



**RAISE Act Council Meeting  
Pre-Meeting Materials and Resources  
August 28-29, 2019**

Annotated Bibliography: Key Family Caregiver Research and Background Materials

**Summary of Key Recommendations & Findings:**

- The majority of caregivers take care of a relative (vs. a non-relative), and more care for a parent than any other relation. Many caregivers feel that they had no choice when taking on the responsibility of providing care for their loved one.
- Family caregivers are a diverse population, both in their backgrounds and the care they provide. Health care systems and professionals must make stronger efforts to recognize family caregivers, offer them instruction on and support for complex care, and proactively outreach to help them manage and coordinate their care recipients' care.
- Update and implement effective assessment tools, specifically within federally-funded and public programs, to better identify family caregivers providing care across populations and provide more robust, population-specific support to family caregivers.
- Evaluate and recognize the economic impact of caregiving and enact policy that provides economic support to family caregivers.

**I. Title:** [Caregiving in the US](#)

**Author:** The National Alliance for Caregiving and the AARP Public Policy Institute

**Overview:** Prepared by the NAC and the AARP, this updated report includes findings from the Caregiving in the U.S. 2015 study, which collected information through online interviews about the numbers and demographics of caregivers, the types of services and duration of care provided by caregivers, and the health status and living environment of care recipients, among other indices.

**Recommendations/Findings:**

1. The study estimates that 43.5 million American adults have been caregivers to an adult or child in the 12 months prior to the study, and that there are 34.2 million adults in the United States who have been a caregiver to an adult age 50 or older in the prior 12 months.
2. The prevalence of caregiving varies by racial/ethnic group: it is highest among Hispanics (21.0%) and lowest among White (Non-Hispanics) (16.9%).
3. Eight in 10 caregivers care for just one adult (82%), 15 percent take care of two adults, and 3 percent care for three or more adults.
4. Three in five caregivers are female (60%) and two in five are male (40%). Two out of three care recipients are female (65%). Higher-hour caregivers tend to be female (62%) caring for a female (64%), similar to lower-hour caregivers.

5. On average, the care recipient is 69.4 years old. Nearly half of caregivers care for someone age 75 years or older, and 39 percent care for someone age 50 to 74.
6. On average, caregivers of adults are 49.2 years old. Nearly half are between the ages of 18 and 49 (48%). Higher-hour caregivers are older on average (51.8 years old), than those providing fewer hours of care (48.0).
7. The vast majority of caregivers take care of a relative (85%), while just 15 percent care for a friend, neighbor, or other nonrelative. More care for a parent (42% than any other relation (31 percent for their mother, 11 percent for father), with an additional 7 percent reporting they care for a parent-in-law. Higher-hour caregivers are more likely to care for a relative (93%), specifically a spouse (24%), than lower-hour caregivers.
8. The average duration of caregiving is 4.0 years. About one-quarter have provided care for 1 to 4 years (26%), or 5 years or more (24%). Higher-hour caregivers have been providing care to their recipient for 5.6 years on average, longer than the 3.2 years of care provided by lower-hour caregivers.
9. When asked if they had a choice in taking on the responsibility to provide care for their loved one, half of caregivers felt they had no choice in taking on this role (49%). Higher-hour caregivers—those providing 21 hours of care or more each week—are more likely to feel they had no choice in taking on their caregiving role (59% vs. 45% of lower-hour caregivers).
10. Most caregivers live within 20 minutes of their care recipient (75%). Higher-hour caregivers tend to live closer to their care recipient: more than 8 in 10 live within 20 minutes of their care recipient (84%), compared with just 7 in 10 lower-hour caregivers (70%).
11. When caregivers are asked to identify their loved one’s main problem or illness that causes them to need care, the three most common problems or illnesses cited by caregivers include: “old age” (14%), Alzheimer’s or dementia (8%), or surgery/wounds (8%). Other illness or conditions for which the recipient needs care include cancer (7%), mobility (7%), mental/emotional illness (5%), heart disease (5%), and diabetes (5%).
12. One in four caregivers have at least some difficulty in coordinating care among their care recipient’s providers (23%) and nearly half claim care coordination was only “somewhat” easy.
13. On average, caregivers spend 24.4 hours per week providing care. About 1 in 4 provide care for 41 hours or more each week (23%) and 3 in 10 provide between 9 and 40 hours of care (31%).

