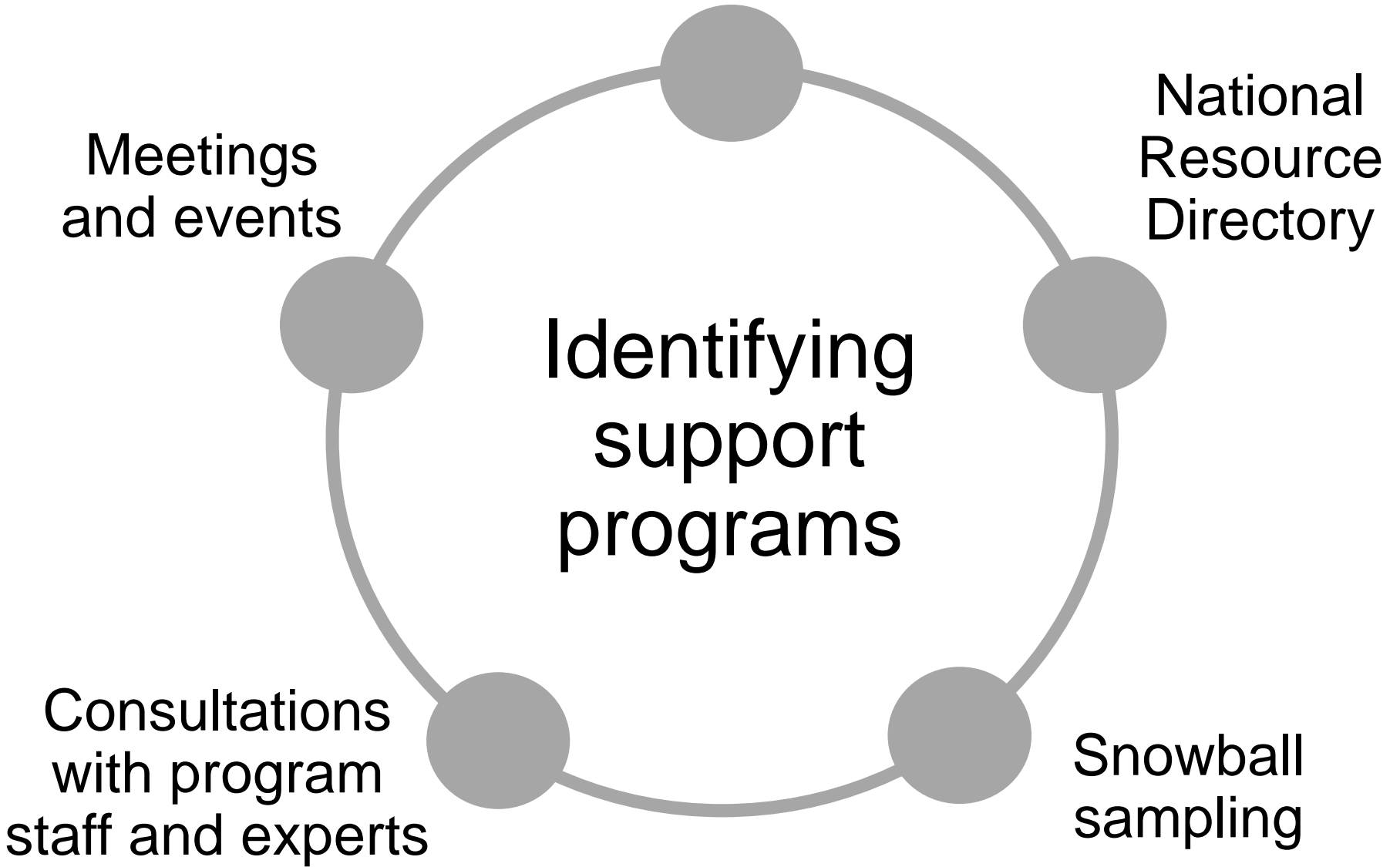
National
Resource
Directory

Meetings
and events

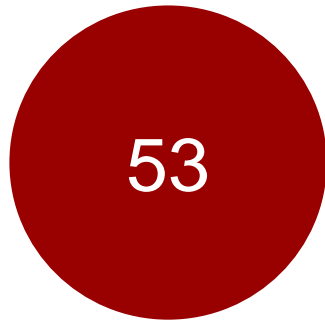
Identifying
support
programs

Snowball
sampling

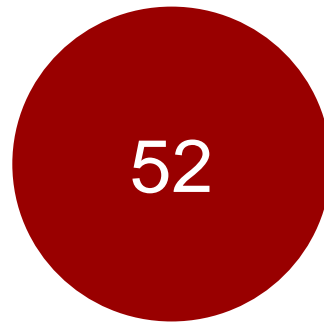
Consultations
with program
staff and experts



Support programs for caregivers



Social support



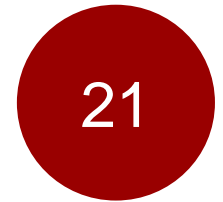
Helping hand



Education/training



Financial stipend



Wellness activities



Health care



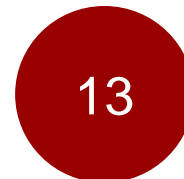
Patient advocacy



Religious support



Respite care

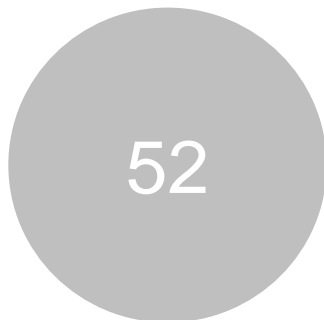


Mental health care

Helping caregivers provide better care



Social support



Helping hand



Education/training



Financial stipend



Wellness activities



Health care



Patient advocacy



Religious support



Respite care



Mental health care

Promoting caregiver well-being



Social support



Helping hand



Education/training



Financial stipend



Wellness activities



Health care



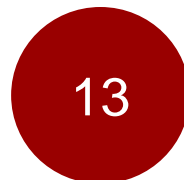
Patient advocacy



Religious support

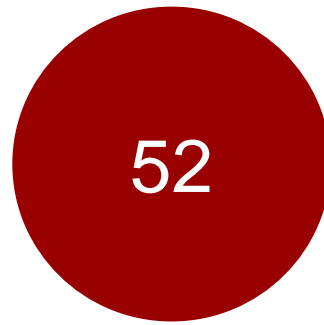


Respite care



Mental health care

Helping caregivers' families



Helping hand



Social support



Education/training



Financial stipend



Wellness activities



Health care



Patient advocacy



Religious support



Respite care



Mental health care

Compensating for income loss



Social support



Helping hand



Education/training



Financial stipend



Wellness activities



Health care



Religious support



Respite care



Mental health care



Patient advocacy

Gaps in service

Programs address
veterans' needs, not caregivers'

