



National Alliance for Caregiving



*Annual National Conference of Caregiver Advocates*  
**aging Caregivers Across the Lifespan**



**A Special Thank You to Our Sponsors:**



## **Welcome and Opening Remarks**

Gail Gibson Hunt, *President & CEO, National Alliance for Caregiving*

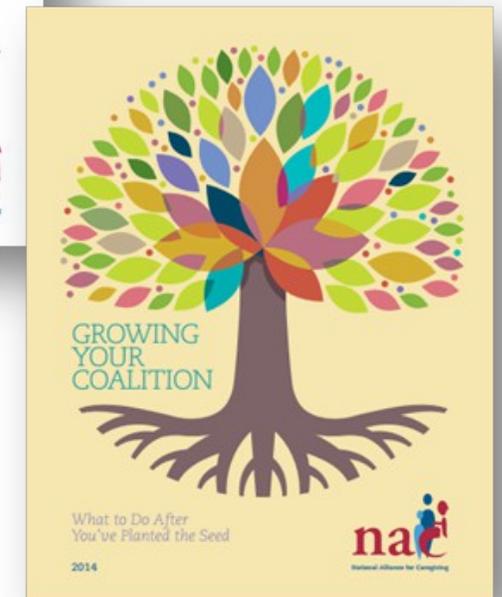
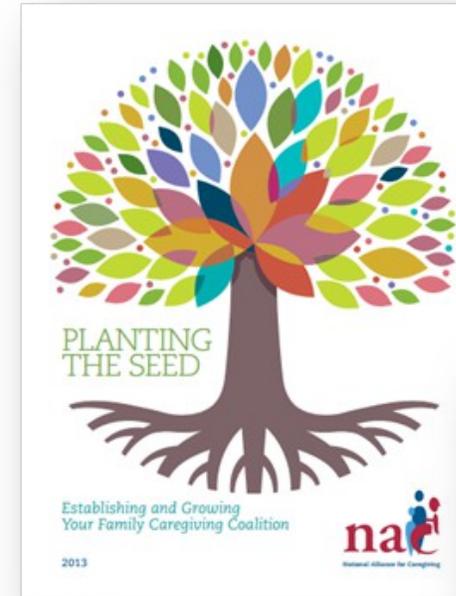
Gail Hunt is President and Chief Executive Officer of the National Alliance for Caregiving, a non-profit coalition dedicated to conducting



# Caregiving Coalition Scholarship Recipients

## What is a caregiving coalition?

A caregiving coalition is a community of representatives that has come together to address the needs of family caregivers across the lifespan. These coalitions support family caregivers, both families of origin or families of choice, with information and referral services, educational outreach, and advocacy. A caregiving coalition presents a united voice working to meet the complex social, medical, physical, financial, spiritual, and emotional needs of family caregivers.

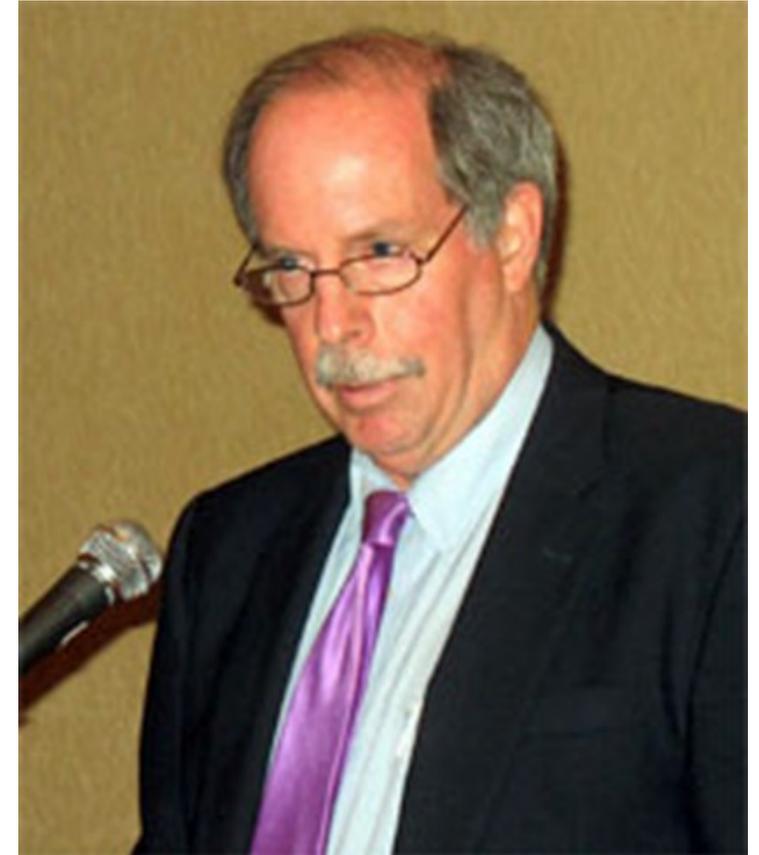


# ASA Guest Speaker: Robert B. Blancato

Bob Blancato is President of Matz, Blancato, & Associates. Bob is the National Coordinator of the Elder Justice Coalition, a non-partisan, 680 member organization. From 2000-2006, Bob served as President of the National Committee for the Prevention of Elder Abuse. He currently serves as the Executive Director of NANASP, the National Association of Nutrition and Aging Services Programs.