**II. Title:** [Families Caring for an Aging America](#)

**Author:** The National Academies of Sciences, Engineering, and Medicine; Edited by Richard Schulz and Jill Eden

**Overview:** Appointed in 2014, the Committee on Family Caregiving for Older Adults was charged with conducting a comprehensive study to assess family caregivers of older adults and resources and supports available to them. The committee conducted its assessment through substantial in-person and virtual deliberation, information gathering, and analysis between November 2014 and March 2016. The committee prepared and published this report, which provides in-depth detail of the committee’s findings and recommendations.

**Recommendations/Findings:**

1. The Secretary of Health and Human Services, in collaboration with the Secretaries of Labor and Veterans Affairs, other federal agencies, and private-sector organizations with expertise in family caregiving, develop and execute a National Family Caregiver Strategy that, administratively or

through new federal legislation, explicitly and systematically addresses and supports the essential role of family caregivers to older adults.

- Develop, test, and implement effective mechanisms within Medicare, Medicaid, and the U.S. Department of Veterans Affairs to ensure that family caregivers are routinely identified and that their needs are assessed and supported in the delivery of health care and long-term services and supports.
  - Direct the Centers for Medicare & Medicaid Services to develop, test, and implement provider payment reforms that motivate providers to engage family caregivers in delivery processes, across all modes of payment and models of care.
  - Strengthen the training and capacity of health care and social service providers to recognize and to engage family caregivers and to provide them evidence-based supports and referrals to services in the community.
  - Increase funding for programs that provide explicit supportive services for family caregivers such as the National Family Caregiver Support Program and other relevant HHS programs to facilitate the development, dissemination, and implementation of evidenced-based caregiver intervention programs.
  - Explore, evaluate, and adopt federal policies that provide economic support for working caregivers.
  - Expand the data collection infrastructures within the Departments of Health and Human Services, Labor, and Veterans Affairs to facilitate monitoring, tracking, and reporting on the experience of family caregivers.
  - Launch a multi-agency research program sufficiently robust to evaluate caregiver interventions in real world health care and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes.
2. State governments that have yet to address the health, economic, and social challenges of caregiving for older adults should learn from the experience of states with caregiver supports, and implement similar programs.
  3. The Secretaries of Health and Human Services, Labor, and Veterans Affairs should work with leaders in health care and long-term services and supports delivery, technology, and philanthropy to establish a public-private, multi-stakeholder innovation fund for research and innovation to accelerate the pace of change in addressing the needs of caregiving families.
  4. In all the above actions, explicitly and consistently address families' diversity in assessing caregiver needs and in developing, testing, and implementing caregiver supports.

**III. Title:** [Caregivers of Younger Adults: A Focused Look at Those Caring for Someone Age 18 to 49](#)

**Author:** National Alliance for Caregiving in collaboration with AARP

**Overview:** Produced by the National Alliance for Caregiving in 2009 as a companion to *Caregiving in the US*, this report focuses exclusively on caregivers providing care to adults aged 18 to 49. The NAC conducted 187 caregiver telephonic interviews, compiled caregiver responses, and published the key trends and findings in this report.

**Recommendations/Findings:**

1. The average age of caregivers who care for younger adults has risen, from an average of 41.0 in 2004 to 45.8 years of age.