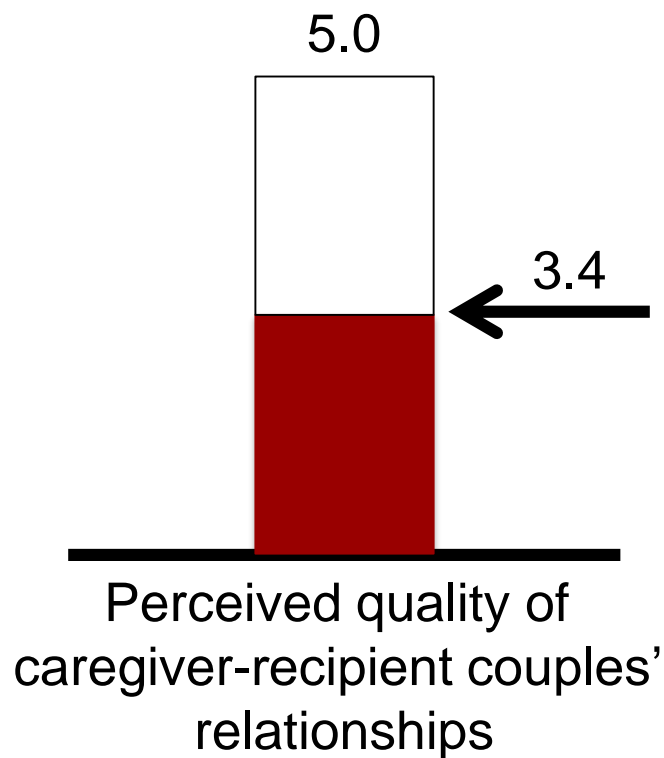
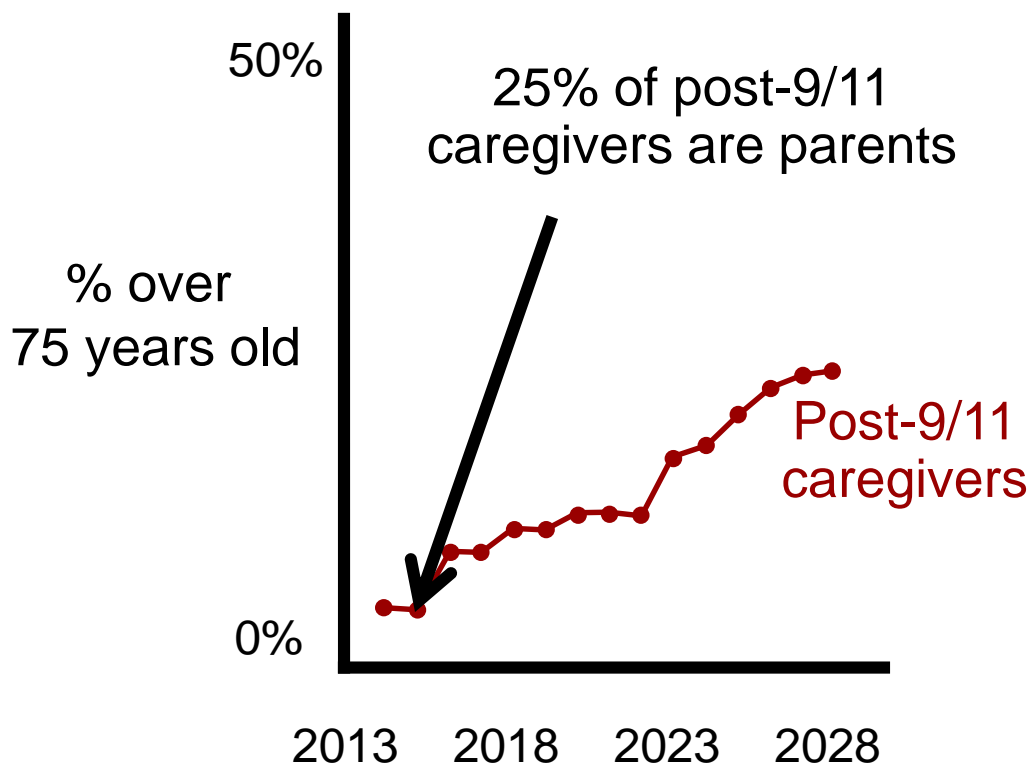
Eligibility targets older beneficiaries (60+),
especially at the state level

Younger/non-family caregivers
often ineligible

The Future of Caregiving



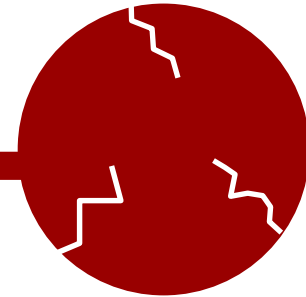
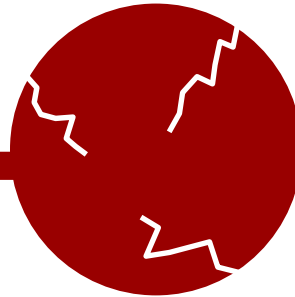
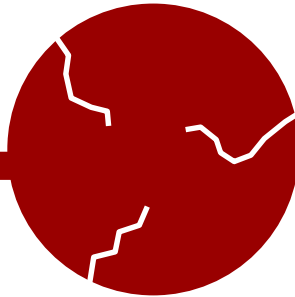
Threats to the future of caregiving: aging parents and young marriages