Bob is a former House of Representatives staff member and spent 17 years on the House Select Committee on Aging. He also served as Executive Director of the 1995 White House Conference on Aging (WHCOA) appointed by President Clinton. He was on the Policy Committee for the 2005 WHCOA appointed by Rep. Nancy Pelosi. Bob most recently became Chairman of the Commonwealth Council on Aging in Virginia.

He holds a Bachelor of Arts from Georgetown University and a Masters of Public Administration from American University.



# Policy Perspectives On Public Health and Family Caregiving

**Lisa McGuire,  
PhD**

*Lead, Alzheimer's  
Disease and  
Healthy Aging*

*Program*

*(AD+HAP)  
Senior Associate of Matz,  
Blancato & Associates*

*National Center  
for Chronic*



**Neelum T.  
Aggarwal, MD**

*Chief Diversity  
Officer, American  
Medical Women's  
Association*







Thank you for joining us!

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# *Engaging Caregivers Across the Lifespan*

- Stephanie K. Firestone, MUP
- Senior Strategic Policy Advisor,
- Health and Age-friendly Communities
- AARP International
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## Use of Caregiving Resources



In the past year...

**27%** of caregivers used caregiving resources

Among those who did not...

**41%** expressed an interest in using caregiving resources



\*Caregiving resources include self-help resources, family therapy, classes or trainings, support groups, or respite care.

## How Stressful and Rewarding is Dementia Caregiving?

### How stressful is caregiving?



**78%** Very or somewhat stressful

**22%** Not stressful

### How rewarding is caregiving?

**85%** Very or somewhat rewarding

**15%** Not rewarding



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[aarp.org/caregiving](http://aarp.org/caregiving)

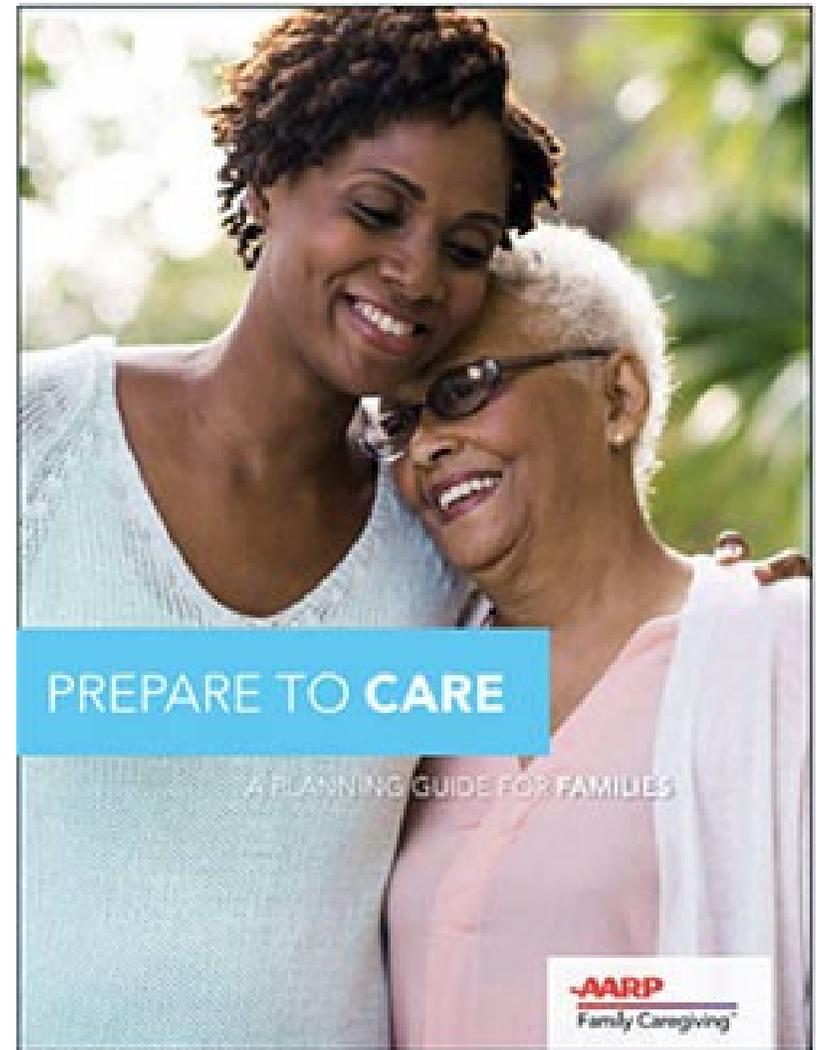
- *Caregiver guides for diverse audiences*
- *State and local level resource guides*
- *Local partnerships*

