

Insight on the Issues

Valuing the Invaluable: 2019 Update

Charting a Path Forward

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In 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately \$470 billion.

INTRODUCTION

Better recognition of and support for family caregivers has become a health, economic, and social imperative. While progress has resulted from decades of research and advocacy calling attention to the essential, but often overlooked, role of the family in long-term services and supports (LTSS) and health care, strengthening support systems must continue—particularly given the demographic reality of population aging and a range of other trends affecting family caregivers.

In both the public and private sectors, family caregiving issues are growing in scope and complexity due to several important factors. Family caregiving is more complex and intense. Family structures are changing. More people in the labor force are juggling work and family caregiving. Thus, the expectation that families alone will provide care for an older person or an adult with a chronic, disabling, or serious health condition is unsustainable.

The experience of Karen, a family caregiver whose story appears on the next page of this report, illustrates the complexity and challenges of

family caregivers today. Her situation highlights the everyday realities of the emotional, physical, and financial impact of caregiving on the family caregiver.

This report is part of the *Valuing the Invaluable* series on the economic value of family caregiving. It provides updated national and individual state estimates of the economic value of family care using the most current data available. This latest report finds that, in 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately \$470 billion in 2017.

This report highlights trends in family caregiving and identifies key policy developments, practice approaches, and research initiatives to support caregiving families since the last *Valuing the Invaluable* report was released in 2015. The report also provides policy recommendations that would enhance the support and well-being of family caregivers and those for whom they care.



Family Caregiving™

ONE CAREGIVER'S STORY

The sound of her mother calling jolted Karen out of her sleep, sending her upright in her bed.

Karen, age 37, grabbed her phone to see the time—3:00 a.m. Perhaps she was dreaming. She lay back down, only to jump up again at the sound of more calls from her mother. No, this was not a dream. Scurrying out of bed, she ran to the bedroom next door—but her mother wasn't there. Karen finally found her lying next to the tub in the bathroom.

Karen's mom, affectionately known as Noni, is 81 years old and lives with dementia. She was recently released from the hospital after a one-month stay due to complications from diverticulitis-related surgery and a subsequent infection. Now life after the infection has been significantly altered for both Noni and Karen. While Noni's serious wound healed well, she must wear an ostomy bag for the remainder of her life. Noni's acute awareness of the ostomy bag, coupled with her dementia, led her to wander into the bathroom to try and change the bag herself. Unfortunately, she lost balance and fell. Karen suddenly found herself thrown into the unknown, and unable to recall what she was taught in the hospital about providing the ostomy care for her mom.

The middle-of-the-night episode sent Karen's mind spinning. How long would she be able to balance the increasing caregiving needs of her mother with her other commitments, especially her day job? The youngest of Noni's five children, Karen is her mom's primary family caregiver. It's a role she was given, assumed, chose—it changes depending on the day. By day, Karen works at a technology firm; by night, she is home with her mom. She moved in with her mom three years ago, when Noni was first diagnosed with dementia. As Noni's health issues increase—congestive heart failure, circulation issues, high blood pressure, diverticulitis, and dementia—so does Karen's anxiety and stress. It is less about the actual care of her mom and more about how to balance it all. Coordinating all her mom's providers, remembering the complex care instructions, and keeping up with multiple medications is a full-time job in itself. It would be easier if Karen didn't have to work, but that isn't an option. She needs a regular paycheck.

While Karen's employer allows her some flexibility, the expectation for her and her co-workers is to work long hours, often 50 or more a week. Prior to becoming her mother's caregiver, that wasn't an issue. Karen liked her job and had the energy to devote to it. But since moving in with her mom, she has spent large amounts of time caregiving—often 25 to 30 hours a week. Karen is exhausted. She has considered talking with her manager but doesn't know where to begin or what to say. Karen knows her mom depends on her and she must try her best to figure out a way to make it work. But how?

**This vignette is a composite of caregiving experiences.*

UPDATING THE NATIONAL ESTIMATED ECONOMIC VALUE OF FAMILY CAREGIVING

The estimated economic value of family caregiving was \$470 billion in 2017, based on about 41 million caregivers providing an average of 16 hours of care per week, at an average value of \$13.81 per hour.

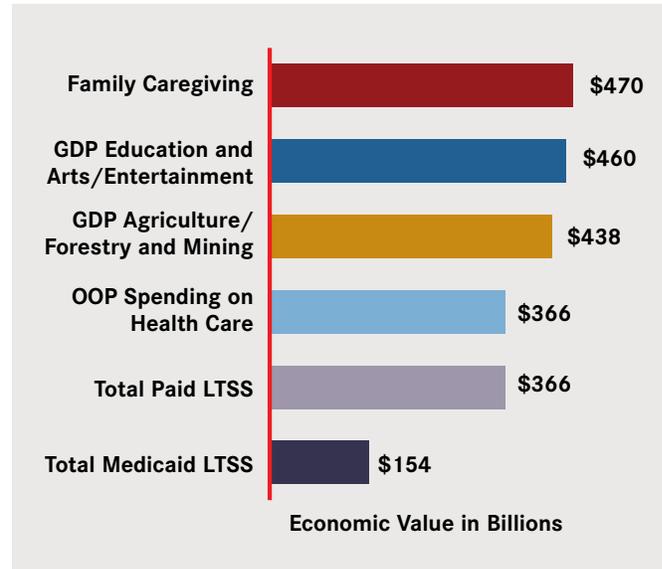
These estimates are based on a meta-analysis of four surveys of family caregivers between 2015 and 2018, adjusted to a common definition: caregiver age 18 or older; care recipient age 18 or older; providing care currently or within the past month; year 2017; and providing assistance with activities of daily living (ADLs; such as bathing and dressing), instrumental activities of daily living (IADLs; such as managing finances or providing transportation), or medical/nursing tasks (such as medication management or preparing special diets). For an overview of data sources and national estimates, see appendix A, page 22. For estimates of the number of family caregivers and economic value at the state level, see table B1, page 24.

The estimated \$470 billion equates to about \$1,450 for every person in the United States (325 million people in 2017).¹ The economic impact of \$470 billion is more than the following:

- All out-of-pocket spending on US health care in 2017 (\$366 billion)²
- Three times as much as total Medicaid spending on LTSS (\$154 billion in 2016)³
- The total spending from all sources of paid LTSS, including post-acute care (\$366 billion in 2016)⁴
- The total combined value added to the US economy by the agriculture/forestry and mining sectors (\$438 billion in 2017)⁵
- The total combined value added to the US economy by the education and arts/entertainment sectors (\$460 billion in 2017)⁶

The estimate of about \$470 billion in economic value is consistent with nearly two decades of prior studies, all of which found (like the current study) that the value of unpaid family care vastly exceeds the value of paid home care. Previous reports in the *Valuing the Invaluable* series have estimated the value at \$470 billion in 2013, \$450 billion in 2009, \$375 billion in 2007, and

EXHIBIT 1
How Much Is \$470 billion?



\$354 billion in 2006.⁷ Earlier estimates showed steady growth in the economic value of family care from less than \$200 billion in 1996 to about \$300 billion in 2004.⁸

TODAY'S FAMILY CAREGIVERS

Adults with a chronic, disabling, or serious health condition rely mainly on family members, partners, or friends—known as *family caregivers*—to provide needed day-to-day supports and services, and manage complex care tasks. Research finds that nearly half of older adults (i.e., ages 65 and older) living in the community have difficulty carrying out daily living activities (such as help with bathing, getting in and out of a chair, or using the bathroom) without assistance. Most all older adults (95 percent) receive some help with these activities from their family or close friends, and almost two-thirds rely solely on these family caregivers.⁹

In addition to helping with self-care or other everyday activities and providing emotional and social support, family caregivers perform complex medical and nursing tasks (such as performing wound care, giving injections, and handling medical equipment) in the home. Most family caregivers receive little instruction or support in

KEY TERMS

Family Caregiver: Broadly defined, refers to any relative, partner, friend, or neighbor who has a significant personal relationship with, and who provides a broad range of assistance for, an older person or an adult with a chronic, disabling, or serious health condition.

Family Caregiving: Providing a wide array of help for an older person or other adult with a chronic, disabling, or serious health condition. Such assistance can include help with personal care and daily living activities (such as bathing, dressing, paying bills, handling insurance claims, preparing meals, or providing transportation); carrying out medical or nursing tasks (such as administering multiple medications, performing wound care, or handling medical equipment); locating, arranging, and coordinating services and supports; hiring and supervising direct care workers (such as home care aides); serving as an “advocate” for the family member or friend during medical appointments or hospitalizations; communicating with health and social service providers; and implementing care plans.

Long-Term Services and Supports (LTSS; also referred to as *long-term care*): The broad range of day-to-day help needed by people with long-term conditions, disabilities, or frailty. This can include personal care (such as bathing, dressing, and toileting); complex care (such as medications or wound care); help with housekeeping, transportation, paying bills, and meals; and other ongoing social services. LTSS may be provided in the home, in assisted living and other supportive housing settings, in nursing facilities, and in integrated settings such as those that provide both health care and supportive services. LTSS also includes supportive services provided to family members and other unpaid caregivers.^a

Family Caregiver Assessment: A systematic process of gathering information about a family caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the caregiver’s ability to contribute to the needs of the care recipient.^{b,c} A family caregiver assessment asks questions of the family caregiver. It does not ask questions of the care recipient about the family caregiver.^d

^a Susan Reinhard et al., *Picking Up the Pace of Change: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (Washington, DC: AARP Public Policy Institute, 2017), <http://www.longtermcarecard.org>.

^b Family Caregiver Alliance, *Caregiver Assessment: Principles, Guidelines, and Strategies for Change*, Report from a National Consensus Development Conference, vol. 1 (San Francisco, CA: Family Caregiver Alliance, 2006).