Threats to program sustainability

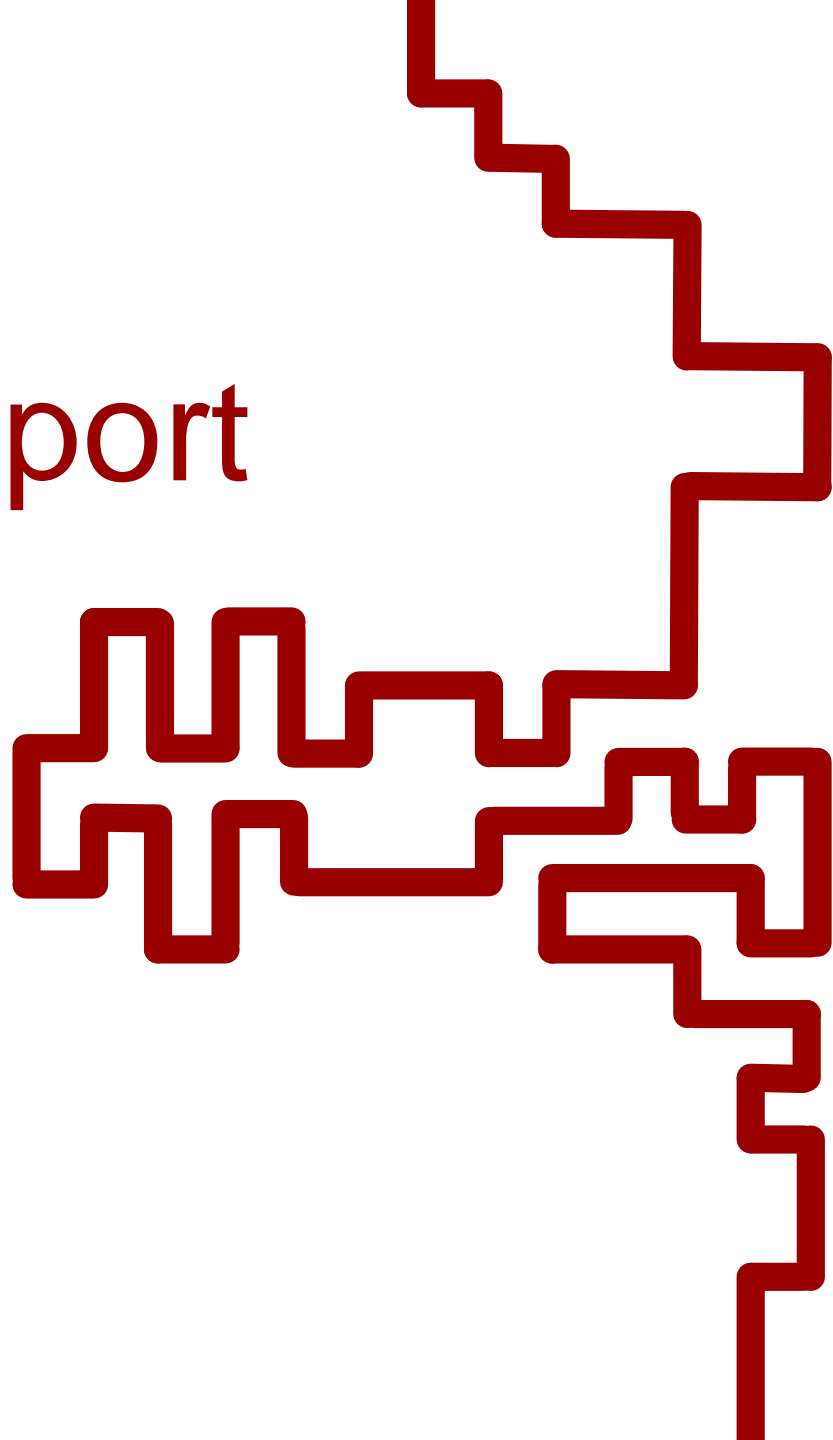
Program maturity

Vulnerability to waning
interest and support



Novel approaches that lack
evidence of effectiveness

A path to better support



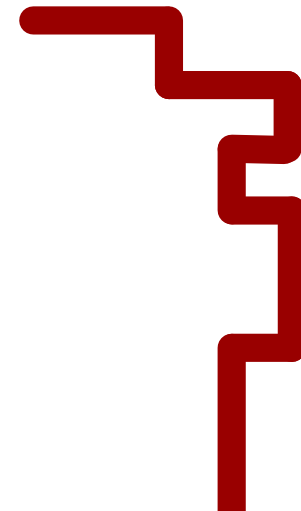
Empower caregivers

Recommendations

Provide training and continuing education

Improve health care coverage and structured support for better health

Raise awareness to match caregivers with services and boost public support

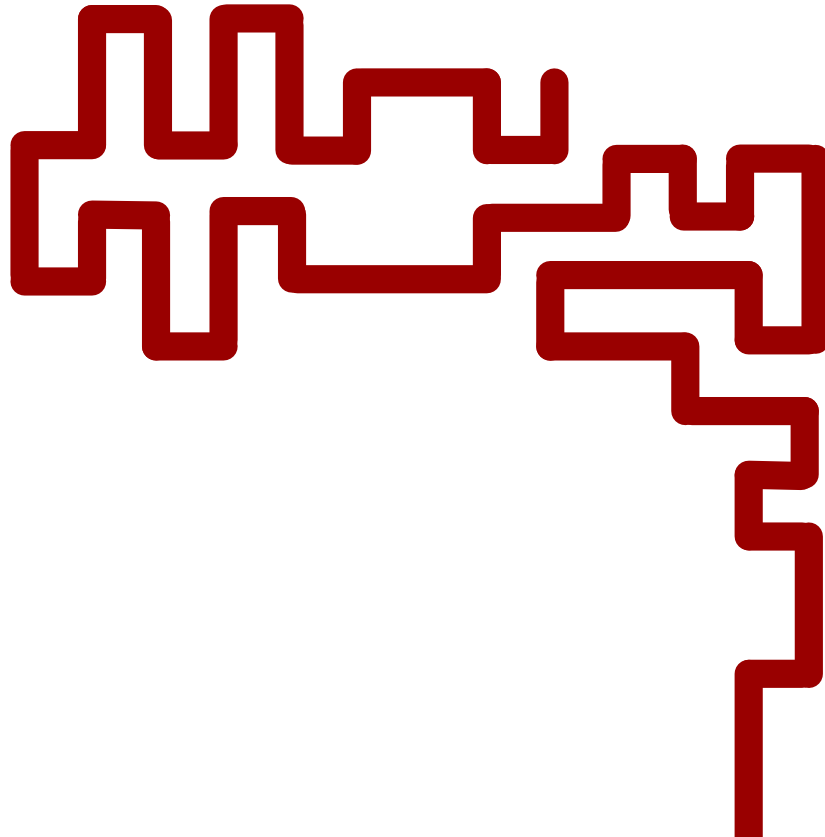


Fill gaps in programs and services

Recommendations

Align resources and eligibility for program participation