Santa Barbara Foundation Community Caregiving Initiative (CCI)

Interim Report Fall 2017



SAN FRANCISCO, CALIFORNIA  
**CAREGIVER RESOURCE GUIDE**

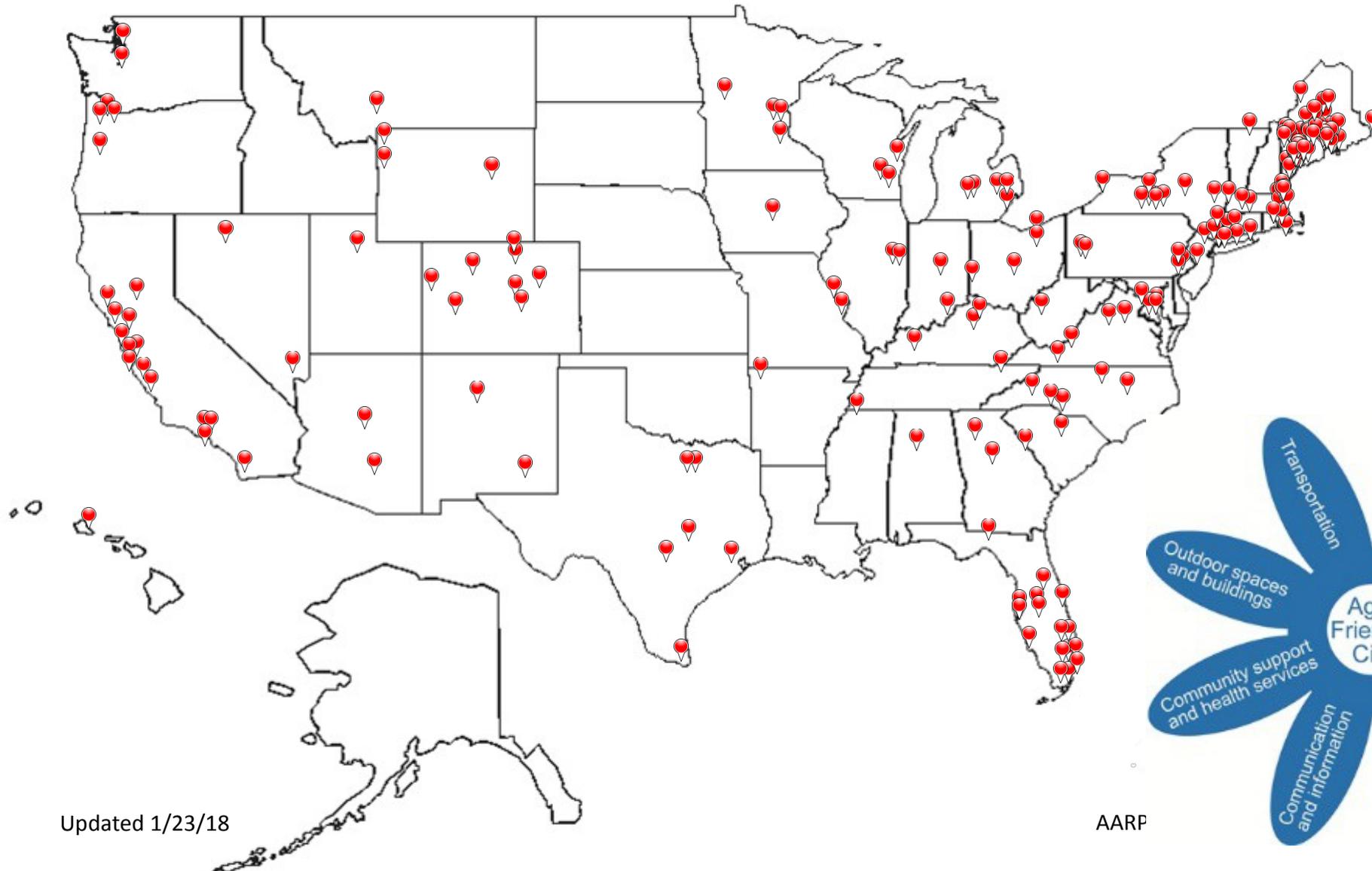




- *Neighborhood-based grassroots organizations*
- *Membership-driven*
- *Run by volunteers and limited paid staff*
- *200 now; over 150 under development*