^c Lynn Feinberg and Ari Houser, *Assessing Family Caregiver Needs: Policy and Practice Considerations* (Washington, DC: AARP Public Policy Institute, June 2012).

^d Kathleen Kelly, Nicole Wolfe, Mary Jo Gibson, and Lynn Feinberg, *Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home- and Community-Based Service Waiver Programs* (Washington, DC: AARP Public Policy Institute, December 2013).

taking on these complex medical and nursing tasks historically provided by trained health care professionals in hospitals and nursing homes.^{10,11} On top of caring for family members or friends with serious health conditions or disabilities, most family caregivers are employed in the workforce.

Today's family caregivers have an array of responsibilities, including advocating for their relatives' preferences and interests, dealing with health insurance claims, communicating and coordinating care with various health care and social service providers and care settings, and providing transportation to medical appointments. They also hire and supervise direct care workers when the individual or family can afford some paid help.

From their role, family caregivers often experience positive effects and feelings of satisfaction and meaning. But the bigger story is that they typically feel highly strained and overwhelmed. The emotional, physical, and financial toll on family caregivers is well documented in research. Common themes include the following:

- Emotional hardships on individual and family relationships
- Financial effects on family caregivers if they have to give up paid work to provide care or incur high out-of-pocket care costs
- Physical demands of exhaustion and less time to take care of one's own health
- Concern of being unprepared for the role, and not having a choice in taking on caregiving responsibilities
- Feelings of worry, isolation, and helplessness in understanding where to seek help, or in how to provide needed care and support to an adult relative or close friend with disabilities or complex health needs^{12,13,14,15}

Family caregivers are at increased risk for chronic loneliness. In a national survey examining social connections, 42 percent of family caregivers reported being lonely compared with non-caregivers (34 percent) in midlife and older ages.¹⁶ One of the top predictors of loneliness is being physically isolated, and, not surprisingly, this is

a common situation for family caregivers who provide intensive care to frail older relatives. Studies consistently show significantly worse outcomes for family caregivers who care for people with high care needs—such as individuals living with dementia, physical frailty, or multiple chronic conditions.¹⁷ This is particularly true for African American family caregivers, regardless of income.¹⁸

TRENDS IN FAMILY CAREGIVING

Americans will have more older relatives or close friends to potentially care for than children in about 15 years. The US Census Bureau projects that, by the year 2035, adults ages 65 and older will outnumber children under the age of 18 for the first time in US history.¹⁹ This fundamental demographic shift is the result of the aging of the US population, increasing longevity, and a declining birth rate.

Americans are having fewer children. Older adults are more likely to be divorced or to have never married. Adult children often live far from their parents, who may need assistance with daily activities.²⁰ As the pool of potential family caregivers shrinks, there are increased pressures on fewer individuals within families.²¹

Not only is the population aging, but a new demographic of the family caregiver is emerging. Key trends in family caregiving include the increasing diversity of family caregivers; the greater complexity of care needs; the larger numbers of employed family caregivers balancing paid work, caregiving responsibilities, and the employment-related and out-of-pocket costs of care; and a growing care gap between the demand for and supply of family caregivers.

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Increasing Diversity of Family Caregivers

Today's family caregivers come from every age, racial, and socioeconomic group, and include both men and women. As a result, the "one-size-fits-all" approach to family caregiver support services no longer addresses the needs of this increasingly diverse range of individuals. Experts and policy makers have called for improved public policies that promote more and better support for family caregivers of older people and adults with disabilities.^{22,23}

Multicultural Family Caregiving

The US population is becoming more racially and ethnically diverse. Research suggests that the overall racial/ethnic composition of family caregivers will become more diverse as a younger generation of family caregivers—millennials—becomes a greater share of the family caregiving population.²⁴ The US Census projects that, in 2045, non-Hispanic Whites will compose approximately half (49.7 percent) of the US population, shifting the racial composition in the United States to a more diverse nation.²⁵

Among multicultural populations, the greatest growth in the next 40 years (between 2018 and 2060) is projected for multiracial populations (176 percent), Asians (93 percent), and Hispanics (86 percent).²⁶ By 2030, nearly 3 in 10 older Americans will identify as a member of a racial/ethnic group, increasing to almost one-half of the older population by 2060.²⁷ These trends highlight the importance of respecting traditions and cultures for all racial/ethnic groups in the provision of care, and developing programs and services that are accessible, affordable, and tailored to the unique needs and preferences of multicultural communities.

Male Family Caregivers

While the majority of family caregivers are women, there is a growing trend for men, especially adult sons, to take on family caregiving tasks for the health and functional needs of their aging parents, other older relatives, or close friends.^{28,29} Men make up an estimated 40 percent—or about 16 million—of family caregivers of adults in the United States.³⁰ More than 4 in 10 (44 percent) of all

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male family caregivers have household incomes of under \$50,000 a year and report moderate to high financial strain as a result of caregiving.³¹

Contrary to popular belief, men are doing more than providing rides or managing finances. They are carrying out a range of caregiving tasks, including helping a parent with bathing or dressing,³² and performing complex care, such as managing pain, helping with incontinence, and preparing special diets.³³ Studies suggest that male family caregivers are less likely than their female counterparts to ask for help and to seek out caregiver support services.^{34,35,36}

Millennial and Younger Family Caregivers

Recent studies have profiled the experiences and challenges of younger adults and the millennial generation who take on a family caregiving role.^{37,38,39} According to the *Caregiving in the US* 2015 survey, about one in four family caregivers is a millennial (defined as being born between 1980 and 1996). A 2018 national poll found that more than one-third (35 percent) of adults under age 40 in the United States have already provided care for an older relative or friend, and another one-third expect to take on a caregiving role within the next five years.⁴⁰

More than half (53 percent) of millennial family caregivers are African American/Black, Hispanic/Latino, or Asian American/Pacific Islander. More than 4 in 10 (43 percent) help a parent or a parent-in-law, and about 22 percent care for a grandparent. Forty percent help a person with mental illness.

Almost three in four (73 percent) millennial family caregivers are employed and provide care for an adult with a disability or an older adult with chronic care needs; one in three (34 percent) employed millennial caregivers earns less than \$30,000 a year.⁴¹ Despite their relatively low incomes,

millennials spend a higher portion of their incomes on caregiving expenses than does any other generation—spending, on average, about 27 percent of their income on caregiving costs in 2016.⁴²

Greater Complexity of Care

Policy makers, practitioners, and researchers are now recognizing that family caregivers are increasingly involved in a range of complex care tasks. For example, family caregivers are being asked to provide pain management, change dressings, and manage medications. These tasks go beyond assisting with traditional ADLs (such as bathing or dressing) and IADLs (such as paying bills or doing housework).^{43,44,45,46,47} Other medical and nursing tasks can include helping with assistive devices, preparing food for special diets, performing wound care, and operating medical equipment.

Family caregivers commonly receive little preparation, hands-on training, or meaningful support when they take on these complex tasks. Experts describe these family caregivers as often invisible in the health care or LTSS system.⁴⁸

New research from the *Home Alone Revisited* study affirms that family caregivers continue to provide intense and complex care without instruction. Instead, family members must learn on their own how to provide care that used to be done by trained medical professionals. They are being asked to manage multiple health conditions and serious illness that can be accompanied by pain. Multicultural family caregivers are more likely to experience strain and live with the worry of making a mistake and the difficulty of performing complex care tasks, regardless of income.⁴⁹

Studies suggest that caregiver support and training can improve health outcomes for both family caregivers and the care recipient. In a recent examination of randomized trials of hospital discharge planning interventions, the planned integration and inclusion of family caregivers during hospital discharge planning was found to reduce hospital readmissions by more than 20 percent.⁵⁰

These findings lead to the recommendation that health care and social service providers should implement new practices and policies to provide greater and more meaningful support and solutions for family caregivers, especially those providing complex care.⁵¹

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More Family Caregivers in the Labor Force

Trends suggest that, with the aging of the baby boomers, an increasing share of family caregivers will be in the labor force in the future, facing the dual demands of employment and complex caregiving responsibilities.⁵²

Already, the majority (60 percent) of family caregivers of adults work at a paying job either full time or part time. Nearly two in three (63 percent) care for an adult age 65 or older, and half (51 percent) of employed family caregivers are

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older workers themselves, ages 50 and older, in their prime working years.⁵³

Family caregivers of adults with complex care needs may need to miss work to accompany the person they assist to physician visits⁵⁴ and be present during hospitalizations.^{55,56,57} Without workplace benefits to support family caregivers—such as using sick days for family care, taking paid family leave, and accessing employee counseling and services such as respite care—employed family caregivers can experience heightened financial and emotional strain.

Recent research from the Harvard Business School found that nearly one in three workers said they quit their jobs for caregiving responsibilities across the lifespan. Among workers who said they quit their jobs due to caregiving responsibilities, nearly one in three (32 percent) left work to care for an older family member with daily living needs, and one in four (25 percent) left to care for an ill spouse, partner, or other family member or relative with disabilities.⁵⁸

Family caregivers who disrupt their careers or leave the labor force entirely to meet full-time caregiving demands can face substantial economic risk and both short-term and long-term financial difficulties. Risks include losing salary and eventual Social Security and retirement benefits, needing to draw from personal retirement savings, diminishing career opportunities, and worse overall financial well-being.^{59,60} Spousal caregivers may be in a particularly vulnerable situation as they move into their retirement years.⁶¹ One recent study estimated the economic cost of forgone earnings by family caregivers of older adults at \$67 billion in 2013.⁶²

High Out-of-Pocket Caregiving Expenses

In addition to forgone earnings, most family caregivers incur steep out-of-pocket costs related to caregiving. Out-of-pocket spending for LTSS and complex care tasks can erode the financial security of family caregivers and take a financial toll.