Expand respite care



Plan for the future

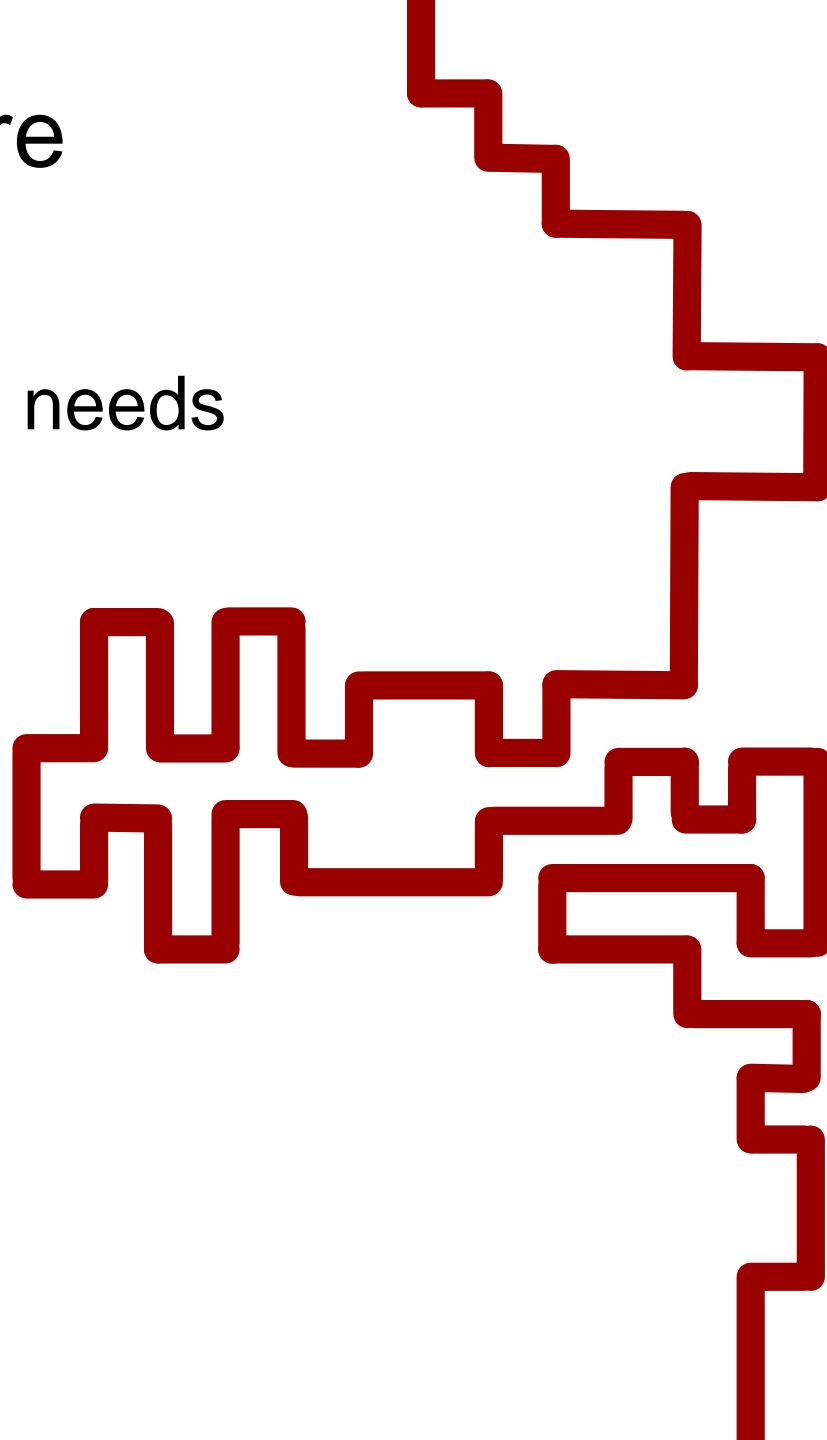
Recommendations

Provide for long-term needs

Enable sustainable programs

Ensure access to quality services

Invest in research



Hidden Heroes





VA Caregiver Support Program Update

Meg Kabat, LCSW-C, CCM
Acting National Director, Caregiver Support Program
Care Management and Social Work Services
Department of Veterans Affairs

September 18, 2014

Caregiver Support Program

Mission Statement: *To promote the health and well-being of family Caregivers who care for our nation's Veterans, through education, resources, support, and services.*

- Allow Veterans to remain at home in the community
- Address specific needs of Family Caregivers with a menu of programs and services
- Promote Veteran & Caregiver health and well-being
- Provide one location to obtain needed information
- Provide training & information on common conditions
- Reduce isolation with professional & peer support
- Provide options to give Caregivers respite
- Sensitize health care providers to the Caregivers' role

Menu of VA Services

In-Home Care

- Skilled Nursing
- Home Health Aide
- Home Based Primary Care
- Veteran Directed Home & Community Based Care

