



Moving Dementia Family Caregiver Support Services Into the Mainstream



*CMS Innovation
Center Summit*

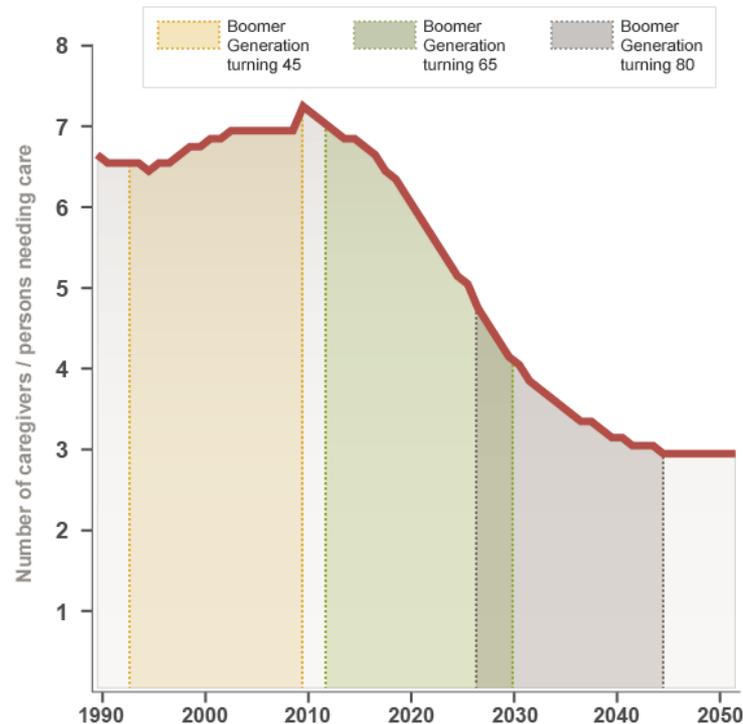
Lynn Friss Feinberg, MSW

September 8, 2017

The Growing Care Gap

You Take Care of Mom, But Who Will Take Care of You?

Caregiver Support Ratio



Source: D. Redfoot, L. Feinberg, and A. Houser, *The Aging of the Baby Boom and the Growing Care Gap*, AARP Public Policy Institute, 2013

Why are Supportive Services Needed by Family Caregivers of Persons Living with Dementia?

- Dementia impacts the person as well as the family
- Dementia caregivers experience more stress than those caring for people with disabilities who do not have dementia
 - Typically spend more hours and years in caregiving role
 - Rates of depression are twice as high

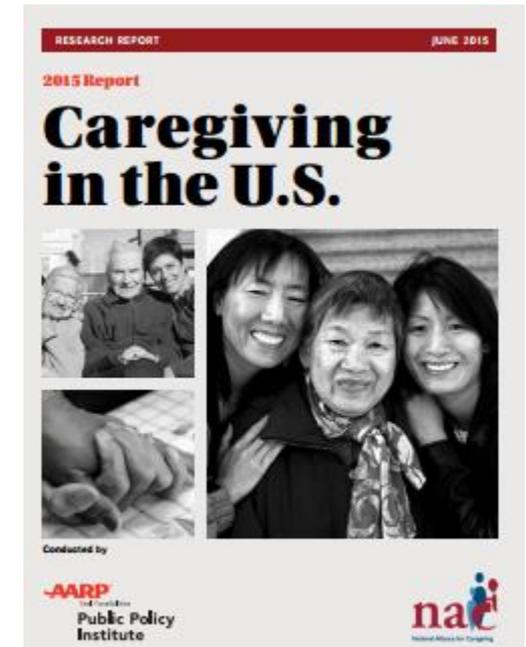


Why are Supportive Services Needed by Family Caregivers of Persons Living with Dementia? (cont'd)

- Dementia is one of the costliest health conditions
 - Financial risks for dementia caregivers are especially high
 - An AARP study found that dementia caregivers reported nearly twice the average out-of-pocket costs in 2016 than those caring for someone who doesn't have dementia (\$10,697 vs. \$5, 758).
 - <http://www.aarp.org/home-family/caregiving/info-2016/caregiving-out-of-pocket-cost-report.html>
- High caregiver stress is a predictor of a person's placement in a nursing home

Caregiving in the U.S. 2015 Survey

- Less than half of dementia caregivers (44%) said a *doctor, nurse or social worker* ever asked them about what was needed to care for their relative/close friend.
- Only about 1 in 4 (24%) said a health provider had asked what they need to care for themselves.