2. In 2009, young adult recipients are more likely than recipients of 2004 caregivers to be single (60% vs. 45%) or widowed (6% vs. 1%), and are less likely to be living with a partner (2% vs. 7% 2004).
3. 2009 saw an increase in the proportion of caregivers of younger adults who help their loved one with transportation (86% vs. 77% in 2004).
4. There has been a drop in the share of caregivers of younger adults who say they are the sole caregivers (from 55% in 2004 to 41% in 2009).
5. Use of medication is more commonly reported by caregivers of younger adults than it was in 2004 (74% 2009 vs. 60% 2004).
6. The proportion of caregivers of younger adults who experienced at least one job impact as a result of their caregiving rose from 58% of those who worked while caregiving in 2004 to 75% in 2009. This is due to the significant increase in caregivers who had to go in late, leave early, or take time off during the day to provide care (53% in 2004 vs. 70% in 2009).
7. There was also an increase in the need for non-English language educational materials from 4% in 2004 to 11% in 2009.
8. Caregivers of younger adults are now older, on average, than were their counterparts in 2004. Their average age is now 45.8 years, compared to 41.0 in 2004.
9. Caregivers of younger adults are more often Hispanic (20%) than in 2004 (11%).
10. Caregivers of younger adults are less likely to have children or grandchildren living in their household in 2009 (30% vs. 42% in 2004). This is consistent with the increase in age of the caregivers.
11. Half of caregivers of younger adults have at least \$50,000 in income (49%), up from 35% in 2004. However, they are less likely to be currently employed (50% 2009 vs. 66% 2004).
12. The 2004 median income of \$41,000 for caregivers 18 or older is equivalent to about \$48,000 in 2009.
13. Half of caregivers of younger adults have at least \$50,000 in income (49%), up from 35% in 2004. However, they are less likely to be currently employed (50% 2009 vs. 66% 2004).
14. The 2004 median income of \$41,000 for caregivers 18 or older is equivalent to about \$48,000 in 2009.
15. Caregivers of younger adults in 2004 and 2009 have a similar pattern of living location and Armed Forces service, as do care recipients age 18 to 49.

**IV. Title:** [Caregiving, intellectual disability, and dementia: Report of the Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities.](#)

**Author:** Tamar Heller, Haleigh M. Scott, Matthew P. Janicki

**Overview:** Produced in 2018 by a working group commissioned for the National Institutes of Health–National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers, this report focuses on caregivers providing care to recipients with intellectual and developmental disabilities (IDD) and dementia. Specifically, this reports identifies commonalities between IDD-specific services and services provided to adults with dementia, as well as recommendations for the caregivers of these populations.

## Recommendations/Findings:

1. Better integrate community education, outreach, research, and supports for caregivers of older adults and caregivers of adults with IDD and dementia to capitalize on the strengths of both programs and promote inclusive practices.
  - Include people with IDDs and their supporters in both generic aging and dementia studies
  - Document the cost of family support programs and how they benefit society and reduce overall cost of nonfamily
  - Acknowledge positive aspects of caregiving ACL
  - Incorporate concepts such as future planning, person-centered planning, and supported decision-making in research and practice
2. Increase research and community programming to support people with IDDs and dementia living in group home settings.
  - Examine the benefits of dementia capable communities “Dementia friendly America” with respect to aiding families caring at home for adults with IDDs
  - Develop and test models of residential supports that are dementia capable for both adults with IDDs and other older adults with dementia
  - Provide sufficient training and financial supports for dementia capable homes
  - Examine the degree of family caregiver supports associated with living out-of-home dementia care of adults with IDDs
3. Acknowledge and respect the diversity of family values and caregiving practices.
  - Develop linguistic and cultural sensitivity among providers based on ethnic and cultural values and practices
  - Consider the special needs of families living in poverty and families not identified by the service system
  - Develop methods of reaching families in rural areas and those in linguistic and/or ethnic geographic groupings
4. Increase early screening and public awareness of dementia and other aging-related issues in people with IDDs and their caregivers.
  - Increase training for clinicians and widespread dissemination of diagnostic instruments developed specifically for people with IDDs
  - Help families and other persons who provide support recognize the signs of dementia in people with IDDs
  - Adopt an early detection and screening instrument for persons with IDDs as part of the annual wellness visit under the Affordable Care Act.
5. Focus on the integration of the aging and developmental disability networks to provide quality continuous care.
  - Examine the impact of the “Perfect Storm”—an aging population, more numbers of persons with dementia, and diminution of numbers of care workers
  - Fund more research on best practices that apply to dementia caregiving including family support models, relationship-based care, and supported decision-making
  - Examine how more cross-cutting collaborations can occur among the aging, dementia care, and disability sectors to address the needs of caregivers of persons with IDDs and dementia

**V. Title:** [Home Alone Revisited: Family Caregivers Providing Complex Care](#)

**Author:** Susan C. Reinhard, Heather M. Young, Carol Levine, Kathleen Kelly, Rita B. Choula, Jean Accius

**Overview:** Produced by the AARP in 2019, this report focuses on caregivers who provide “medical/nursing tasks,” which include services such as “administering multiple medications, changing dressings, and handling medical equipment.” This report summarizes the responses from an online, population-based survey of nearly 3000 caregivers across the US.

