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 research and developing national programs for family caregivers and the professionals who serve them.

Ms. Hunt was President of her own aging services consulting firm for 14 years. She conducted corporate eldercare research for the National Institute on Aging and the Social Security Administration, developed training for caregivers with AARP and the American Occupational Therapy Association, and designed a corporate eldercare program for EAPs with the Employee Assistance Professional Association.

Prior to having her own firm, she was Senior Manager in charge of human services for the Washington, DC, office of KPMG Peat Marwick. Ms. Hunt attended Vassar College and graduated from Columbia University.
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), National Center for Chronic

Neelum T. Aggarwal, MD
Chief Diversity Officer, American Medical Women's Association

Meredith Ponder Whitmire, JD
Senior Associate of Matz, Blancato & Associates
Thank you for joining us!

A Special Thank You to Our Sponsors:
Engaging Caregivers Across the Lifespan

- Stephanie K. Firestone, MUP
- Senior Strategic Policy Advisor,
- Health and Age-friendly Communities
- AARP International
- sfirestone@aarp.org
- Tel: 202-434-3787
- Twitter: @firekrone

AARP®
Real Possibilities
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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Real Possibilities

Michigan Medicine
University of Michigan

Directed by

Institute for Healthcare Policy & Innovation
University of Michigan
- Caregiver guides for diverse audiences
- State and local level resource guides
- Local partnerships
• 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
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
“People living with dementia and their care partners”
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
- 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
- Dementia Friendly America adopted the ACT model and number of engaged communities is over 200 – www.dfamerica.org
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

@NA4Caregiving @NAMICommunicate
#Caregiving
The Big Picture:

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

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

Partners: MHA, NAMI

Findings:

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<th>Mental Health</th>
<th>All Caregivers</th>
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<tr>
<td>Duration of care</td>
<td>8.7 years</td>
<td>4 years</td>
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<td>Intensity of care</td>
<td>32 hours/week</td>
<td>24 hours/week</td>
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<th>Caregiver Burden</th>
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<tr>
<td>Recipient financially dependent</td>
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<td>Parent plan for future caregiving responsibility</td>
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<td>Negative effect on caregiver health</td>
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<td>Difficult to talk with others about issues</td>
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<td>High emotional stress</td>
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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.

*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 navigate challenges.

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.
Circle of Care Mental Health Guidebook

@NA4Caregiving
@NAMICommunicate
#Caregiving
Fact Sheet: Communicating 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
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
**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
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

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.
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
- Percentage of caregivers employed: 47%
- Percentage of caregivers with a support network: 71%
- Percentage of caregivers age 30 or younger: 11%

**The Spouse**
- Percentage of caregivers employed: 63%
- Percentage of caregivers with a support network: 47%
- Percentage of caregivers age 30 or younger: 37%

**Recipients**
- Care recipients who have a behavioral health condition: 36%
- Percentage of care recipients who have a VA disability rating: 30%

Care recipients who have a behavioral health condition: 64%
- Percentage of care recipients who have a VA disability rating: 58%

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

laurel@elizabethdolefoundation.org