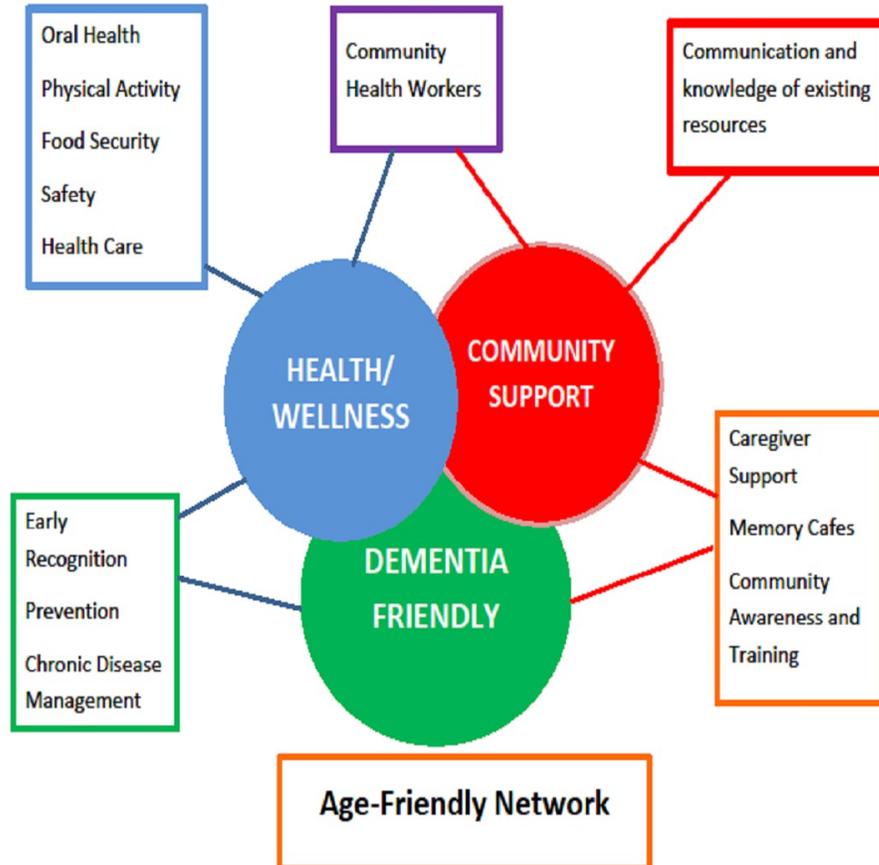
# AARP Network of Age-Friendly Communities



Updated 1/23/18

AARP

# Caregiving in Age-friendly Community Action Plans



Source: Age-friendly Community Action Plan,  
New Bedford, MA

## Montgomery County, MD:

- Senior Fellow coordinates outreach
- Communication in multiple languages

## Austin, TX:

- Public awareness of respite care, palliative care, other HCBS
- Expand culturally responsive caregiving programs and resources

## Washington, DC:

- Expand compensated respite care for low-income unpaid caregivers



# Dementia Friendly America®

“People living with dementia and their care partners”