Source: National Alliance for Caregiving and AARP Public Policy Institute, *Caregiving in the U.S. 2015*. <http://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html>

Types of Community-Based Caregiver Supportive Services

- Assessing Needs, Values and Preferences
- Care Coordination
- Counseling and Support Groups
 - Family Meetings
- Legal and Financial Consultations
- Education and Skills Training
- Transportation Services and Nutrition Programs
- Respite Care
 - In-home, Adult Day Centers
- Employee Assistance Programs
 - FMLA, paid family leave
- Hospice and Palliative Care



10 Common Attributes of Evidence-Based Caregiver Support Programs

- 1) Adopting the principle of person- and family-centered care
- 2) Targeting family members/friends most likely to benefit from the program
- 3) Building a trusting relationship with the person and the family
- 4) Ensuring appropriate language access and cultural sensitivity
- 5) Assessing the family caregiver's unique needs, problems, strengths, and resources, as identified by the family caregiver



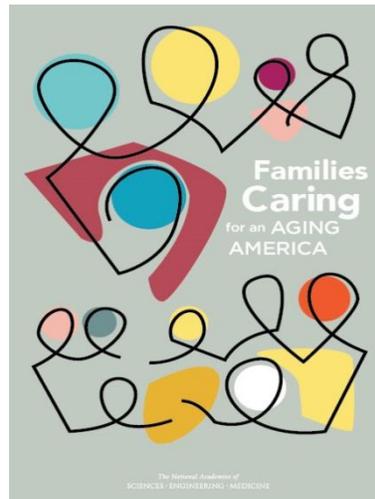
10 Common Attributes of Evidence-Based Caregiver Support Programs

- 6) Providing the family caregiver with a combination of services to address multiple areas of unmet needs
- 7) Tailoring services to the family caregiver's specific concerns and needs
- 8) Utilizing trained staff
- 9) Offering periodic follow-up support as needs change over time
- 10) Evaluating caregiver outcomes to improve the program

Adapted from: L. Feinberg, in press, *From Research to Standard Practice: Advancing Proven Programs to Support Family Caregivers of Persons Living with Dementia*, AARP Public Policy Institute.

Going Forward

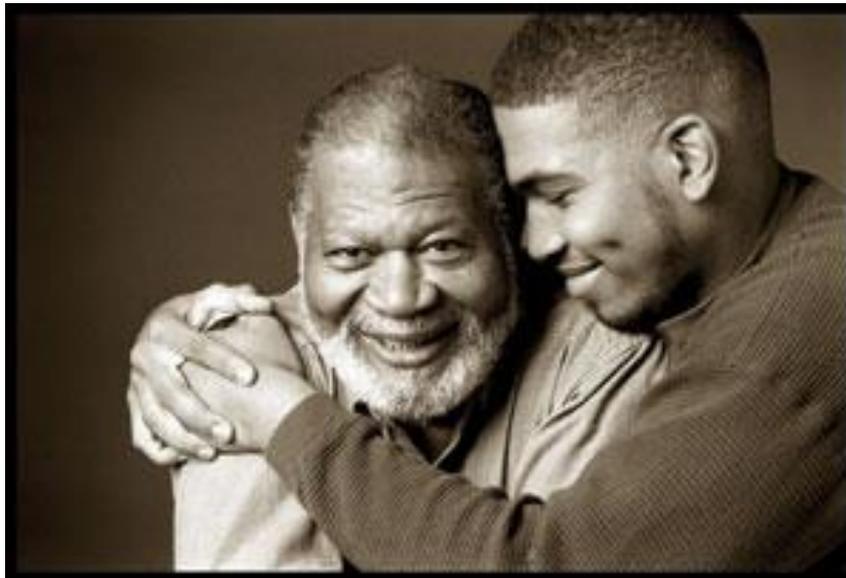
- It is time to treat family caregiving with an urgency and make it a national priority.



www.nationalacademies.org/caregiving

Going Forward

- Evidence-based dementia caregiver interventions should be scaled up and made *available, accessible, and affordable* to the families who need them.



Contact

Lynn Friss Feinberg, MSW
Senior Strategic Policy Advisor
AARP Public Policy Institute
Lfeinberg@aarp.org

202-434-3872

 @FeinbergLynn