Respite Care

Services to Address Mobility

- Equipment
- Home Modification
- Automobile Modification

Education and Training

Financial Support

- Aid and Attendance
- Caregiver Stipend (Post 9-11)

Information and Referral

- Caregiver Web site: www.caregiver.va.gov
- Caregiver Support Line: **1-855-260-3274**

Caregiver Support

- Caregiver Support Coordinators
- Peer Mentoring Program
- Building Better Caregivers™
- Spouse Telephone Support
- REACH VA
- Support Groups



Caregiver Outreach

Caregiver Support Line

- More than 145,000 calls received
- Averaging ~ 200 calls per day

Caregiver Web site

- List serve members = 39,000+
- Average visits per day = 866
- Pages viewed per visits = 3

www.caregiver.va.gov



Call VA's Caregiver Support Line toll-free today.

1-855-260-3274

 Department of Veterans Affairs



Caregiver Education, Training, and Support

Expanding Evidence-Based Interventions & Best Practices

REACH VA

- Designed to provide education support, and teach problem-solving for Caregivers of Veterans with Alzheimer's Disease/dementia
- Currently being expanded to MS, Mental Health, and SCI/D

Spouse /Caregiver Telephone Support

- Groups of Post 9/11 spouses meet with a VA clinician to learn problem solving skills, resiliency training, and to receive support
- Currently being expanding to broader audience

Building Better Caregivers™

- An interactive, web based workshop developed by Stanford University and provided in partnership with the National Council on Aging (NCoA)

Peer Support Mentoring Program

- New Caregivers are matched to more experienced Caregivers

Program of Comprehensive Assistance for Family Caregivers – Program Overview

- Clinical Program, providing the following additional services directly to Family Caregivers of eligible Veterans injured in the line of duty on or after September 11, 2001:
 - Stipend
 - Enrollment in CHAMPVA
 - Mental Health
 - Beneficiary Travel
 - Education and Training
 - Additional respite
- Program participation **must**:
 - Be in the clinical best interest of the Veteran
 - Support the Veteran’s progress in treatment

Program of Comprehensive Assistance for Family Caregivers - Eligibility Criteria

Veteran or Servicemember undergoing medical discharge incurred or aggravated a serious injury in the line of duty on or after September 11, 2001 (includes Traumatic Brain Injury, psychological trauma or other mental disorders).

and

Veteran or Servicemember requires on-going assistance from a Caregiver for a minimum of 6 months to:

- Assist with the management of personal care functions required in everyday living;
- Significantly enhance the Veteran's or Servicemember's ability to live at home safely;
- Support the Veteran or Servicemember's potential progress in rehab.

*****Note: there are additional criteria beyond what is listed here.***

Program of Comprehensive Assistance for Family Caregivers – Current Data*

- Applications filed: 35,258
- Participating Caregivers/Veterans: 17,367
 - Tier 3 – 6,573 (stipend national average \$2,330 per month)
 - Tier 2 – 6,616 (stipend national average \$1,510 per month)
 - Tier 1 – 4,178 (stipend national average \$630 per month)
- New Healthcare Coverage enrollees: 4,577
- Caregiver Demographics:
 - Gender: 91% women
 - Relationship: spouses (77%), parents (12%)
 - Age: 26-40 yrs old (53%), 41-64 years old (35%)

Program of Comprehensive Assistance for Family Caregivers Caregiver Education and Training

Standardized Core Curriculum

- Developed in collaboration with Easter Seals
- In-person, workbook/DVD, or web-based
- Includes modules on:
 - Caregiver Self-Care
 - Home Safety
 - Basic Caregiver Skills (vital signs, etc)
 - Providing Personal Care
 - Managing Challenging Behaviors
 - Resources (legal, financial, VA, community, advocacy)



Training Data Update:

- More than 21,900 Family Caregivers have completed training to date

Program Evaluation

In FY 2013, healthcare utilization of a cohort of nearly 9,000 Veterans participating in the Program of Comprehensive Assistance for Family Caregivers was reviewed during the six months before participating and during the first six months of participation.

