

Advocacy Starts at Home

Strengthening Supports for Low-Income Older Adults and Family Caregivers

SPECIAL REPORT • FEBRUARY 2016

Written By

Fay Gordon

Staff Attorney, Justice in Aging

Vanessa Barrington

Communications Director, Justice in Aging

With the support of The Albert and Elaine Borchard
Center on Aging

Introduction

Margaret is a middle-aged, middle income woman with teenagers at home, a husband, a job, and a 91-year old mother with a limited income who lives alone in an adjacent town.

She checks on her mother daily, brings her groceries, drives her to appointments, helps with her bills, and worries constantly about what would happen if her mother fell. No matter what else is happening in her life, she's always on call in case her mother needs her. Margaret is a family caregiver,¹ one of nearly 35 million Americans who provide unpaid care to an adult age 50 or older.²

Like Margaret, many of us will be called upon to provide care for a loved one at some point in our lives. Caregiving is an issue that touches every family, rich or poor. Yet for too long, the issue of family caregiving has not gotten the attention it needs and the interplay between the needs of older adults and those of their family caregivers has been underappreciated.

Fortunately, due to the great work of many advocates and organizations, there is growing attention to family caregiving—both in the news and in political platforms. There is recognition that as the population ages, the need for family caregivers and the resources to support them is growing, and that we must do more. As much as caring for a family member is a labor of love, it's also a challenge for families. And it's even more of a challenge for families without resources.

1 The National Alliance for Caregiving and AARP Public Policy Institute, *Caregivers of Older Adults: A focused Look at Those Caring for Someone Age 50+* (June 2015), available at: <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>.

2 Id.

As 10,000 people turn 65 every day, and growing numbers of older Americans age into poverty, we need to act to ensure low-income older adults, and the family caregivers they rely on, have the support they need to live in dignity. Without action, the expense of caregiving and burden of stress will continue to challenge family caregivers' economic security and health. Thankfully, there are clear solutions to this problem and momentum is growing to make them a reality:

1. Improve and strengthen older adult support systems to relieve pressure on family caregivers.
2. Expand existing and adopt new policies to directly support family caregivers so they are better able to care for aging loved ones.

Taking action on these issues will benefit everyone, but they are crucially needed now for low-income older adults and the families that care for them.

Part One: The Problem

The Strain of Poverty on Low-Income Older Adults and Family Caregivers

Providing care for a family member can be a challenge for anyone, as it requires a flexible schedule, financial resources, and the support of other family members. Poor families often lack these supports and resources, making unpaid caregiving both an economic and health strain. Poverty has a disproportionately harmful impact on low-income older adults and family caregivers in the following ways

Low-income women are particularly impacted by the gender wage gap and caregiving career interruptions. Not only is caregiving more difficult for families who are already poor, but the act of caregiving itself can lead to increased poverty, particularly for women. The typical family caregiver is a woman (60% of caregivers are female)³ with a median age of 50.⁴ Women of all incomes experience an earnings gap

relative to men.⁵ When women leave the workplace to care for family members, it is more difficult to reenter the workforce later.⁶ The combination of the wage gap and career interruptions make a female family caregiver more vulnerable to falling into poverty.

The poverty statistics for women who are family caregivers also point to a clear relationship between poverty and family caregiving. Family caregivers are 2.5 times more likely than non-caregivers to live in poverty and five times more likely to

³ Id.

⁴ Id.

⁵ Ellen Patten, Pew research Center, *On Equal Pay Day, Key facts about the Gender Pay Gap* (April 2015), available at: <http://www.pewresearch.org/fact-tank/2015/04/14/on-equal-pay-day-everything-you-need-to-know-about-the-gender-pay-gap>.

⁶ C. Wakabayashi and K. M. Donato, "Does caregiving increase poverty among women in later life? Evidence from the Health and Retirement Survey," *The Journal of Health and Social Behavior* 47, no.3 (2006): 258–74.

receive Supplemental Security Income (SSI).⁷ Caregiving data suggest that lower-income women shoulder a disproportionate amount of family caregiving hours, as 52% of women caregivers with incomes at or below the national median of \$35,000 spend 20+ hours per week providing care.⁸ Poverty intensifies a family caregiver's financial vulnerability, as financial assistance is often part of the package of caregiving for a low-income older adult. According to a 2011 study, 23% of non-working and 20% of working female caregivers are providing financial assistance to parents for whom they are caregiving.⁹

Low-income women of color struggle to weather the financial pressure of family caregiving. Due to already existing income disparities for women of color (the poverty rate for single African American women over 65 is 30.7%, and for single Hispanic women it is 40.8%)¹⁰ it is even more difficult for low-income caregiving women of color to weather the financial shock of lowered earnings and extra expenses. According to the Family Caregiver Alliance,¹¹ minority and low-income caregivers may face additional challenges both in meeting their basic needs and being able to afford support services and supplemental paid care that higher income people may rely on. As a result, lower-income caregivers are half as likely as higher-income

caregivers to have paid home health care or assistance available to provide support for and relief from their caregiving functions.¹²

Family caregivers are at risk of increased stress and compromised health status.