According to a 2016 AARP national study, more than three in four (78 percent) family caregivers incurred out-of-pocket costs as a result of caregiving. This study found that, in 2016, caregivers spent, on

average, nearly \$7,000 on caregiving expenses that included home modifications, paid care at home, and transportation. To cover caregiving expenses, family caregivers reported tapping into personal savings (30 percent), reducing retirement savings contributions (16 percent), or dipping into existing retirement savings (11 percent) to cover out-of-pocket caregiving costs.^{63,64}

Another analysis predicted that, by 2030, more than half (53 percent) of total LTSS spending for people of all ages will be covered out of pocket by individuals and their families. This assumes no changes in public and private financial options for LTSS.⁶⁵

Growing Care Gap

Historically, family members and close friends have been the mainstay of emotional support and care that allows older people and adults with disabilities to live in their homes and in the community as their care needs increase. But with smaller families that are more dispersed than in previous generations, the family's capacity as the major care provider for older relatives and those with disabilities is becoming increasingly strained.

According to a recent analysis, retiring adults are less likely than in the past to have a relative living nearby to help with health and functional needs. In 1994, more than two-thirds (68 percent) of retiring adults lived within 10 miles of an adult child. By 2014, that share dropped to just over half (55 percent).⁶⁶ This same study suggested that older Americans in the future would be “unlikely to have

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the level of support from family caregivers that they enjoyed in the past” due to changing marriage patterns, greater childlessness, and fewer relatives living nearby to provide daily care if needed.⁶⁷

The stark reality is that the ratio of older adults at risk of needing LTSS (those ages 80 and older) to potential family caregivers (mostly adult children ages 45–64)—known as the *caregiver support ratio*—is declining dramatically. In just 11 years (by 2030), the ratio is projected to decline to four to one, from a high in 2010 of seven potential family caregivers for every person in the high-risk years of 80 and older. By 2050, when all baby boomers will be in the high-risk years of 80 and older, the ratio will fall to less than three potential family caregivers for every person age 80 or older.⁶⁸

Experts suggest that these dramatic changes will necessitate new investments in family caregiver supports and greater demand for paid LTSS in the coming decades.^{69,70,71,72,73} The projected increase in the number of people with dementia is expected to be a major driver in the future demand for LTSS.⁷⁴

POLICY AND PRACTICE CHANGE ON THE RISE

Meaningful change is underway. Federal and state policy makers have taken notice, as have practitioners and employers. The change is fueled by an increasing awareness among stakeholders and policy makers of the potential serious emotional, physical, and financial risks that arise when family needs are unrecognized and not supported as family caregivers provide demanding and often complex care for another person with health or functional needs.

Consequently, there is growing recognition among experts and policy makers of the importance of coordinated care delivery in health care and LTSS that focuses on person- and family-centered care as standard practice.^{75,76,77,78} This approach is centered on health and social service providers systematically identifying, and routinely assessing and addressing, the care goals, needs, and preferences of *both* the individuals needing care and their family caregivers, as well as providing meaningful and culturally appropriate supportive services and guidance tailored to their unmet needs.

There is growing recognition of the importance of coordinated care delivery in health care and LTSS that focuses on person- and family-centered care as standard practice.

Significant federal and state policy developments and meaningful steps, in both the public and private sectors, have taken place in the four years since the 2015 *Valuing the Invaluable* report was released. Advancements in LTSS, health care, and workplaces policies have all contributed to better support the well-being of caregiving families.

Federal Level

Bolstered by a landmark report that highlighted the urgency of addressing the unmet needs of family caregivers of older adults (see next page), a national family caregiver support strategy across the lifespan is on the horizon. The Medicare and Medicaid programs continue to better identify and support family caregivers in health care and LTSS. Policy and training initiatives continue to evolve toward adopting person- and family-centered care, and strengthening the training and capacity of health care and social service providers to recognize and engage family caregivers.

Major Initiatives

- **Consensus report on family caregiving:** In 2016, the National Academies of Sciences, Engineering, and Medicine (formerly the Institute of Medicine) issued an evidence-based consensus report, *Families Caring for an Aging America*. The report raised serious concerns about the current situation of family caregiving of older adults in the United States, and urged that “support of family caregivers be recognized as an integral part of the nation’s collective responsibility for caring for older Americans.”⁷⁹ A key report recommendation called for developing and executing a national family caregiver strategy to address the health, economic, and social issues

facing caregiving families. The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, enacted less than two years later, is consistent with this 2016 recommendation.

- **National family caregiver strategy:** On January 22, 2018, the RAISE Family Caregivers Act (Public Law 115-119) was signed into law. This historic law directs the Secretary of Health and Human Services (HHS) to develop, maintain, and update a strategy to recognize and support family caregivers of an individual (of any age) with a chronic or other health condition, disability, or functional limitation. A Family Caregiving Advisory Council advises the Secretary of HHS on family caregiving issues.^{80,81}

— The law states that the national strategy will identify recommended actions that communities, providers, government, and others are taking or may take related to promoting greater adoption of person- and family-centered care in all health and LTSS settings; assessment and service planning involving family caregivers and those for whom they care; information, education and training supports, referral, and care coordination; respite options; and financial security and workplace issues.⁸²

— A Family Caregiver Resource and Dissemination Center, led by the National Academy for State Health Policy, will support the Advisory Council's work.⁸³

Medicare

- **Supplemental benefits under Medicare Advantage:** Beginning in 2019, Medicare Advantage (MA)⁸⁴ plans—covering about one-third of Medicare beneficiaries in managed care—have new flexibility to offer beneficiaries new and expanded supplemental services, such as LTSS and support services for family caregivers of enrollees, which Medicare does not routinely cover.⁸⁵ These supplemental benefits implement new policies adopted by the Centers for Medicare & Medicaid Services (CMS) and enacted as part of the Bipartisan Budget Act of 2018.⁸⁶ An AARP analysis found that, while relatively few MA plans are offering the new benefits in 2019,

an estimated 13 percent of plans are covering family caregiver supports, including respite care, counseling, and education.⁸⁷ More plans are expected to include family caregiver support services and other supplemental benefits under the new flexibility in 2020.

- **Home health provisions:** Effective January 2018, CMS implemented a new final rule for home health agencies, laying out new conditions those agencies must meet to be reimbursed by Medicare and Medicaid. The rule includes provisions for identifying, engaging, and training family caregivers of home health beneficiaries. As part of the beneficiary's comprehensive assessment, it requires home health agencies to identify the family caregiver of the person receiving home health services and include the caregiver's contact information in the person's clinical record. It also requires home health agencies to inform the older person or adult with disabilities of his or her rights, and to notify the individual, family caregiver, and physician if a change to the care plan occurs. The rule requires agencies to evaluate the family caregiver's willingness, ability, availability, and schedule to provide assistance when developing the person's care plan, and offers education and training to the family caregiver.⁸⁸
- **Coverage for telehealth:** Since 2018, CMS has expanded Medicare reimbursement for some services under the Physician Fee Schedule, including family psychotherapy, patient-focused and caregiver-focused health risk assessment, advance care planning, and chronic care management, that can be delivered by telehealth for Medicare beneficiaries and their family caregivers.⁸⁹ Starting in plan year 2020, CMS will allow MA beneficiaries to access additional telehealth benefits, including receiving health care services in their homes rather than being required to go to a medical office.⁹⁰
- **Cognitive impairment assessment and care planning services:** In January 2017, CMS began paying primary care providers (such as physicians, nurse practitioners, and physician assistants) for face-to-face care planning services for individuals with cognitive impairment. Care

planning visits can be conducted in the person's home, in physician offices, or in assisted living facilities. The written care plan—based on an assessment of the needs of both the person and the family caregiver—is developed and shared with the person with cognitive impairment and family caregiver, and made part of the Medicare beneficiary's medical record. An important new element of the care planning process is the identification of the family caregiver(s) and understanding his or her knowledge, needs, available resources, and availability and willingness of to provide care.^{91,92,93}

- **Caregiver health risk assessment:** In 2017, CMS permitted a brief, limited assessment to screen for health risks (such as depression) in the family caregiver for the benefit of the Medicare beneficiary.⁹⁴
- **Advance care planning:** Effective January 2016, Medicare added voluntary advance care planning as a new benefit. The service includes in-person conversations among the physician or other qualified health professional, the Medicare beneficiary, and his or her family member(s) or surrogate regarding advance directives with or without completing relevant, standard forms, such as living wills or health care power of attorney.^{95,96} As of 2018, advance care planning can also be delivered by telehealth.⁹⁷

Medicaid

- **Managed care regulations acknowledge family caregivers:** Effective May 2016, CMS issued a final rule updating Medicaid regulations for managed care programs that deliver managed LTSS to older people and adults with disabilities. While the final rule falls short in strengthening Medicaid's focus on person- and family-centered care,⁹⁸ where appropriate, it does acknowledge family caregivers and allows states to consider the "critical importance of caregivers in supporting enrollees as they develop education, outreach, and support strategies."⁹⁹
- **Managed LTSS programs begin to support family caregivers:** As of January 2019, about half the states now provide LTSS to some Medicaid beneficiaries through managed care programs.¹⁰⁰

Although key family caregiver supportive services, such as assessment of the needs and situation of the member's family caregiver, are not yet commonplace in managed LTSS practice, family caregiver supports are an emerging innovation to promote person- and family-centered care.¹⁰¹