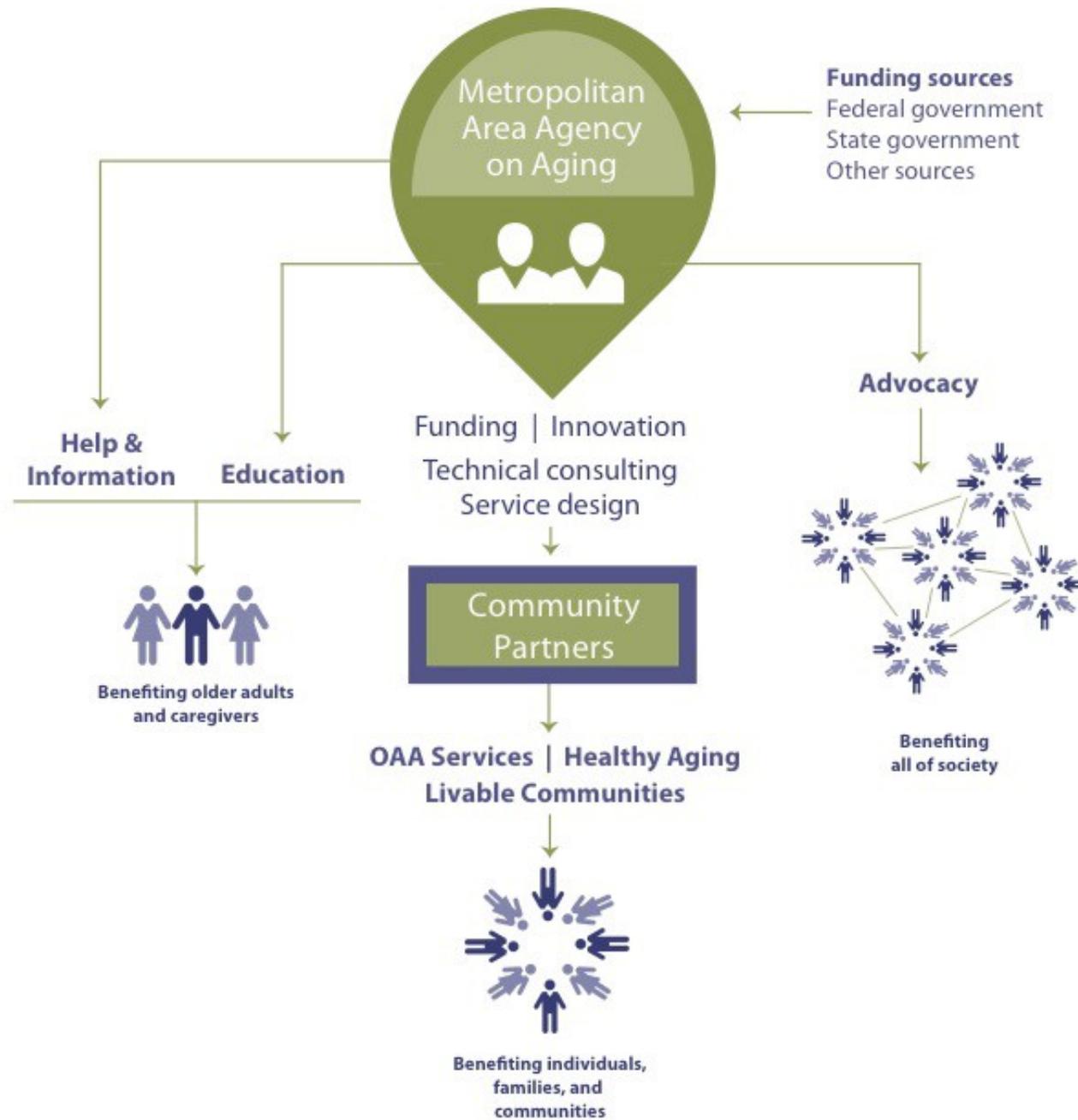
 <b>Dementia Friendly Essentials</b> All sectors of community can play a valuable role in fostering dementia friendliness <a href="#">VIEW GUIDE</a>	 <b>Banks and Financial Services</b> Banks and Financial Services are dementia-aware and responsive <a href="#">VIEW GUIDE</a>	 <b>Neighbors and Community Members</b> Neighbors and community members are understanding and supportive <a href="#">VIEW GUIDE</a>
 <b>Legal and Advance Planning Services</b> Legal and Advance Planning Services are dementia-aware and responsive <a href="#">VIEW GUIDE</a>	 <b>Local Government</b> Transportation, housing, and public spaces enable people with dementia to navigate community <a href="#">VIEW GUIDE</a>	 <b>Health Care Throughout the Continuum</b> Health care throughout the continuum promotes early diagnosis and specialized care <a href="#">VIEW GUIDE</a>
 <b>Libraries</b> Libraries provide access to resources, services, and programs for people living with dementia and their families <a href="#">VIEW GUIDE</a>	 <b>Faith Communities</b> Communities of faith are welcoming, engaging, and accommodating to those with cognitive impairment <a href="#">VIEW GUIDE</a>	 <b>Businesses</b> Businesses foster dementia-supportive customer service and environments and support employee caregivers <a href="#">VIEW GUIDE</a>
 <b>Community-based Services and Supports</b> Independent living options maximize quality of life through meaningful engagement and community supports <a href="#">VIEW GUIDE</a>	 <b>Residential and Specialty Care</b> Memory loss supports and services that are provided through specialized, dementia friendly residential options <a href="#">VIEW GUIDE</a>	 <b>Hospitals</b> Improve care for people with dementia with dementia friendly environments in acute care settings <a href="#">VIEW GUIDE</a>

## Perspectives on Caregiver Support from an Area Agency on Aging

Dawn Simonson  
Executive Director  
Metropolitan Area Agency on Aging  
Minneapolis – St. Paul, Minnesota

## ...and their family caregivers

- Aging Network – created under the federal Older Americans Act
- State Units on Aging/Area Agencies on Aging/Local Providers



# ...focus on family caregivers



- Information
- Access Assistance
- Caregiver Counseling and Support Groups
- Respite
- Supplemental

# What have we learned in Minnesota?

Results from a study by Wilder Research  
St. Paul, MN (2016)

- Respond to what caregivers say they need and will use – they put the needs of the care recipients first
- Emphasize easy and practical services as initial forms of support
- Offer supports that help caregivers provide for their care recipients
- Attend to the fact that over half of family caregivers are caring for someone with dementia

# Engaging community

- Minnesota's ACT on Alzheimer's initiative has major focus on supporting family caregivers
- [www.actonalz.org](http://www.actonalz.org)
- Since 2011, 65 communities engaged in becoming dementia friendly
- Results for caregivers: additional respite options, more support groups, Memory Cafes, creative arts programs such as Giving Voice choirs, increased awareness and support for the caregiving role

# Recommendations for Policy Directions – Wilder Research 2016

- Create a governor's task force on aging
- Include a significant focus on caregivers
- Bring attention to complexity and urgency of caregiver needs
- Promote collaboration among various state agencies, and with private sector and health care entities
- Promote understanding that may produce increased capacity and funding



# Paid Leave Means **Time to Care** For All of Us

**Vicki Shabo**  
Vice President for  
Workplace Policies &  
Strategies

National Conference of  
Caregiving Advocates  
March 26, 2018



# Supporting Caregivers of People with Mental Illness

National Alliance for Caregiving  
Conference  
San Francisco  
March 26, 2018



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# The Big Picture:

8.4 million caregivers of adults with mental illness in U.S.



