United States House of Representatives
Committee on Education and Labor
Subcommittee on Civil Rights and Human Services
Examining the Older Americans Act:
Promoting Independence and Dignity for Older Americans
Wednesday, May 15, 2019, 10:15 A.M.
2175 Rayburn House Office Building, Washington, D.C.

Written Testimony of
C. Grace Whiting, J.D., President and CEO, National Alliance for Caregiving

Good morning, Chair Bonamici, Ranking Member Comer, and members of this Subcommittee. Thank you for your time today to talk about the Older Americans Act's (OAA) Title III(e), National Family Caregiver Support Program – a necessary cornerstone to supporting the dignity and independence of older adults, adults with disabilities, and the friends or family who provide care to them.

My name is Grace Whiting, and I am the President and Chief Executive Officer of the National Alliance for Caregiving (NAC). NAC is a 501(c)(3) nonprofit organization dedicated to improving the quality of life for friends and family who provide unpaid caregiving to millions of Americans across the lifespan. Our core work includes public policy research on caregiving, national advocacy on federal caregiving initiatives, and support for a state network of grassroots caregiver coalitions. We are also the founder and Secretariat for the International Alliance of Carer Organizations, a multi-national coalition of 16 non-governmental entities around the world who are working to build a global understanding and respect for the role of caregivers.

Family caregiving is a public health issue. Millions of Americans are providing high-touch, high-impact activities to support older adults and adults living with disabilities. In a nationally representative research study conducted in partnership with AARP, we estimated that there are 34.5[1] million people caring for older adults and adults 18 – 59 with disabilities. If we add to this the number those who care for children with disabilities, that estimate rises to 44 million Americans. One in five Americans. For reference, forty-four million people is roughly the same size as the entire population of Argentina.[2]

Many of your Congressional colleagues share in the challenges of caregiving. We applaud the Members of the Assisting Caregivers Today Caucus, and champions such as U.S. Representatives Jan Schakowsky, Debbie Dingell, Jacky Rosen, Jim Langevin, and other leaders who have spoken openly about their caregiving journey.[3]

The Older Americans Act, including the National Family Caregiver Support Program, supports our long-term care ecosystem in three key ways:

---

[1] National Alliance for Caregiving and AARP Public Policy Institute, Caregiving in the U.S. 2015 (June 2015), www.caregiving.org/caregiving2015.

[2] Current population estimate is 43,847,430; see United Nations Department of Economic and Social Affairs, Population Division. World Population Prospects: The 2017 Revision (2017). Available at https://population.un.org/wpp/DataQuery/.

[3] See Congressional Stories of Family Caregiving (November 2017), https://www.caregiving.org/wp-content/uploads/2018/02/GSA-Congressional-Stories-of-Caregiving-briefing-paper.pdf

1. **Health care providers can rely on caregiver supports in the OAA to improve the ability of friends and family to provide informal care.**

2. **Employers who face productivity losses due to caregiving can use OAA programs as a resource to support caregivers in the workforce.**

3. **OAA programs can protect the health, wealth, and well-being of aging caregivers.**

For the purposes of today's testimony, we use the term "caregiver" as it is defined in the recently enacted RAISE Family Caregivers Act. A caregiver is "an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation."[4]

Health care providers can rely on caregiver supports in the OAA to improve the ability of friends and family to provide informal care.

In 2008, Dr. Donald Berwick, of the Institute for Healthcare Improvement and a former Administrator of the Centers for Medicare and Medicaid Services (CMS)[5], challenged health policy experts to rethink the framework for health reform. He identified three key pillars of successful reform typically described as the "Triple Aim." The framework posits that reform should (1) improve the quality of individual health, (2) improve the health of populations, and (3) reduce the cost of health care. Family caregivers support these three pillars, and health care providers have started to take note.

We know from research and personal experience that family caregivers improve the quality of care offered to individuals by providing personalized care:

- Caregivers provide support for activities of daily living such as help with bathing or eating, instrumental activities of daily living such as managing finances, and medical/nursing tasks such as giving injections.