- A 2017 AARP study found that some plan administrators identified family caregiver supports as an area that needs increased focus, recognizing that family caregivers play a key role in helping high-need members live at home and in the community.¹⁰²
- **Work requirements:** In 2018, CMS issued guidance to states that allows them to seek Medicaid waivers to impose work or volunteer engagement requirements on certain Medicaid enrollees as a condition of enrollment or continued enrollment in the program. Some states have received waiver approvals to implement work requirements or have pending proposals.¹⁰³
 - Most (60 percent) adults who receive Medicaid are already working. Those who are not working likely have significant health problems or disabilities, or have family caregiving responsibilities that prevent them from working.¹⁰⁴
 - Some states have chosen to exempt certain groups, including family caregivers, from work requirements or count caregiving hours toward the requirements,¹⁰⁵ but these "caregiver" exemptions vary widely among states and are often difficult to understand.¹⁰⁶
 - The complexity of navigating and reporting compliance with work requirements could result in some family caregivers losing their Medicaid coverage, making it more difficult, if not impossible, for them to meet their own health needs and those for whom they care.¹⁰⁷
- **Spousal impoverishment protections:** In 2019, spousal impoverishment protections were extended to ensure the spouse of a person receiving Medicaid home- and community-based services (HCBS) isn't required to spend down

all of his or her assets in order for the spouse to receive supportive services.¹⁰⁸

Veterans Affairs

- **Expanded supports for caregivers of veterans:**

- The VA MISSION Act, signed into law on June 6, 2018, expands eligibility of the Department of Veterans Affairs' (VA) caregiver support program to family caregivers of eligible veterans injured before September 11, 2001. Under the law, eligible family caregivers can receive a financial stipend, training, access to health insurance, counseling, respite care, and legal and financial planning services.¹⁰⁹
- In November 2017, the Elizabeth Dole Foundation, in partnership with the VA, established the Campaign for Inclusive Care, a national initiative to integrate military and veteran caregivers into their veteran's health care team. The goal is to improve outcomes for veterans, their caregivers, and their health care providers.¹¹⁰

Other Initiatives

- **Engagement of and training for family caregivers:** Since 2015, the Health Resources & Services Administration (HRSA) has supported the Geriatric Workforce Enhancement Program (GWEP) across the United States. The program aims to develop a health care workforce that maximizes person and family engagement and improves health outcomes for older adults. The GWEP partners with community-based organizations to provide educational programs in local communities to improve the knowledge and skills of family caregivers.¹¹¹
- **Training resources for health care providers and family caregivers:** In 2017, the CMS Medicare-Medicaid Coordination Office released two resource guides for health care professionals and family caregivers of older adults that aim to provide both groups with resources on managing behaviors associated with dementia. Another guide focuses on how health care providers can involve family caregivers and support them when caring for older adults with complex medical needs.¹¹² In 2018, the HRSA released a training

curriculum on dementia care to teach health care providers and to help the primary care workforce address family caregiver needs.¹¹³

- **Home Alone AllianceSM:** Founded as a collaborative of AARP in December 2017, the Home Alone Alliance (HAA) serves as a catalyst to change the way health care organizations and professionals interface with family caregivers, particularly those who perform medical and nursing tasks such as wound care and managing multiple medications. The HAA has produced family caregiver "how to" video series and related resource guides on topics such as wound care, mobility, managing medications, special diets, managing incontinence, and other complex care tasks.¹¹⁴
- **Clinical practice guidelines for quality palliative care:** Updated practice guidelines in 2018 encourage clinicians and health care organizations to integrate palliative care into the services they provide for all people living with serious illness and their families, regardless of the person's diagnosis, prognosis, or age. The guidelines aim to improve access to quality palliative care by fostering consistent standards, fostering continuity of care across settings, and emphasizing person- and family-centered care—calling for providers to utilize a family caregiver assessment process to identify specific problems and address unmet family needs, including caregiver education and support.¹¹⁵
- **Caregiving volunteer program:** In 2018, Congress provided \$5 million in funding for a National Volunteer Care Corps, based on the Care Corps Demonstration Act. This program establishes care corps grants that place volunteers in communities to provide nonmedical services to older adults and individuals with disabilities to assist them and their family caregivers in staying in their homes and communities.¹¹⁶

State Level

The 2017 edition of the AARP Public Policy Institute's *Long-Term Services and Supports State Scorecard*, which measures state-level LTSS system performance from the viewpoint of users of services and their families, reported slow and uneven

progress since the previous *Scorecard* release in 2014, with considerable variation among states. Yet the pace of change was especially promising in the movement toward new person- and family-centered practices that support family caregivers. Most of the progress in this area occurred in two areas: (a) passage of the CARE Act (described in the first bullet below) in a vast majority of states and US territories, and (b) assessment of family caregivers' own needs and preferences in HCBS programs. Most of these family caregiver assessments occurred in smaller, state-funded family caregiver support programs rather than in the larger Medicaid program.¹¹⁷

States are leading the way in adopting work/family policies that better meet the needs of employees with family caregiving responsibilities. More states have also implemented laws that permit nurses to delegate tasks to direct care workers to help maintain the care recipients' health and to better support their family caregivers.¹¹⁸

Policies on Complex Medical/Nursing Tasks

- Forty states, Puerto Rico, the US Virgin Islands, and the District of Columbia have enacted the Caregiver Advise, Record, Enable (CARE) Act within four years, as of August 2019.¹¹⁹ The CARE Act supports family caregivers when their relatives go into the hospital and as they transition home. State CARE Acts vary, but in general they require hospitals to (a) record the name and contact information of the patient's family caregiver (with the patient's permission) in the patient's electronic health record; (b) give advance notice to family caregivers regarding when the patient is to be discharged; and (c) educate and instruct the family caregiver on medical and nursing tasks (such as medication management, injections, and wound care) he or she is expected to perform for the patient at home.
- Beginning in September 2016, a national scan of hospitals and health systems in 11 CARE Act states has been led by the AARP Public Policy Institute to identify emerging trends, elevate promising practices, and evaluate any barriers to the legislation's success.¹²⁰ Results will identify themes and related scalable practices for health

system leaders and organizations that address the implementation of the CARE Act and ultimately provide practical ways to better support family caregivers in the hospital setting.¹²¹

- Twenty-two states (**Alaska, Arizona, Colorado, Connecticut, Hawaii, Idaho, Iowa, Maine, Maryland, Minnesota, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Oregon, Rhode Island, South Dakota, Vermont, Washington, and Wyoming**) and the **District of Columbia**¹²² (up from 17 in 2013) allow nurse practitioners to practice to the full scope of their education and clinical training, benefiting both adults with health and functional needs and their family caregivers.¹²³
- State Nurse Practice Acts generally determine the extent to which direct care workers (such as home care aides) can help individuals and their family caregivers get help with carrying out health maintenance tasks, known as *nurse delegation*.¹²⁴ When states restrict registered nurses from delegating these tasks to aides to perform in home settings, strains on family caregivers can increase, especially for working family caregivers who may have to leave work during the day to carry out these medical/nursing tasks. Such tasks include administering medications, administering eye drops, performing tube feedings, and performing ventilator care.
 - Seventeen states (**Alaska, Colorado, Idaho, Iowa, Kentucky, Minnesota, Missouri, Montana, Nebraska, New Jersey, New Mexico, North Carolina, Oregon, Texas, Utah, Vermont, and Washington**) permit registered nurses to delegate the full set of 16 health maintenance tasks to qualified unlicensed direct care workers caring for adults with chronic, stable conditions in home-based settings, an increase from nine states in 2013.¹²⁵

Financial Assistance for Family Caregivers

- In January 2018, **Hawaii** became the first state to provide some financial assistance to employed family caregivers of older adults with functional needs (such as needing help with dressing or feeding). The initiative—known as the Kupuna Caregivers Program—allows frail older adults

to remain at home while helping the family caregiver to continue to provide care and also to remain in the labor force. Up to \$210 per week in vouchers are made available to eligible family caregivers to offset the costs for HCBS, including adult day services, homemaker and chore services, personal care, home-delivered meals, respite care, and transportation.¹²⁶

- In May 2019, **Arizona** enacted the Family Caregiver Grant Program to provide some financial relief for family caregivers. The grant program reimburses family caregivers for certain qualifying expenses that relate directly to caring for a qualifying family member (such as installing grab bars in a bathroom or building a wheelchair ramp). Eligible family caregivers can be reimbursed up to \$1,000 when the program begins in January 2020.¹²⁷
- **Caregiver tax credits:** To offset the financial costs of caring for a family member with a serious illness or disability, states are examining ways to provide tax credits for families that need help with caregiving expenses. In 2017, **New Jersey** enacted a state income tax credit (effective 2018) specifically for eligible family caregivers of wounded veterans with service-connected disabilities from a war or conflict on or after September 11, 2001.¹²⁸ At least 10 other states considered a caregiver tax credit bill in 2019.