For caregivers at every income level, caring for family members can be overwhelming, compromising not just earning power and income, but also their own health. Only 55% of female family caregivers are employed and only 19% have health insurance. And over half (51%) of female family caregivers have a chronic condition of their own.

These challenges contribute to significant caregiver stress, with more than one in four caregivers labeling stress as the most significant challenge they face.¹³ The time commitment of caring for a relative can be an incredible burden for caregivers without help. One-third of caregivers who participate in the Administration for Community Living respite program report that they spend 40 hours per week caring for an older relative.¹⁴ The time requirement for caregivers with children can put stress on the rest of the family, and 41% of female family caregivers have children under 18 in the household.

The loss of income, health problems, stress, and lack of time will hit more people as the population ages and more adults become family caregivers. We need to address the challenges facing family caregivers immediately. We already have the system in place to support older adults and family caregivers, but steps must be taken now to strengthen and improve the system, particularly for low-income families.

7 Rice University, *Rice University Sociologists Calculate Caregivers Risk of Living in Poverty*, (2004), available at: <http://news.rice.edu/2004/08/16/rice-university-sociologists-calculate-caregivers-risk-of-living-in-poverty/>.

8 Family Caregiver Alliance, *Women and Caregiving: Facts and Figures*, (Retrieved January, 2016), available at: <https://www.caregiver.org/women-and-caregiving-facts-and-figures>.

9 *The MetLife Study of Caregiving Costs to Working Caregivers*, (June 2011), <https://www.metlife.com/assets/cao/mmi/publications/studies/2011/Caregiving-Costs-to-Working-Caregivers.pdf>.

10 Family Caregiver Alliance, *Women and Caregiving: Facts and Figures*, (Retrieved January, 2016), available at: <https://www.caregiver.org/women-and-caregiving-facts-and-figures>.

11 Family Caregiver Alliance, *Facts and Figures*.

12 Id.

13 Shefali Luthra, "Who are America's Caregivers? Nearly a Quarter are Millennials," Kaiser Health News, (December 2015), available at: <http://khn.org/news/who-are-americas-caregivers-nearly-a-quarter-are-millennials>.

14 Id.

Part Two: Solutions

There are two discrete sets of solutions that work in tandem to support older adults and their caregivers. Both are essential. We must: 1) Improve the public benefits programs and sets of services that provide direct support to older adults. These include health care, income supports, and supportive services like transportation and meals. 2) Improve current policies and services and create new initiatives that will better support family caregivers to lessen the financial and health stresses they face.

Improve and strengthen older adult support systems to relieve pressure on family caregivers

Health and economic security programs help low-income older adults meet their needs. When these programs work, they relieve caregiver stress by providing a foundation of reliability and support. When they don't work, the job of caregiving becomes that much more difficult. To fully support family caregivers, we need to strengthen and expand the systems low-income older adults and their families rely on.

Improve the operation and accessibility of the Social Security and Supplemental Security Income (SSI) Programs. Social Security and SSI provide a basic income that allows low-income older adults to pay rent, buy groceries, and meet other basic needs. When these programs operate well, without disruption, and deliver the benefits seniors are entitled to, older adults have some economic stability. Taking care of a loved one can require significant financial and

employment sacrifice on the part of family caregivers. With this financial burden, family caregivers should not have to worry about their loved ones losing or not qualifying for their Social Security and SSI benefits. We need to expand the Social Security program and restore SSI¹⁵ to ensure the benefits of both programs are available and accessible to all who qualify, without discrimination and arbitrary disruptions.

Help older adults access and navigate Medicare and Medicaid benefits without complications. Without Medicare and Medicaid to cover health care costs, low-income older adults and their families have to pay out-of-pocket for visits to their doctors, medicine, medical equipment, long-term care, and hospital visits. Given that this is impossible even for higher income individuals, it's crucial that low-income older adults have access to these benefits. Older adults and their caregivers need both programs to have clear and understandable coverage explanations, navigable forms in a multiple languages, and an appeals system that works properly.

Ensure long-term care is person-centered and considers the contributions of unpaid family caregivers. Experts have long recognized that person-centered care planning that takes into account the needs and desires of the individual can ensure a better quality of life for people receiving long-term care. Part of this planning should include assessing the family caregiver and incorporating the caregiver's needs. Unfortunately, these care

15 Justice in Aging, *Supplemental Security Income FAQs*, available at: http://www.justiceinaging.org/wp-content/uploads/2015/05/SSIFAQs_April2014.pdf.