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The Circle of Care Guidebook emerged from the 2015/2016 NAC study of mental health caregivers.

Partners: MHA, NAMI

## Findings:

	Mental Health	All Caregivers
Duration of care	8.7 years	4 years
Intensity of care	32 hours/week	24 hours/week

Caregiver Burden	
Recipient financially dependent	49%
Parent plan for future caregiving responsibility	32%
Negative effect on caregiver health	62%
Difficult to talk with others about issues	48%
High emotional stress	74%

*Data from On Pins & Needles: Caregivers of Adults with Mental Illness, in partnership with NAMI and Mental Health America. Learn more at [www.caregiving.org/research](http://www.caregiving.org/research).*

*\*from Caregiving in the U.S. 2015, National Alliance for Caregiving and AARP Public Policy Institute*

# Challenges:

## *Caregiver perspective*

- ☹ **Diagnosis:** 11.8 years on average to arrive at an accurate diagnosis. 39% think diagnosis may be incorrect
- ☹ **Care planning:** 55% feel excluded from communication with mental health care providers
- ☹ **Hospital discharge:** 70% feel the recipient was discharged too quickly at some point
- ☹ **Financial dependence:** 49% report the recipient is partly or fully financially dependent on family & friends
- ☹ **Future planning:** Only 32% had plan if they can no longer provide care. Only 35% can rely on other family
- ☹ **Other challenges:** Provider shortage, insurance barriers, self-harm, arrest, homelessness, stigma, self-care

**Caregivers requested a guidebook to help**

*Data from On Pins & Needles: Caregivers of Adults with Mental Illness, in partnership with NAMI and Mental Health America. Learn more at [www.caregiving.org/research](http://www.caregiving.org/research).*

**navigate challenges**

# Circle of Care Mental Health Guidebook



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# Fact Sheet

## Communication with Mental Health Professionals

### Challenge:

**Health privacy law** limits communication, yet family caregivers can play a crucial role

### Information:

- ☾ How federal law protects/permits communication

- ☾ Communication planning

  - ☾ What will be communicated, how & when?

  - ☾ Discuss with care recipient in person centered way

    - ☾ Submit consent to release information

  - ☾ Meet with provider to discuss conditions

- ☾ Record keeping to:

  - ☾ Provide accurate, useful information

  - ☾ Promote continuity of care

- ☾ Resources



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# Fact Sheet:

## *Planning for the Future*

### Challenges:

☹ **Financial dependence:** 49% of caregivers report recipient is financially dependent on family & friends

☹ **Future planning:** Only 35% have a future plan

### Information:

☹ What is future planning?

☹ Components

☹ Benefits and financial planning

☹ Residential planning

☹ Support networks

☹ Taking the first step

☹ Emotional barriers

☹ Service system barriers

☹ Complexity of legal/financial planning

☹ Resources



# Circle of Care Guidebook: *Who will use it?*

Family caregivers & care recipients

Other unpaid caregivers

Mental health care providers

Referring health care providers

Hospitals

Government agencies



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# Public Policy Solutions

## ☹️ Assist with navigation

- ☹️ SAMHSA helpline & treatment locator

  - ☹️ 21st Century Cures Act

- ☹️ Boundary spanners: school, justice, housing...

- ☹️ Nonprofit mental health helplines

  - ☹️ NAMI, MHA

## ☹️ Include caregivers in the care team

- ☹️ Health privacy education: providers, lawyers, care recipients, caregivers

  - ☹️ 21st Century Cures Act

- ☹️ Include caregivers in hospital discharge planning

  - ☹️ CARE Act, state legislation

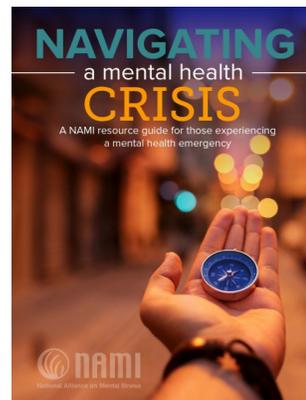
## ☹️ Educate/provide resources to caregivers

- ☹️ National Family Caregiver Support Program for mental health caregivers (not yet proposed)

  - ☹️ Support for caregiver mutual education and support programs



# National Alliance on Mental Illness



[www.nami.org/crisisguide](http://www.nami.org/crisisguide)