Family Caregiver Assessment and Supportive Services

- Since 2013, 14 more states (**Alabama, Colorado, Mississippi, Montana, Nebraska, Nevada, North Carolina, Ohio, Oregon, Rhode Island, Tennessee, Texas, Utah, and Wisconsin**) and the **District of Columbia** are conducting some form of assessment of family caregiver needs in their HCBS and caregiving programs, for a current estimated total of 32 states.¹²⁹ Family caregiver assessments ask questions of the care recipient's family member about his or her own health and well-being, and any services or support he or she may need to be better prepared for the caregiving role.¹³⁰
- Effective September 2017, **Washington State** is implementing a five-year demonstration that allows the state under Medicaid—for the first

time—to provide person- *and* family-centered care. The aim is to assist family caregivers, help prevent caregiver burnout, and keep at-risk older adults at home and in the community.¹³¹ The Medicaid waiver permits the state to tailor support for near-poor older adults and their family caregivers through two programs that utilize a family caregiver assessment process to target caregiver supports effectively:

- The Medicaid Alternative Care (MAC) program provides a range of supportive services to unpaid family caregivers of adults (ages 55 and older) who are eligible for Medicaid and who meet the nursing home level of care.¹³²
- The Tailored Supports for Older Adults (TSOA) program provides a similar range of supportive services as in the MAC program to family caregivers of adults (ages 55 and older) who are financially ineligible for Medicaid.¹³³
- In June 2019, the statewide system of **California** Caregiver Resource Centers received a one-time-only investment of \$30 million over three years in state general funds to expand and improve services for family caregivers across the state.¹³⁴
- In 2019, **Oregon** included a directive to the state's Department of Human Services in collaboration with the Oregon Health Authority in the state's budget bill to explore ways to obtain federal funding for the Oregon Project Independence program and family caregiver respite programs. It will form an advisory committee to make recommendations on program design and benefits, and the application for federal approval.¹³⁵

Work/Family Policies

- In 2016, **New York** became the fourth state (following California, New Jersey, and Rhode Island) to enact a paid family leave (PFL) program, effective 2018. The **District of Columbia** and **Washington State** enacted PFL programs in 2017 (effective for benefits in 2020). **Massachusetts** enacted its state program in 2018, and **Connecticut** and **Oregon**¹³⁶ did so in 2019 (Massachusetts and Connecticut are effective for benefits in 2021; workers in Oregon will start receiving benefits in

2023). This brings the total to eight states and the District of Columbia that have modernized their work/family policies to include PFL for family caregiving, including eldercare. These state PFL programs differ in eligibility and waiting period requirements, qualifying family members, amount of benefits paid, maximum length of paid leave, whether a worker's job is protected during PFL, and how the program is funded.^{137,138}

- Starting in 2018, **California** raised the weekly wage replacement rate for the lowest-paid workers taking PFL from 55 to 70 percent.¹³⁹ In June 2019, **California** expanded the maximum length of paid family leave from six to eight weeks, effective July 2020.
- In February 2019, **New Jersey** made several improvements to its state PFL program to protect working families. Expansions include providing workers with a larger percentage of their weekly wage during time off, doubling the length of paid leave (from 6 to 12 weeks), and expanding coverage to allow paid leave to care for relatives beyond the immediate family, among other provisions.¹⁴⁰ The new law also includes funding for an education and outreach campaign to increase awareness in the state about paid leave.
- Since 2015, 10 more states (**Arizona**, **Maine**,¹⁴¹ **Maryland**, **Michigan**, **Nevada**,¹⁴² **New Jersey**, **Oregon**, **Rhode Island**, **Vermont**, and **Washington**) require paid sick leave—also known as *paid sick days*—for certain workers. In all, 13 states (including the early adopter states of Connecticut, California, and Massachusetts) and the District of Columbia now have paid sick days laws that cover family caregivers.^{143,144} Several cities and localities have guaranteed access to paid sick days since 2015. As of July 2019, nearly 40 local jurisdictions in nine states (California, Illinois, Maryland, Minnesota, New Jersey, New York, Pennsylvania, Texas, and Washington) have passed paid sick days legislation.¹⁴⁵
- States have also enacted other workplace flexibility laws. Effective January 2017, **Illinois** implemented Eligible Leave for Employee Caregiving Time (ELECT)—commonly known as the Illinois Employee Sick Leave Act—requiring employers that offer unpaid or paid sick leave benefits to allow their employees to use up to six months' worth of earned sick leave benefits for family caregiving activities, including accompanying a relative to a medical appointment.¹⁴⁶ Effective July 2017, **Georgia's** Family Care Act requires employers to allow their eligible employees to use up to five days of earned paid sick leave per year to care for immediate family members.¹⁴⁷ Effective June 2019, **New Mexico's** Caregiver Leave Act allows employees who currently earn sick leave to use that sick leave for family caregiving purposes.¹⁴⁸
- Thirteen states and the District of Columbia have expanded one or more of their state unpaid family and medical leave provisions—beyond what the federal Family and Medical Leave Act (FMLA) provides—to benefit more working family caregivers.¹⁴⁹
- In January 2016, **New York City** expanded the protections of the city's Human Rights law against employment discrimination to include caregivers of a minor child or an individual with a disability. The law adds "caregiver status" as an additional protected category for which employment discrimination is prohibited.¹⁵⁰ Effective December 30, 2016, **Delaware** implemented a law protecting workers (and applicants for employment) from discrimination based on their family caregiving responsibilities. At least 15 localities or states and the District of Columbia have laws to protect workers from employment discrimination.¹⁵¹

State Caregiving Task Forces

- Since 2015, seven states have created caregiving task forces through legislation: **Idaho** (2015), **Louisiana** (2015), **Maryland** (2015), **California** (2016), **Alabama** (2017), **New Jersey** (2018), and **Wisconsin** (2019). Four additional states (**Delaware**, **Hawaii**, **Mississippi**, and **New Mexico**) enacted caregiving task forces in 2014. These state task forces highlighted both the value of and needed supports for caregiving families, often preparing a blueprint with recommended state actions to better address the needs of family caregivers.¹⁵²

Advance Planning and Guardianship

When an individual is no longer able to manage his or her own financial or personal affairs, a court can appoint an individual or a professional to act on behalf of that person, called *guardianship* (also known as *conservatorship* in some states). Since 2015, most states have enacted guardianship reforms aimed at helping vulnerable adults while providing their caregivers with the tools they need to make important decisions for the person under guardianship, consistent with the individual's needs and preferences, and across state lines.^{153,154,155}

- Powers of attorney are important tools for delegating authority to family caregivers or others to act on one's behalf. Since 2015, eight states (**Georgia, New Hampshire, North Carolina, South Carolina, Texas, Utah, Washington, and Wyoming**) have enacted the Uniform Power of Attorney Act (UPOAA), providing more uniformity of law about powers of attorney from state to state. By 2019, 26 states had adopted the UPOAA.¹⁵⁶

Coverage for Telehealth

As of spring 2019, all 50 states and the District of Columbia have some form of Medicaid reimbursement for telehealth services to improve health care access for patients and their family caregivers.¹⁵⁷ Although some telehealth Medicaid reimbursement may exist, many of the state reimbursements are limited, resulting in continued barriers to telehealth services.

- As of spring 2019, 14 states have policies that allow a patient to receive some health care in his or her home via telehealth services.¹⁵⁸
- As of July 2019, 29 states and the District of Columbia allow the licensing of qualified physicians to practice in multiple states, and 34 states allow nurses to do so to, especially in rural areas.¹⁵⁹

Other Innovative State Initiatives

- In May 2019, **Washington State** enacted the Long-Term Care Trust Act, becoming the first state to establish a public long-term care insurance program. Beginning in 2022, state workers will pay into the new state fund through payroll deductions to offset the costs of long-

term care (also known as *long-term services and supports*).¹⁶⁰

- In November 2018, five states—**Alabama, Iowa, New Hampshire, South Carolina, and Virginia**—were invited to form a multistate learning group on family caregiving. The states receive technical assistance from leading experts on creating uniform policies and developing strategies to support family caregivers, such as how to identify, assess, and track unmet needs; provide hands-on education and training; and expand access to respite care.¹⁶¹
- In 2018, **Massachusetts** enacted a law mandating that, by October 2021, all hospitals implement a plan for addressing people with Alzheimer's disease and related dementias, and their family caregivers. The law requires health care professionals to have training on the diagnosis, treatment, and care of people with dementia, before they can obtain or renew their license to practice. It also requires physicians who have diagnosed an individual with Alzheimer's and who have obtained the person's expressed or implicit consent, to inform a family member or legal representative about the diagnosis, care planning, and options for services and supports.¹⁶²

Research Developments

Researchers have provided valuable, evidence-based information, trends, and promising practices for best serving family caregivers.

- **National Study of Caregivers** – First fielded in 2011, the federally funded National Health and Aging Trends Study (NHATS) and its companion National Study of Caregiving (NSOC) examine a nationally representative sample of Medicare beneficiaries (ages 65 and older) in the United States and the family and other unpaid caregivers who help older adults with their daily activities.^{163,164} The NSOC was conducted with NHATS in 2011, and again in 2015 and 2017.¹⁶⁵
- **Behavioral Risk Factor Surveillance System (BRFSS)** – The Centers for Disease Control and Prevention's (CDC's) BRFSS helps states survey adults on a wide range of health-related issues. Because caregiving is viewed as an important

public health issue, the CDC worked with partners to revise the BRFSS Caregiver Optional Module to be used by states beginning in 2015. The Caregiver Module collects state information about the health, quality of life, and behaviors of people in a state who self-identify as family caregivers, to aid in developing appropriate programs and policies for family caregivers. Between 2015 and 2018, 44 states, the District of Columbia, and Puerto Rico administered the Caregiver Module at least once.¹⁶⁶

- **New Family Caregiving Institute** – In 2017, the Family Caregiving Institute was launched at the Betty Irene Moore School of Nursing at the University of California, Davis. The institute aims to identify and disseminate research and education to increase capacity for both caregivers and health care professionals to improve systems of support for family caregivers.¹⁶⁷
- **New Center for Veteran and Caregiver Research** – In 2018, the VA established a Center of Excellence for Veteran and Caregiving Research. Through evidence-based research and dissemination of best practices, the center will explore new ways to support family caregivers and the veterans for whom they care.¹⁶⁸

CONCLUSIONS

Family caregivers play a vital and key role in the delivery and coordination of health care and LTSS in the United States. In 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately \$470 billion.

Nevertheless, the 2017 estimate of the value of unpaid family caregiving for adults is conservative because it does not quantify the physical, emotional,

The aging of the population can no longer be viewed as a private, family-only issue.

and financial costs of care, or the greater complexity of care today. Despite some important federal and state policy developments that have occurred since the last *Valuing the Invaluable* report was released in 2015, more action is needed to address the unmet needs of caregiving families and accelerate the pace of change. This means new policies, educational efforts for providers and families, and, most of all, a collective priority to change the culture of care in the United States.

Better support for family caregivers means adopting the principle of person- and family-centered care in policy and everyday practice, especially for family caregivers who are caring for older individuals with complex care needs. Because most family caregivers now hold paying jobs too, workplace reforms are also needed that enable workers to fulfill both their family caregiving and paid work responsibilities.