- Preliminary findings demonstrate:
 - An average decrease of 30% in inpatient admissions
 - A 2.5-day average reduction in the number of days spent in the hospital if the eligible Veteran was hospitalized
 - A 5% average decrease in the number of outpatient visits per month for eligible Veterans

Launch of CSP's Caregiver Partnered Evaluation Center

Program Launch: June 1, 2014

- Aim 1: Assess the impact of the Comprehensive Program on the health and well-being of Veterans by examining health care encounters expected to be sensitive to Caregiver support (potentially avoidable utilization).
- Aim 2: Assess the impacts of the Comprehensive Program on the health and well-being of Primary Family Caregivers.
- Aim 3: Understand how Caregivers use and value components of the Comprehensive Program and the General Program.
- Aim 4: Generate a detailed profile of the costs and services provided under the Comprehensive Program and the General Program.

Questions?

Meg Kabat, LCSW-C, CCM
Acting National Director, Caregiver Support Program
Department of Veterans Affairs
202-461-6072
Margaret.Kabat@va.gov



Deb McKay RN, MSN (USN, ret)

Vice President, Atlas Research
Assistant Director, Easter Seals NVCTP

Atlas Research

Atlas Research is a partner on the Easter Seals NVCTP. Atlas Research is an award-winning, SDVOSB consulting firm providing strategic advisory, education and training, and applied research to federal health and social service agencies.

Atlas Research is the leading contractor in the Veterans' Homelessness Space.

Caregiver Self Care Education and Training

- In 2013, the VA Caregiver Program moved forward with adding Self Care courses for General Caregivers
- Caregiver Self Care Courses are designed for Caregivers of Veterans of all era's enrolled in the VHA
- Courses are offered as Face to Face classroom sessions throughout the Country and Territories in English and Spanish.

Caregiver Self Care Education and Training

- The General Self Care Series includes four courses:
 - Stress Management
 - Communication and Problem Solving
 - Taking Care of Yourself
 - Utilizing Technology

Courses were deployed in October 2013 and to date we have trained 1223 Caregivers of WW II, Korea, Vietnam, first Gulf War, Operation Iraqi Freedom, Enduring Freedom, and New Dawn Veterans.

Caregiver Self Care Education and Training

- All courses are facilitated by 2 trainers that are licensed health care professionals
- Approximately 20 trainers are located across the country and originate from Easter Seals affiliates or partner organizations
- Cultural competence is an essential part of Train the Trainer sessions while interacting with vastly different cultures (Puerto Rico, Samoa)

USO Warrior and Family Care Caregiver Education Series

- Joint effort between USO, Easter Seals and Atlas Research to develop Caregiver materials directed toward Caregivers of Recovering Service Members
- USO Caregiver Education Series includes four courses:
 - Strategies for Taking Care of Yourself
 - Strategies for Managing Stress
 - Strategies for Addressing Challenging Behavior
 - Strategies for Accessing Caregiver Resources

Elizabeth Dole Foundation's National Coalition for Military Caregivers

- Collaborated with the Dole Foundation for Military Caregivers to present a series of six webinars available to the general public
- To date the following webinars have been produced:
 - From Daunting to Doable: The Power of Caregiver Resilience.”
 - Military Caregivers in the Workplace
 - Military Strong: Receiving with Grace

Elizabeth Dole Foundation's National Coalition for Military Caregivers

- Next webinar scheduled for November 13
- Dealing with the Caregiver “Blues”, when it becomes Depression.
- Webinars are being supported by an incredible group of organizations. They include:
 - **Atlas Research**
 - **Caregiver Action Network**
 - **Family Caregiver Alliance**
 - **National Alliance for Caregiving**
 - **Rosalynn Carter Institute for Caregiving**
 - **USO**

Final thoughts

- By and large this is a very different, younger Caregiver cohort
- Only 1% of our Country's population have been deployed to war zones over the past decade
- Many of the Service members have been deployed 3-4 times
- 99% of the Country's population does not have direct exposure to the perils of war and sequelae experienced by Service Members and their families

Questions

dmckay@atlasresearch.us

703-868-5185