- More than half (57%) of America's caregivers provide medical/nursing tasks individual patients, through medical/nursing tasks such as giving injections, tube feedings, catheter and colostomy care, and other complex care responsibilities often without prior education or support. Nearly half of caregivers help with managing medication (46%).[6]

- The majority of caregivers help with transportation (78%), which reduces social isolation and allows older adults to stay engaged in the community.

---

[4] From P.L. No: 115-119, available at https://www.congress.gov/bill/115th-congress/house-bill/3759. In research and in advocacy, "caregiver" may be described as: informal caregiver, care partner, caretaker, and related terminology. In an international context, the term "carer" is often used. It should be noted that an estimated 1.4 million children in the U.S. are unpaid caregivers (NAC and United Hospital Fund, Young Caregivers in the U.S. (2005) at https://www.caregiving.org/data/youngcaregivers.pdf).

[5] Donald M. Berwick, Thomas W. Nolan, and John Whittington. The Triple Aim: Care, Health, and Cost. Health Affairs (Vol. 27, No. 3, May/June 2008). Available at https://www.healthaffairs.org/doi/full/10.1377/hlthaff.27.3.759.

[6] See n. 1; see also Susan Reinhard, Heather Young, Carol Levine, Kathleen Kelly, Rita Choula and Jean Accius. AARP Public Policy Institute. Home Alone Revisited: Family Caregivers Providing Complex Care (April 2019). Available at https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf.

- Nearly one-third of caregivers (32%) are "high intensity" and provide care for at least 21 hours a week, on average providing 62.2 hours of care each week.

- Caregivers play the role of advocates, with a majority advocating with health care providers, coordinating services, and navigating health care systems such as insurance.

Caregiving is a constant balance between activity and worry, as one caregiver describes:[7]

> *"No matter how good things are, you are always on pins and needles… You worry about a possible relapse, you worry about him not being able to get his medication on time, you worry he will stop taking his medicines…"*

We know from research that family caregivers, when supported, can improve the health of populations. Research has shown that caregivers can help avoid unnecessary hospital readmissions as individuals are discharged from hospital to the home, reducing admissions by 25% at 90 days and 24% at 180 days.[8] When it comes to Alzheimer's and dementia, caregivers can help an older adult to live longer in the community and delay the cost of institutionalization.[9]

And we know from economic analysis that family caregivers can reduce overall health system costs. AARP has estimated that if we replaced each family caregiver of an adult with a direct care worker, it would cost our economy $470 billion[10] a year. Providers are aware of this cost savings, and emerging trends in managed care rely on caregivers to bridge gaps, reduce health system costs, and improve shared savings.[11]

Although caregivers offer these services without pay, these services are not free. In many cases, caregiving can strain an individual's finances, their health, their social connections and relationships, and even their overall wellness. If we are asking families to take on $470 billion worth of care with little support, they need education, respite, and support to be effective. Providers in some spaces have noticed this, providing assessment of caregiver needs through programs like the Home- and Community-Based Waivers Program under Medicaid. Yet this use of assessment is not universal, and in many cases, there are no standard assessment tools to identify caregiver needs and refer caregivers to services.[12]

The National Family Caregiver Support Program offers an entry point for identifying caregiver needs and can help to address the need for caregiver education, respite, and support. Since 2000, the program

---

[7] National Alliance for Caregiving in partnership with Mental Health America and the National Alliance on Mental Illness. On Pins & Needles: Caregivers of Adults with Mental Illness (February 2016). Available at https://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf.

[8] Rodakowski, et al. "Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis," Journal of the American Geriatric Society (April 2017), at http://onlinelibrary.wiley.com/doi/10.1111/jgs.14873/full

[9] See e.g., Mittleman, et al. "An intervention that delays institutionalization of Alzheimer's disease patients: treatment of spouse-caregivers," Gerontologist (1993), https://www.ncbi.nlm.nih.gov/pubmed/8314099

[10] Reinhard, S., Feinberg, L. F., Choula, R., & Houser, A., Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps. (2015), at https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html

[11] See e.g., Richard Schulz, National Academies for Science, Engineering, and Medicine, Families Caring for an Aging America, "Family Caregivers' Interaction with Health Care and Long-Term Services and Supports." (2016). Available at https://www.ncbi.nlm.nih.gov/books/NBK396396/.