The aging of the population and its impact on families has implications for all sectors of US society and can no longer be viewed as a private, family-only issue. US public policies have not kept pace with these changing realities and the increasingly complex demands of family caregiving, the growing care gap, and the other changing demographic and social trends highlighted in this report. Investments in family caregiver supports now can help to build a more caring society for our families and ourselves.

Investments in family caregiver supports now can help to build a more caring society for our families and ourselves.

POLICY RECOMMENDATIONS

National Strategy

- Ensure that a broad national family caregiving strategy sets out the strategic direction for executing current and future federal, state, and local policies, services, and supports to alleviate financial hardships, reduce the complexity of care, and maintain the health and well-being of family members and friends in their caregiving role. A national family caregiving strategy should be implemented by stakeholders in both the public and private sectors, and in new partnerships, to achieve better supports for family caregivers in health care, LTSS, and workplaces. The strategy should also address the needs of the increasingly culturally and ethnically diverse caregiver population.

Financial Relief

- Provide financial assistance and relief for family caregivers through a federal or state tax credit (or other mechanism) to ease some of the financial costs of caregiving.
- Consider reforms that would recognize the impact of Social Security benefits for time spent out of the workforce for family caregiving reasons. People who disrupt their careers for full-time caregiving responsibilities can lose substantial benefits and retirement security.
- Evaluate all proposals designed to ensure the long-term solvency of Social Security for their impact on family caregivers. Policy makers should not adopt changes that worsen the financial situation of family caregivers.
- Expand participant-directed (sometimes referred to as *consumer-directed*) service models in publicly funded HCBS programs that permit payment of family caregivers. Such models allow consumers and their families to choose and direct the types of services and supports that best meet their needs and preferences.

Work/Family

- Strengthen family-friendly workplace flexibility policies that accommodate the growing numbers of employed family caregivers, including flexible work options and telecommuting, job-sharing,

use of existing leave for caregiving duties, referral to supportive services in the community, and caregiver support programs in the workplace. Because most family caregivers now hold paying jobs too, employed family caregivers need access to workplace flexibility and benefits that enable them to fulfill both their caregiving and paid work responsibilities.

- Improve the federal FMLA and state FMLAs, such as expanding protections to apply to employers with fewer than 50 employees and covering all primary caregivers, including extended family and affinity relationships.
- Enact paid family leave programs as long as adequate funding is available and their creation would not jeopardize adequate funding of or benefits under preexisting social insurance programs. Many working caregivers cannot afford to take unpaid leave to care for an ill family member.
- Require employers to provide a reasonable number of earned sick days that workers can use for short-term personal or family illness, or to take relatives to a medical appointment.
- Advance public awareness campaigns at the federal, state, and local levels related to all aspects of family leave policies—including coverage for eldercare—and the FMLA and paid family leave programs in states that offer such policies, to ensure that workers know how to access benefits if needed. Efforts should be made to coordinate with health care and social service providers and faith-based communities in states with paid family leave programs, to promote greater awareness of the benefits.
- Protect current benefits and the rights workers enjoy under the Fair Labor Standards Act and other fair employment laws in any proposals to help working caregivers.
- Encourage employers to use existing tax incentives, such as flexible spending accounts for dependent care, to provide dependent care or family care benefits.
- Prohibit discrimination against workers with family caregiving responsibilities. This should

include requirements for employers to provide reasonable accommodations to family caregivers.

Caregiver Assessment and Support Services

- Ensure that family caregivers are routinely identified and that their needs are assessed and supported in the delivery of health care and LTSS—especially for those who are providing complex care—to improve the ability to tailor supports for family caregivers and those for whom they care.
 - Understanding the family caregiving situation is a critical step in the process for linking family caregivers to the most appropriate support services to help maintain the health and well-being of the caregivers, sustain their ability to provide care, produce better outcomes for care recipients, and prevent or delay nursing home placement.
 - Research shows that the most effective caregiver training and service interventions begin with health care and social service providers' understanding of both the person and the family's needs, problems, strengths, and resources.
- Promote the identification of family caregivers in the care recipient's medical record and HCBS care plan as well as in the caregiver's own medical record.
- Advance assessment of family caregivers' needs (at the federal, state, and local levels) as part of a person- and family-centered care plan, such as through Medicaid and other publicly funded HCBS, primary care, admission and discharge from hospitals and emergency rooms, home health care services, and care coordination and care transition programs. Family caregiver assessment tools should, at a minimum, ask family caregivers about their own health and well-being, their level of stress and whether they feel overwhelmed, whether they are employed and are available to provide needed care, what tasks they perform (including personal care and medical/nursing tasks), and the types of training and supports they might need to continue in their role.
 - To capture the complexity and trajectory of care, update existing caregiver assessment tools to routinely include the caregiver's capabilities and limitations in performing medical and nursing tasks.
 - Promote (through federal and state programs, including managed LTSS programs) the adoption of a range of culturally appropriate services geared to the needs of diverse family caregivers, such as caregiver assessments to help improve targeting of services; supportive services such as skills training, support groups, family meetings, counseling, and respite care; home modifications and assistive technologies; transportation; and other supportive services.
 - Ensure that all publicly funded programs and caregiver supportive services (at the federal, state, and local levels) reflect the multicultural and language access needs of the diverse population of family caregivers.
 - Encourage managed LTSS programs to collaborate with the Older Americans Act's National Family Caregiver Support Program in local communities to better leverage caregiver services and supports in managed LTSS to target family caregivers in greatest need.
 - Develop caregiver education and training programs that prepare family caregivers to perform not only difficult personal care tasks such as bathing, but also medical and nursing tasks such as medication management and wound care.
 - Expand funding for the National Family Caregiver Support Program (NFCSP) to keep pace with demand and better address the unmet needs of caregiving families. To strengthen the NFCSP, caregivers' unmet needs should be routinely assessed as standard practice.
 - Preserve and expand state and federal funding for respite programs, including the federal Lifespan Respite Care Act, to ensure that more family caregivers can have a break from their caregiving duties. Respite programs (including adult day services) supplement caregiving by relatives, friends, and neighbors, and enable

them to continue caregiving at home and in the community.

- Widely disseminate and implement locally those caregiver support services that are shown to be effective. Such programs should better address the practical and emotional needs of caregiving families and improve outcomes for both the family caregiver and the care recipient.

Health Professional Practices

- Promote policies that make consumer and family caregiver engagement a health priority. Policies should address the importance of consumers and family caregivers playing an active role in their health care as well as their need to have access to information and support. Consumers should have the right to designate a family caregiver as an advocate and partner in the consumer's health care decisions. Policies and practices should promote shared decision making between consumers, family caregivers, and their health care team.
- Provide incentives for primary care providers and other health professionals to routinely identify Medicare beneficiaries who are family caregivers as part of the health risk assessment during the "Welcome to Medicare" preventative visit and annual wellness visits. Primary care providers and other qualified health professionals should routinely ask beneficiaries if they are caring for another family member or close friend with a chronic, disabling, or serious health condition. This would better track the beneficiary's health status and potential risks from caregiving, including physical strain, emotional stress, and depression.
- If the individual's care plan depends on having a family caregiver, ensure that his or her electronic health record includes the family caregiver as a point of contact. This would facilitate better communication among individuals, family members, and providers.
- Provide professional development opportunities for health care professionals to assist them in learning ways to better communicate with and instruct family caregivers who provide care, particularly those who provide complex care.
- Develop systemwide implementation plans that incorporate the tenets of the CARE Act into the policies and procedures of the hospitals, clinics, and rehabilitation centers.
- Encourage electronic health record vendors to create a standard field in the patient record that provides a place for the family caregiver to be identified. This field should be part of the basic record, available without cost during a scheduled upgrade, not a fee-based upgrade.
- Ensure that the Joint Commission (formerly known as the Joint Commission on Accreditation of Healthcare Organizations) utilizes surveyors of hospitals and other health care organizations who are qualified to assess family caregiver training and support programs.
- Remove barriers for advance practice registered nurses to practice by permitting them to practice to the full extent of their education and training.
- Enable registered nurses to delegate medical and nursing tasks to qualified direct care workers who provide assistance with a broad range of health maintenance tasks. Such nursing practices can ease the burden on family caregivers.
- Encourage clinicians—including physicians, nurses, social workers, and others—to advance greater awareness about the benefits of paid family leave programs in the workplace in states and businesses that offer such policies. Clinicians should ensure that the working family caregivers of their patients know how to access these benefits if needed.
- Ensure that performance measures for quality and clinical practice improvement activities are based on measures that are meaningful for individuals and family caregivers, including measures of the person's and family's experience of care.
- Develop educational programs, including continuing education, to prepare health care and social service professionals with the technical and communication skills needed to recognize and include family caregivers in the care team and engage them as partners in care. Viewing family caregivers not just as a resource for the individual with care needs, but also as a partner in care and

as someone who may need information, training, and supportive services, is a key component of person- and family-centered care.

- Remove barriers that limit or prevent accessing of health care via telehealth for family caregivers and those for whom they care.

Advance Planning and Guardianship

- Strengthen guardianship and power of attorney policy and practice. Comprehensive reforms would help protect vulnerable adults and provide their family caregivers with the tools they need to make important decisions for the care recipient as quickly as possible, regardless of where they live.