**Findings:**

1. Today’s caregivers provide intense and complex care, including performing medical/nursing tasks and managing multiple health conditions that are often accompanied by pain.
  - Half of family caregivers are performing medical/nursing tasks for individuals with challenges in physical, cognitive, and behavioral health. They carry a heavier responsibility than those who do not perform these tasks, spending more than twice as many hours per week providing care.
  - Seven out of 10 family caregivers who perform medical/nursing tasks face the practical and emotional strain of managing pain.
2. Today’s caregivers are diverse and so are their experiences.
  - Caregiving is a cross-generational issue for both men and women. Different age cohorts face distinct challenges for their life stage. For example, one in four of these caregivers is a millennial, and 40 percent of millennials and younger caregivers are supporting someone with a behavioral health condition.
  - Multicultural family caregivers are more likely to experience strain and worry about making a mistake, regardless of income.
3. Caregivers who are socially isolated or have no choice about caregiving are more at risk for experiencing difficulties with complex care.
  - Social isolation compounds difficulties with complex care, across generations and cultural groups.
  - Most family caregivers who perform medical/nursing tasks feel they have no choice.
4. Caregivers performing more medical/nursing tasks experience both positive and negative impacts.
  - About half of caregivers who perform medical/nursing tasks are worried about making a mistake. The more complex the task, the greater the worry.
  - Stress, worry, financial concerns, and feeling the need to be vigilant rise as complex care demands increase.
  - The more medical/nursing tasks they perform, the more caregivers feel they are keeping their family member out of a nursing home.
5. Many family caregivers are still on their own—health systems should do more to prepare these vital members of the team.
  - Caregivers are largely on their own in learning how to perform medical/nursing tasks they find difficult to perform, such as managing incontinence and preparing special diets.
  - Three out of five caregivers whose family members were hospitalized in the past year report that they received instruction on how to perform medical/nursing tasks, but more work needs to be done in ensuring hospitals identify family caregivers and give them timely notification of discharge.

**Recommendations:**

1. Increase awareness of the current realities for family caregivers among the general public, health care professionals, health care delivery systems, and policy makers.
2. Update assessment tools for family caregivers to include medical/nursing tasks and capture the complexity and trajectory of care.
3. Public programs should include assessments of family caregivers who are providing complex care for consumers who identify these caregivers in their person-centered plan of care.
4. Health care and social service professionals must elicit and respond to the worries of these family caregivers.
5. Health care systems and professionals must make stronger efforts to recognize family caregivers and offer them instruction on and support for complex care.
6. Health care and social service professionals must recognize that family caregivers are diverse in many ways and need proactive outreach to help them manage complex care.
7. Health care and social service professional education must include preparation to support family caregivers who provide complex care.
8. The private sector—employers and industry—can help to better recognize and support employees who are also family caregivers.
9. Community-based organizations should include in their programs and services targeted resources that address the needs of all family caregivers, particularly those engaged in complex care.
10. Further research could advance understanding of the experiences of these family caregivers and generate evidence-based solutions for them.

**Additional Reading and Resources:**

**Title:** [Informal Caregiving for Older Americans: An analysis of the 2011 National Study of Caregivers](#)

**Author:** Brenda C. Spillman, Jennifer Wolff, Vicki A. Freedman, Judith D. Kasper; Office of the Assistant Secretary for Planning and Evaluation (ASPE), Department of Health and Human Services (2014)

**Title:** [Rare Disease Caregiving in America](#)

**Author:** National Alliance for Family Caregiving (2018)

**Title:** [Process Evaluation of the Older Americans Act Title III-E National Family Caregiver Support Program \(NFCSP\): Final Report](#)

**Author:** The Lewin Group, Inc. (2016)

**Title:** [Research on Family Caregiving Support in the United States: A Strategic Plan](#)

**Author:** Brian R. Grossman, Sandra Magana, Randa Abdelrahim, Sandra Vanegas (2018)