Margaret and Sadie

Last year, Margaret (referred to earlier in this report) nearly had to put her mother in a nursing home. Not because her mother was incapable of living independently, but simply because the system meant to support families like Margaret and Sadie's failed to provide the support they needed. Sadie at 91, lives alone in the modest home where she'd lived with her husband before his death. Her small income makes her eligible for Medicaid. Into her late 80s, she was a caregiver herself, caring for her late husband as his health and mental capacity declined due to Alzheimer's. Because his Medicaid benefits only covered three hours a day of home health care, the burden of bathing him, dressing him, and helping him get around fell mostly to her, but she kept him at home with her until the end of her life—and this is what she and Margaret both want for her as well.

Until recently, Sadie was almost completely independent. Margaret would check on her every few days and bring her family over for dinner to enjoy Sadie's home cooked meals. Then Sadie fell and broke her femur. After a short stay in a skilled nursing facility, she returned home to find her Medicaid benefits had been terminated due



▶ Watch Margaret and Sadie's story

to a coding error by the facility. She had no help at home other than her daughter Margaret and faced thousands of dollars in bills for charges that should have been covered. She nearly lost her home. Margaret stayed with Sadie and cared for her until she was able to resolve the issue with the help of some advocates and legal services attorneys.

Without her daughter there to both advocate for her and care for her, Sadie could have ended up homeless, or worse. There are systems in place to ensure that people like Sadie can age at home, safely and with dignity. But we must take steps now to ensure they work better for low-income older adults and their family caregivers.

plans sometimes ignore caregiver's needs, or worse, wrongly take advantage of family caregivers¹⁶ to reduce costs. Unpaid caregivers provide care valued at \$470 billion a year.¹⁷In 2009, the average family caregiver provided nearly 20 hours per week of care for

nearly five years.¹⁸ Our long-term supportive services system must ensure family caregivers are not forced into draining or uncertain care situations.¹⁹ Truly person-centered care plans must assess family caregivers for their needs and provide enough paid care hours to pro-

16 See Technical Assistance Brief, ("What are the best strategies to take advantage of family caregiver supports and reduce overall LTSS costs?"), Center for Health Care Strategies, *Developing Capitation Rates for Medicaid Managed Long-Term Services and Supports Programs: State Considerations*, available at: http://www.nasuad.org/sites/nasuad/files/MLTSS-Rate-Setting_Final2.pdf.

17 Reinhard, et al., *Valuing the Invaluable: 2015 Update*, AARP Public Policy Institute, (July 2015), available at <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>.

18 Lynn Feinberg & Rita Choula, *Understanding the Impact of Family Caregiving on Work*, AARP Public Policy Institute, (October 2012), available at: http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf.

19 Julie Carter, *Person-Centered Planning? Not without Family Caregivers!*, American Bar Association, (October 2015), available at: http://www.americanbar.org/publications/bifocal/vol_37/issue_1_october2015/person_centered_planning.html.

tect against over-reliance on already stretched family caregivers.

Strengthen Older Americans Act programs that help older adults remain at home and in their communities. For over 50 years, the Older Americans Act (OAA) has served as the nation’s primary vehicle for coordinating and delivering the home and community-based services—including home care, congregate and home delivered meals, and transportation—that help older adults with the greatest economic need age at home and in the communities. In addition, the OAA supports the legal services and ombudsman programs that advocate for older adults’ right to age with dignity and justice. Together, the various categories of direct services and supports provided by OAA help older adults remain at home and avoid institutionalization. Unfortunately, despite its history of success, the OAA has not been reauthorized in 10 years, and the current reauthorization bill sits in the Senate. Leadership and action are needed in the House of Representatives to ensure this vital support system is reauthorized and funded at levels to serve the growing needs of low-income older adults.

Implement new and expand existing policies to support family caregivers helping older adults

Family caregivers need both financial and practical support in order to provide the care the older adults in their lives need to age in dignity. We need to build a framework that directly supports the important role family caregivers play today and the greater role they will play in the future:

Modernize employment policies to strengthen family caregiver’s job and economic security. Taking time to care for a loved one should not jeopardize the family caregiver’s current employment or future retirement security. The average cost impact of caregiving on lost wages and Social Security benefits for women (the caregiving majority) is \$324,044.²⁰ Caregivers should be able to earn Social Security credits that count toward retirement income. Secretary Clinton has proposed a plan to help caregivers, and pay back up to \$1,200 of the money they spend on caregiving, as well as giving Social Security credits to people who stop working because of their caregiving responsibilities.²¹

In addition, we need to support caregivers who continue to work by incentivizing employers to provide flexible schedules, generous paid family leave policies, and job protection for employees who must take time off to care for a family member. Employers should implement policies that recognize the impact that caregiving has on employees and find ways to support employees during difficult times.²²

Educate and train the health care system to better support family caregivers. Family caregivers’ needs should be assessed as part of an individualized care plans, and they should

20 MetLife Mature Market Institute, *The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for their Parents* 2011), as cited in Feinberg et al., *Valuing the Invaluable: 2011 Update*, AARP Public Policy Institute (June 2011), available at: <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>.