Research Recommendations to Inform Policy Development

- Promote common terminology and standard definitions of family caregiving in federally funded and other national and state surveys to better characterize the size, scope, tasks, and outcomes of family caregiving.
- Support more research on effective care practices and programs for diverse caregiving families and situations. Of particular focus should be caregivers who are LGBTQ, in multicultural families, millennials, men, living in rural communities, or living a long distance from the care recipient.
- Encourage the Centers for Medicare & Medicaid Innovation (CMMI) to design and conduct a Medicare pilot project to test family caregiver interventions for Medicare beneficiaries that can improve care and outcomes for beneficiaries, help family caregivers, and demonstrate measurable savings in Medicare.
- Develop a common definition and unit of measurement for respite care (at the federal and state levels) as a useful indicator of LTSS system performance. Respite care is one of the most commonly requested caregiver support services. However, definitions of *respite* vary among programs and states, making comparisons difficult.
- Conduct more research to examine whether access to and usage of paid family leave in the workplace influences the use of HCBS, and whether it delays or prevents more costly nursing home utilization.
- Improve data collection on working caregivers with eldercare responsibilities (including surveys conducted by the Department of Labor, Department of Health and Human Services, and Department of Commerce). This would ensure that challenges about work/family responsibilities and access to workplace leave benefits and protections are identified and addressed for employees providing eldercare.
- Improve the evaluation of state paid family leave programs by separating out categories of family leave claims to monitor, track, and better understand the usage and impact of paid family leave programs for eldercare. A common limitation of research on existing state paid family leave programs is combining claims for family leave across all kinship relationships (i.e., child, spouse, and parent).
- Conduct research on increasing the cultural sensitivity of health and social service professionals who work with multicultural caregiving families.

APPENDIX A: SOURCES AND METHODOLOGY OVERVIEW

The *Valuing the Invaluable* estimates of 41 million family caregivers, 34 billion care hours, and \$470 billion in economic value in 2017 are based on a meta-analysis of four surveys of caregivers between 2015 and 2018 (see Table A1).

Each source has a different definition of *caregiving*, determined by the question used to identify family caregivers and other characteristics of the survey (see Table A1). Using detailed data on caregivers, care recipients, and the care relationship from these and additional sources, each definition was adjusted to a common definition for consistent comparison:

- Caregiver age 18 or older
- Care recipient age 18 or older
- Providing care currently or within the past month
- Year of estimate (2017)
- Providing assistance with daily activities (ADLs, IADLs, or medical/nursing tasks)

More detail about the sources, adjustments to the common definition, and other methodology can be found in the Detailed Methodology document, available online at <http://www.aarp.org/valuing>.

The meta-analysis approach is preferred because it takes into account more information than any one particular survey. Also, the adjustment to the common operational definition brings the different estimates into a tighter cluster (see table A2). This increases confidence that the *Valuing* prevalence, hours, and economic value estimates are not significantly under- or overestimated based on a single outlier data source.

To present consistent state and national estimates of the economic value of caregiving, the number of family caregivers and the economic value of caregiving were estimated separately at the state level and then summed to get national estimates. At the state level, the economic value was calculated as (number of caregivers in 2017) × (hours of care per caregiver per week) × (52 weeks/year) × (economic value of one hour of family care).

TABLE A1

Main Data Sources for *Valuing the Invaluable* 2019 Estimates

Source	Data Years	Citation
American Time Use Survey (ATUS)	2015–16 (combined)	Bureau of Labor Statistics, “Unpaid Eldercare in the United States–2015–16 Summary,” 2017, http://www.bls.gov/news.release/elcare.nr0.htm .
Behavioral Risk Factor Surveillance System (BRFSS)	2015–17 (weighted to 2017)	AARP Public Policy Institute, unpublished analysis of data from the 2015–2017 Behavioral Risk Factor Surveillance System, 2019, https://www.cdc.gov/brfss/data_documentation/index.htm .
The Long-Term Care Poll (AP-NORC)	2018 (weighted to 2017)	AARP Public Policy Institute, unpublished analysis of data from the AP-NORC Center’s 2018 Long-Term Care Poll, Long-Term Care in America: Increasing Access to Care, 2019, https://www.longtermcarepoll.org/project/long-term-care-in-america-increasing-access-to-care/ .
National Study of Caregiving (NSOC)	2015	Winnie Chi et al., <i>Community-Dwelling Older Adults with Dementia and Their Caregivers: Key Indicators from the National Health and Aging Trends Study</i> (Washington, DC: Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, 2019), https://aspe.hhs.gov/system/files/pdf/260371/DemChartbook.pdf .

Table A2
Adjusted and Unadjusted National Estimates of Caregivers and Care Hours

Source	Year	Unadjusted Number of Caregivers (millions)	Adjusted Number of Caregivers in 2017 (millions)	Average Hours per Caregiver per Week	Total Adjusted Number of Care Hours (billions)
ATUS	2015-16	39.9	47.8	5.2	13.0
BRFSS	2015-17*	46.1	41.3	19.9	42.7
AP-NORC	2018*	39.2	39.1	16.6	34.1
NSOC	2015	21.6	34.0	16.8	29.8
National Estimates (2017)**			41	16	34

* Weighted to the 2017 population.

** Based on a weighted average of all four sources: BRFSS 1/2 weight; ATUS, AP-NORC, and NSOC 1/6 weight each. The greater weight for BRFSS is due to a more robust sample size than the other sources.

The number of family caregivers was based on a weighted average of the four data sources, adjusted to the common definition, and multiplied by a state factor based on sources with state-specific prevalence data (2015-17 BRFSS; additional sources from the 2015 *Valuing the Invaluable* report) to account for significant variation in the age structure and age-adjusted prevalence of caregiving across states.

The economic value of 1 hour of care was estimated at the state level as the average of the state minimum wage, median home health aide wage,

and median private pay cost of hiring a home health aide. State-level estimates of caregiving intensity from analysis of the BRFSS data did not differ significantly from the national average in 43 of 45 states, so a single estimate of 16 hours per week was used for all states.

The national average value per hour of \$13.81 is the average value for all care hours across all states. In the states, the average value per hour ranges from \$10.57 in Louisiana to \$18.01 in Alaska (see appendix B for state data).

APPENDIX B: STATE DATA

TABLE B1

Number of Family Caregivers, Hours, and Economic Value of Caregiving, by State, 2017

State	Total State Population	Number of Caregivers	Number of Care Hours (millions)	Economic Value/Hour	Total Economic Value (millions)
Alabama	4,870,000	760,000	640	\$11.15	\$7,100
Alaska	740,000	82,000	69	\$18.01	\$1,240
Arizona	7,020,000	870,000	730	\$14.50	\$10,600
Arkansas	3,000,000	460,000	380	\$12.14	\$4,700
California	39,500,000	4,700,000	4,000	\$16.02	\$63,000
Colorado	5,610,000	620,000	520	\$15.07	\$7,800
Connecticut	3,590,000	460,000	390	\$15.27	\$5,900
Delaware	962,000	129,000	108	\$14.67	\$1,580
District of Columbia	694,000	81,000	68	\$15.03	\$1,020
Florida	21,000,000	2,900,000	2,400	\$13.02	\$31,000
Georgia	10,430,000	1,280,000	1,070	\$12.32	\$13,200
Hawaii	1,428,000	157,000	131	\$15.95	\$2,100
Idaho	1,717,000	200,000	171	\$13.17	\$2,300
Illinois	12,800,000	1,480,000	1,240	\$13.98	\$17,300
Indiana	6,670,000	850,000	710	\$13.08	\$9,300
Iowa	3,150,000	300,000	260	\$14.77	\$3,800
Kansas	2,910,000	330,000	280	\$13.27	\$3,700
Kentucky	4,450,000	630,000	530	\$12.65	\$6,700
Louisiana	4,680,000	680,000	570	\$10.57	\$6,000
Maine	1,336,000	181,000	152	\$14.83	\$2,200
Maryland	6,050,000	790,000	660	\$14.53	\$9,600
Massachusetts	6,860,000	840,000	700	\$17.10	\$12,000
Michigan	9,960,000	1,320,000	1,100	\$13.66	\$15,100
Minnesota	5,580,000	640,000	540	\$16.02	\$8,600
Mississippi	2,980,000	470,000	400	\$11.93	\$4,700
Missouri	6,110,000	730,000	610	\$13.16	\$8,000
Montana	1,050,000	114,000	96	\$14.75	\$1,410
Nebraska	1,920,000	240,000	199	\$14.60	\$2,900
Nevada	3,000,000	330,000	280	\$14.01	\$3,900
New Hampshire	1,343,000	177,000	148	\$15.67	\$2,300
New Jersey	9,010,000	1,080,000	910	\$14.18	\$12,900
New Mexico	2,090,000	270,000	230	\$12.95	\$3,000
New York	19,850,000	2,500,000	2,100	\$14.94	\$31,000
North Carolina	10,270,000	1,330,000	1,110	\$11.74	\$13,100
North Dakota	755,000	68,000	57	\$17.20	\$980
Ohio	11,660,000	1,510,000	1,270	\$13.22	\$16,800
Oklahoma	3,930,000	530,000	440	\$13.08	\$5,800
Oregon	4,140,000	460,000	390	\$15.23	\$5,900
Pennsylvania	12,810,000	1,590,000	1,330	\$13.67	\$18,200
Rhode Island	1,060,000	136,000	114	\$15.76	\$1,790
South Carolina	5,020,000	730,000	610	\$12.42	\$7,600
South Dakota	870,000	80,000	67	\$15.60	\$1,040
Tennessee	6,720,000	990,000	830	\$12.12	\$10,100
Texas	28,300,000	3,400,000	2,900	\$12.10	\$35,000
Utah	3,100,000	350,000	290	\$13.75	\$4,100
Vermont	624,000	74,000	62	\$16.16	\$1,010
Virginia	8,470,000	1,040,000	870	\$12.81	\$11,200
Washington	7,410,000	860,000	720	\$16.73	\$12,000
West Virginia	1,816,000	280,000	240	\$12.01	\$2,800
Wisconsin	5,800,000	580,000	490	\$14.10	\$6,900
Wyoming	579,000	74,000	62	\$15.90	\$980
United States	326,000,000	41,000,000	34,000	\$13.81	\$470,000

Note: State numbers may not add up exactly to the US totals because of rounding.