NAMI  
Caregiver  
Resources

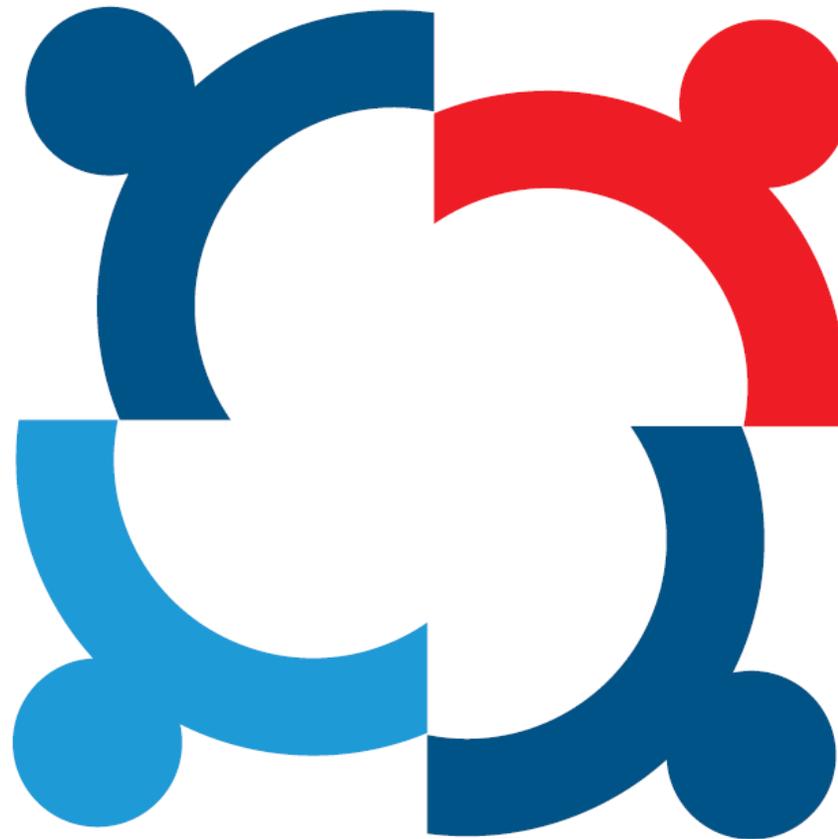
[www.nami.org](http://www.nami.org)

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# Q&A



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**Circle of Care** Guidebook  
[www.caregiving.org/circleofcare](http://www.caregiving.org/circleofcare)



# Improving Support for America's Hidden Heroes

March 26, 2018





## OUR MISSION

To strengthen and empower American military caregivers and their families by raising public awareness, driving research, championing policy, and leading collaborations that make a significant impact on their lives.

### Fundamental Principles:

- Conduct evidence-based research on the needs of military and veteran caregivers
- Empower caregivers
- Drive innovation
- Promote collaboration
- Raise awareness

# OUR **PROGRAMS**

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**Eight core programs and projects** drive the mission of the Foundation:

1. Dole Caregiver Fellows
2. Hidden Heroes Caregiver Community
3. Impact Forum
4. **Military and Veteran Caregiver Journey Map**
5. Hidden Heroes Fund
6. Hidden Heroes Cities
7. Campaign for Inclusive Care
8. **Legislation and Policy**



# MILITARY & VETERAN CAREGIVER JOURNEY MAP

- The Military and Veteran Caregiver Journey map outlines the **typical stages, needs, and intervention points in the military and veteran caregiver journey**, from day one through decades to come.
- In November, we convened more than 400 military caregivers, government, nonprofit, and industry leaders to map out two journey maps, one representing a **young military caregiver named “Kelly”** and the other representing a **daughter (“Patricia”) caring for her aging veteran father**.
- Goal: continue shaping the map throughout 2018, to make this a widely-embraced tool for service providers in improving critical support and resources for military and veteran caregivers.