21 Amanda Baker, “Clinton proposes tax credit for family caregiving costs,” (November 2015), <http://www.reuters.com/article/us-usa-election-clinton-idUSKBN0TB0RF20151123>.

22 Family Caregiver Platform Project, *Caregiver Platform Planks*, and (accessed January 2016), available at: <http://caregivercorps.org/planks>.

be included in the care planning process.²³ When family members are discharged from a hospital, the family member's home caregiving needs should be discussed with the family caregiver and arrangements should be made for caregiver training and support.²⁴ Currently, 18 states²⁵ and Puerto Rico have passed the "Caregiver Advise, Record, Enable (CARE) Act," which supports family caregivers at the hospital, by ensuring hospitals record the name of a family caregiver during hospital admission, notify the caregiver when the family member is discharged from the facility, and inform the caregiver of the medical tasks s/he may need to provide at home.²⁶

Each of these initiatives are important, but incremental solutions can only go so far to help family caregivers. A holistic strategy that identifies actions government, communities, providers, employers, and others can take to recognize and support family caregivers is critically needed. Recently, the Senate passed the "Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act,"²⁷ which would develop a national caregiving strategy. Advocates are pushing for action in the House of Representatives.

Reauthorize the Older Americans Act and strengthen respite services for caregivers. As discussed earlier, the OAA

23 Family Caregiver Platform Project.

24 Family Caregiver Platform Project.

25 Dawn R. Crumel, "Initiative to Improve Quality After Discharge: New Caregivers' Laws," *The National Law Review* (January, 2016). <http://www.natlawreview.com/article/initiative-to-improve-quality-after-discharge-new-caregivers-laws>.

26 Elaine Ryan, *The CARE Act: Caring for Family Caregivers*, (March 2014), available at: <http://blog.aarp.org/2014/03/10/the-care-act-caring-for-family-caregivers>.

27 RAISE Family Caregivers Act (S. 1719/H.R. 3099). See AARP Bulletin for more information: <http://www.aarp.org/politics-society/advocacy/info-2015/rally-congress-for-caregivers-raise-act.html>.

is the cornerstone of the nation's home and community-based services system, helping older adults age at home. In addition to helping older adults, the OAA administers the National Family Caregiver Support Program (NFCSP). The NFCSP offers a range of supportive services for family caregivers, like counseling and support groups and respite care services. Nearly half of the caregivers who participate in NFCSP services report that they would not be able to continue caring for their loved one at home without the OAA supportive services.²⁸ As the aging population increases, the demands on family caregivers will increase, as well. We must reauthorize the OAA and adequately fund NFCSP services like counseling and respite to provide relief and support to family caregivers.

Conclusion

The challenges of aging and caregiving will hit every family, regardless of income, but those challenges are even more acute for those with greatest financial need. Rich or poor, families and friends are a far better support system for older adults than institutions. With greater numbers of older adults than ever aging into poverty, we need to elevate the role caregivers can play in supporting them, and create a system that works for both older adults and their caregivers. This will help families stay intact and ensure that more older adults can remain at home and in their communities.

28 National Family Caregiver Support Program, OAA Title III E, available at: http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver.

About Justice in Aging

Justice in Aging is a national non-profit legal advocacy organization that fights senior poverty through law. Formerly the National Senior Citizens Law Center, since 1972 we've worked for access to affordable health care and economic security for older adults with limited resources, focusing especially on populations that have traditionally lacked legal protection such as women, people of color, LGBT individuals, and people with limited English proficiency. Through targeted advocacy, litigation, and the trainings and resources we provide to local advocates, we ensure access to the social safety net programs that poor seniors depend on, including Medicare, Medicaid, Social Security, and Supplemental Security Income (SSI). And we work to build a health care system that honors choice and includes strong consumer protections for all seniors.

For more information, visit our website at www.justiceinaging.org.

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

WASHINGTON

1444 Eye Street, NW, Suite 1100
Washington, DC 20005
202-289-6976

LOS ANGELES

3660 Wilshire Boulevard, Suite 718
Los Angeles, CA 90010
213-639-0930

OAKLAND

1330 Broadway, Suite 525
Oakland, CA 94612
510-663-1055