[12] See Kathleen Kelly, Mary Jo Gibson, Lynn Feinberg. AARP Public Policy Institute, Listenting to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid HCBS Waiver Programs (December 2013). Available at https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/the-need-to-include-family-caregiver-assessment-medicaid-hcbs-waiver-programs-report-AARP-ppi-ltc.pdf

.

has provided grants to states and territories to help older adults and people with disabilities stay in the home as long as possible.

There are five types of services offered under the program:

- Information about available services
- Assistance to gain access to services
- Individual counseling, organizational of support groups, and caregiver education
- Respite care, to allow caregivers to take a break, and
- Supplemental services.

The Administration for Community Living has noted that these programs can enable caregivers to provide care longer, which can help older adults and people with disabilities to delay or even avoid the need for institutional care.[13] Nearly two thirds (74%) of caregivers who evaluated the program indicated that services enabled them to provide care longer than would have been possible otherwise. Almost nine out of ten (88%) reported that the services they received helped them to be a better caregiver, and more than half (62%) indicated that without the services they received, the person receiving care would be living in a nursing home.

Employers who face productivity losses due to caregiving can use OAA programs as a resource to support caregivers in the workforce.

As of the 2016 Reauthorization of the Older Americans Act, four key populations are served by the National Family Caregiver Support Program:

- Adults who care for people age 60 or older
- Adults who care for people of any age with Alzheimer’s disease and related disorders
- Relatives age 55 and older, excluding parents, who care for children under age 18; and
- Relatives age 55 and older, who care for adults with disabilities between ages 18 and 19.

People in each one of these groups are at least ten years shy of being eligible for retirement. Our research has shown that as many as six out of ten caregivers are balancing work and care.[14] We have estimated that caregivers age 50 or older who step out of the workforce to care for aging parents lose just over $300,000 in lost wages, pension, and Social Security income.[15]

Employers also face losses as America ages. Employers with caregiving employees must make workplace accommodations for caregivers in the workforce. Many employers face caregiving costs including retention, rehiring, absenteeism, crisis in care, workday interruptions, additional time to manage employees, unpaid leave, and reduced hours. In total, these costs total an estimated $33.6 billion a year for employers.[16]

---

[13] See https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program.

[14] See n. 1.

[15] National Alliance for Caregiving. The MetLife Study of Caregiving Costs to Working Caregivers (June 2011). Available at https://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf.

[16] National Alliance for Caregiving. The MetLife Caregiving Cost Study: Productivity Losses to U.S. Businesses (July 2006). Available at https://www.caregiving.org/pdf/research/Caregiver%20Cost%20Study.pdf.

In addition to work, many juggle multiple care responsibilities, as shared by caregivers in a forthcoming study on Crohn's disease and ulcerative colitis:

> *"I have been my husband's caregiver and confidant since he was diagnosed in 1993. Our oldest daughter was also diagnosed at the age of 18, my experience with her was far different from the one with my husband. She was allergic to every medication that was tried and spent most of that summer in the hospital."*
>
> *"My house is always a disaster because all my time goes to cooking and transportation to and from appointments. My younger child has not had the benefit of participating in sports or extracurricular activities because I no longer have time to take her to those activities, and instead of having a typical childhood, her young years are being spent visiting her brother in the hospital."*

Employers and human resources experts have taken notice of the need to address caregiving and work. The U.S. Equal Employment Opportunity Commission has issued guidance for "Employer Best Practices for Workers with Caregiving Responsibilities" including eldercare.[17] An analysis of family responsibilities discrimination from the UC Hastings College of Law found in 2016 that employee lawsuits involving eldercare had increased by 650%, with "further growth expected to continue as the population ages."[18] Innovators have partnered with AARP and the Respect a Caregiver's Time Coalition to identify promising best practices for corporate eldercare.[19] Public and private sector leaders alike are looking for solutions to keep caregivers at work and to improve the balance between our work lives and our family responsibilities.