# Military & Veteran Caregiver Experience Journey

## PERSONA



### About Kelly

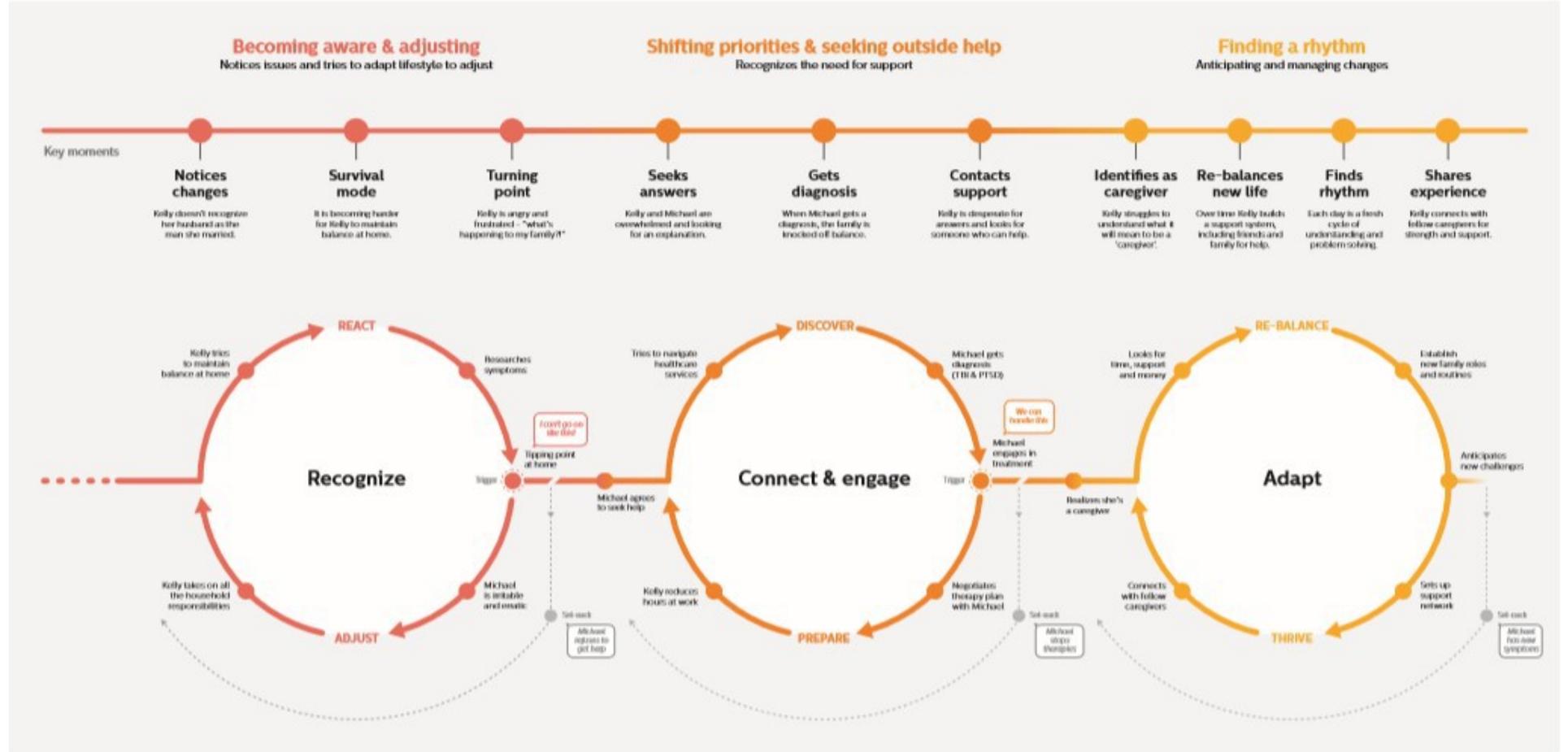
- Gender:** Female
- Age:** 38 when caregiving begins
- Care for:** Spouse who served for 7yrs, multiple deployments
- Household:** Lives with her husband, son and daughter
- Education:** Some college, general studies
- Career:** Full-time office manager, annual salary \$20,000

- Has two children, both in elementary school and had been using childcare while the family was being on base
- Manages all household business, childcare arrangements, grocery shopping, health appointments and to her kids
- Took temporary, short-term leave of absence for 8 weeks when her husband first returned from serving in Iraq
- Homeless twice, involuntarily at school
- Needs to go back to school to give her kids a better life
- Patience and service oriented

### About Michael

- Age 38
- Associates degree
- Difficulty with maintaining employment
- Suffers from a mild TBI and PTSD but undiagnosed at the time of discharge
- Hard of hearing after roadside bust, experiences chronic back and neck pain
- Self-medicating alcohol usage

## EXPERIENCE FLOW



DRAFT | November 13, 2017



# Improving Support for America's Hidden Heroes

A RESEARCH BLUEPRINT



Terri Tanielian  
Kathryn E. Bouskill  
Rajeev Ramchand  
Esther M. Friedman  
Thomas E. Trail  
Angela Clague

## EVIDENCE-BASED RESEARCH

### RAND Studies

- Over the years, the Foundation has commissioned two RAND studies on military and veteran caregiving that guide us in our programmatic and policy decisions.
- View the studies on our website here:  
<https://www.elizabethdolefoundation.org/landmark-research/>

CAREGIVERS GIVING CARE TO PEOPLE WHO SERVED **pre-9/11**

differ from

CAREGIVERS GIVING CARE TO PEOPLE WHO SERVED **post-9/11**

**the child**

caregiver is most commonly

**the spouse**

**47%**

percentage of caregivers employed

**63%**

**71%**

percentage of caregivers with a support network

**47%**

**11%**

percentage of caregivers age 30 or younger

**37%**

**RECIPIENTS**

**36%**

care recipients who have a behavioral health condition

**64%**

**30%**

percentage of care recipients who have a VA disability rating

**58%**

**RECIPIENTS**



# CHAMPIONING POLICY

## **Caregiver Legislation:**

- Expansion of the VA's Program of Comprehensive Assistance for Family Caregivers
  - Caring for Our Veterans Act (S. 2193)
  - Military and Veteran Caregiver Services Improvement Act (S. 591/H.R. 1472)
- RAISE Family Caregivers Act
- National Defense Authorization Act of 2018

## **Foundation Activity:**

- 450+ Hill meetings with our Dole Caregiver Fellows
- Participate in hearings & roundtables surrounding caregiver legislation
- Work with Congressional Leaders and VA & VSO partners to shape policy





**THANK YOU**

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