In addition to the supports in the National Family Caregiver Support Program, the OAA offers services to older adults that can supplement the care provided by working caregivers. Title III programs provide states with grants to support case management and information and referral for the older adult who needs care. Nutrition programs provide support when a caregiver may not be available to make dinner; senior centers may offer an additional form of respite; and transportation support can make it possible for the older adult to stay independent and the caregiver to use that time for other needs. These services enable employers to meet caregivers where they are and protect employers from having to cover all the social care needs that are required to help older adults and people with disabilities stay independent.

OAA programs can protect the health, wealth, and well-being of aging caregivers.

The United Nations has noted that globally, populations aged 60 or older are growing faster than all younger age groups.[20] In Europe, one out of four people is over 60 as of 2017. The United States is not far behind, with one out of five over 60. As family sizes shrink, the number of available people to care is shrinking too—meaning that we must act now to protect caregivers.

---

[17] EEOC. Employer Best Practices for Workers with Caregiving Responsibilities (January 2011). Available at https://www.eeoc.gov/policy/docs/caregiver-best-practices.html.

[18] Cynthia Thomas Calvert. Caregivers in the Workplace: Family Responsibilities Discrimination Litigation Update 2016 (2016). Center for WorkLifeLaw, UC Hastings College of the Law. Available at https://worklifelaw.org/publications/Caregivers-in-the-Workplace-FRD-update-2016.pdf.

[19] ReACT and AARP. Supporting Working Caregivers: Case Studies of Promising Practices (2017). Available at https://respectcaregivers.org/wp-content/uploads/2017/05/AARP-ReAct-MASTER-web.pdf.

[20] United Nations. Work Population Prospects (2017 Revision). Available at https://esa.un.org/unpd/wpp/Publications/Files/WPP2017_KeyFindings.pdf.

In the United States, more than half of our caregivers are 50 or older. Seven percent (7%) are 75 years old or older.[21] We see the same trends in other studies of caregiving across the lifespan. More than one in four caregivers of adults with disabilities under age 60 are themselves aged 50 or older—think the aging parents of adults with down syndrome, the aging wife of the wounded warrior from Desert Storm. Over a third of people who reported that they care for someone with a rare disease, condition, or disorder are over 50.[22] In mental illness, almost six out of ten caregivers are over age 50 and four percent (4%) are 75 or older.[23]

Yet the current National Family Caregiver Support program supports only 700,000 older adults as of the last estimate from the Administration for Community Living; if we use the most conservative estimate of the number of caregivers of adults (17.7 million via RAND Corporation in 2014), that means this program only serves four percent (4%) of caregivers in our country. We believe that the number is closer to two percent (2%).[24]

These services can reduce caregiver depression, anxiety, and stress, enabling caregivers to provide care longer and thereby avoiding or delaying the need for costly hospital and institutional care. They offer a way for family and friends to take a break from care and to be present with the people they love.

One personal story before I end. About six years ago, I had the honor of being invited to a celebration at the White House for caregivers of Veterans. The event was part of a bipartisan program led by Senator Elizabeth Dole to recognize the hidden heroes who care for wounded warriors when they return from combat. I was standing in the Green Room, talking to one of the Elizabeth Dole Fellows, a young woman who was caring for her husband who had been wounded in Iraq.

I said to her, “Can you believe this? I grew up in rural Louisiana, I went to high school in southern Mississippi, I never in a million years thought I’d be standing in the White House looking out at the tourists.” She looked at me, and at this celebration to honor her commitment as a caregiver, in a room that most Americans will never have the chance to visit, she said, “All I can think about is my husband back at the hotel and whether he’s okay.”

That’s the type of person that this program serves. Caregivers who are too tired, too overwhelmed, and too busy to advocate for themselves. People who need your voice to support them and the role they play in supporting our health care, social care, and long-term care systems. Family is the “basic unit of society.” And our society needs these families to survive.

Thank you.

---

[21] See n. 1.

[22] National Alliance for Caregiving in partnership with Global Genes. Rare Disease Caregiving in America (February 2018). Available at https://www.caregiving.org/wp-content/uploads/2018/02/NAC-RareDiseaseReport_February-2018_WEB.pdf.

[23] See n. 6.

[24] See https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program; RAND Corporation, Hidden Heroes (2014), https://www.rand.org/pubs/research_reports/RR499.html; NAC and AARP, *Caregiving in the U.S. 2015*, n. 1.