ENDNOTES

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- 111 <https://www.hrsa.gov/grants/fundingopportunities/default.aspx?id=4c8ee9ff-617a-495e-ae78-917847db86a9>.
- 112 The resource guides and a webinar were developed in collaboration with the Lewin Group. See: https://resourcesforintegratedcare.com/sites/default/files/Involving_and_Supporting_Family_Caregivers_Resource_Guide_0.pdf.
- 113 Seven supplemental learning modules are designed to help family and other caregivers of people living with dementia take care of their own health and understand and cope with the challenges of caregiving. Three additional supplemental modules for providers address providers and caregivers as allies, shared decision making, and how to interact effectively with caregivers. The training curriculum can be accessed at <https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum>.
- 114 Founding partners of the Home Alone Alliance (HAA) include the Betty Irene Moore School of Nursing at the University of California-Davis, Family Caregiver Alliance, and United Hospital Fund. HAA currently has 25 members and growing, engaging health care professionals and multisector leaders through convenings, research and analysis, outreach, and resource development. Videos and resource guides have been translated into Spanish. Funders of HAA include The John A. Hartford Foundation, Ralph C. Wilson Jr. Foundation, the CENTENE Charitable Foundation, and the Retirement Research Foundation. See: <http://www.aarp.org/nolongeralone>.
- 115 National Consensus Project for Quality Palliative Care, *Clinical Practice Guidelines for Quality Palliative Care*, 4th ed. (Richmond, VA: National Coalition for Hospice and Palliative Care, 2018), <https://www.nationalcoalitionhpc.org/ncp/>.
- 116 Congress appropriated \$5 million in funding for fiscal year (FY) 2019 to establish the care corps grants program. See: <https://www.congress.gov/bill/115th-congress/house-bill/3493/t?q=%7B%22search%22%3A%5B%22care+corps%5Cr%5Cn%22%5D%7D&r=3&s=4>.
- 117 Susan Reinhard et al., *Picking Up the Pace of Change, A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (Washington, DC: AARP Public Policy Institute, 2017), <http://www.longtermscorecard.org>.
- 118 Ibid.
- 119 As of August 2019, states that have enacted the CARE Act are Alaska, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Hawaii, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, Texas, Utah, Virgin Islands, Virginia, Washington, West Virginia, and Wyoming. Tennessee has implemented provisions of the CARE Act by regulation. South Dakota passed a version of the CARE Act that is limited to mental health treatment facilities.
- 120 As part of the national scan, CARE Act site visits to health systems and hospitals have been conducted in Arkansas, California, Colorado, Illinois, Michigan, Nevada, New Jersey, New York, and Virginia. The project is funded by The John A. Hartford Foundation and Ralph C. Wilson, Jr. Foundation. See: <https://www.aarp.org/ppi/initiatives/home-alone-alliance/>.
- 121 Susan C. Reinhard, Heather M. Young, Elaine Ryan, and Rita B. Choula, *The Care Act Implementation: Progress and Promise* (Washington, DC: AARP Public Policy Institute, 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf>.
- 122 “State Practice Environment,” American Association of Nurse Practitioners, 2018, <https://www.aanp.org/advocacy/state/state-practice-environment>.
- 123 Reinhard et al., *Picking Up the Pace*.
- 124 Susan C. Reinhard, “A Case for Nurse Delegation Explores a New Frontier in Consumer-Directed Patient Care,” *Generations* 34 (1996): 377-409.
- 125 For a full list of the 16 tasks, see: Reinhard et al., *Picking Up the Pace*.
- 126 The Kupuna Caregivers Act provides vouchers for eligible family caregivers that can be used to help pay for services and supports. Employed family caregivers who work at least 30 hours per week are eligible when caring for an older adult age 60 years or older with limitations in daily activities. The benefits are paid directly to contracted service providers, not the family caregivers. In July 2017, the Hawaii legislature allocated startup funds of \$600,000 for this program. Hawaii doubled the initial funding to \$1.2 million for FY 2018-19. The state appropriated \$1.5 million to the program in FY 2019-20 and changed the maximum allocation for family caregivers from \$70 per day

- to \$210 per week to increase flexibility for employed family caregivers. See: <http://www.care4kupuna.com/>; https://www.hawaiiadrc.org/Portals/_AgencySite/EOA%20SFY2018.pdf; and <https://www.kitv.com/story/40410197/house-passes-298-bills-to-end-2019-legislative-session>.
- 127 The Arizona Family Caregiver Grant Program was funded in May 2019 for \$1 million in the state budget for three years, beginning January 2020. Qualifying expenses include improving or altering the individual's primary residence, and purchasing or leasing equipment or assistive technology to assist the qualifying family member to carry out daily activities. Caregiving expenses that are not covered under this grant program include food, clothing, transportation, or ordinary household maintenance. Family caregivers who receive a grant cannot apply for another grant for three years. The program is due to sunset on June 30, 2023. See: <https://apps.azleg.gov/BillStatus/GetDocumentPdf/467544>.
- 128 New Jersey's Wounded Warrior Caregivers Credit is equal to 100 percent of the federal veteran disability compensation, or \$675, whichever is less. To be eligible, a qualified family caregiver's gross income may not exceed \$100,000 as a joint tax filer or \$50,000 or less if single or married, filing separate. See: <https://www.state.nj.us/treasury/taxation/military/taxinformation.shtml>.
- 129 For a full list of the 32 states, see: Reinhard et al., *Picking Up the Pace*.
- 130 Kathleen Kelly et al., *Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home- and Community-Based Service Waivers* (Washington, DC: AARP Public Policy Institute, 2013).
- 131 The LTSS initiative under Washington State's five-year 1115 waiver is known as the Medicaid Transformation demonstration led by the Washington State Health Care Authority. See: "Medicaid Transformation Resources," (Washington State Health Care Authority, 2019), <https://www.hca.wa.gov/about-hca/healthier-washington/medicaid-transformation-resources>.
- 132 Services include transportation, home-delivered meals, durable medical equipment, caregiver skills training, counseling and support groups, respite care (including adult day health), and personal emergency response systems. See: Columbia Legal Services, *Questions and Answers on Tailored Support for Older Adults (TSOA) Program and Medicaid Alternative Care (MAC) Program* (Seattle, WA: Columbia Legal Services) 2019, https://www.washingtonlawhelp.org/files/C9D2EA3F-0350-D9AF-ACAE-BF37E9BC9FFA/attachments/D3890080-0C98-4D8D-8E53-D5D13B85FD2F/5171en_qna-on-tsoa-and-mac-programs.pdf.
- 133 Ellen O'Brien, Wendy Fox-Grage, and Kathleen Ujvari, *Home- and Community-Based Services beyond Medicaid: How State-Funded Programs Help Low-Income Adults with Care Needs Live at Home* (Washington, DC: AARP Public Policy Institute, 2019).
- 134 The California Caregiver Resource Centers' (CRC) state general fund appropriation in FY 2018–19 was \$4.918 million. The one-time investment in FY 2019–20 of \$30 million over three years will bring the statewide CRC appropriation to \$14.918 million through FY 2021–22. See: <https://www.caregiver.org/scaling-services-meet-new-demands-changing-family-caregiver-demographic>.
- 135 See: <https://adrcoforegon.org/consite/explore-oregon-project-independence.php> and <https://olis.leg.state.or.us/liz/2019R1/Downloads/CommitteeMeetingDocument/204344>.
- 136 Oregon's paid family leave law is the first in the nation to pay low-income workers 100 percent of their wages during family leave, with weekly benefits capped at about \$1,215 when the new law becomes effective in 2023.
- 137 Lynn Friss Feinberg, *Breaking New Ground: Supporting Employed Family Caregivers with Workplace Leave Policies* (Washington, DC: AARP Public Policy Institute, 2018).
- 138 Lynn Friss Feinberg, "Paid Family Leave: An Emerging Benefit for Employed Family Caregivers of Older Adults," *Journal of the American Geriatrics Society* 67 (2019): 1336–41.
- 139 For all other workers, California raised the rate of wage replacement to 60 percent. In 2018, California also eliminated the waiting period to begin using paid family leave. See: Feinberg, *Breaking New Ground*.
- 140 The expansions of New Jersey's paid family leave insurance program with enhanced payments (increasing wage replacement to 85 percent of a worker's weekly wage, up to a maximum of \$860 per week) and expanded length of paid family (from 6 to 12 weeks) take effect July 2020. All other changes take effect immediately, including expanding job protection to workers in businesses with 30 or more employees, expanding the definition of *family* (to include parents-in-law, siblings, grandparents, grandchildren, other blood relatives, and any other individuals who can be shown to have the equivalent of a family relationship), and including benefits to care for a family member who is a victim of domestic or sexual abuse. See: <https://nj.gov/governor/news/news/562019/approved/20190219a.shtml>.
- 141 Maine's new earned employee leave law, enacted May 2019, makes Maine the first state to require that private employers provide earned paid leave for any reason, including family caregiving concerns, not just sick leave. The law requires that private businesses with 10 or more employees guarantee access to 1 hour of paid leave for every 40 hours worked, up to a maximum of five paid days or 40 hours per year. The law takes effect on January 1,

2021. See: <https://www.natlawreview.com/article/maine-becomes-first-state-to-mandate-paid-leave-any-reason>.
- 142 Nevada’s new law, enacted June 2019, requires private-sector employers with 50 or more employees to provide earned paid leave, which employees may use for any reason, including for sick leave or family caregiving purposes. The amount of leave in a year is limited to 40 hours or five paid days. The law takes effect on January 1, 2020. See: <https://www.blr.com/HR-Employment/Benefits-Leave/Sick-Leave-in-Nevada>.
- 143 Feinberg, *Breaking New Ground*.
- 144 “Paid Sick Days—State and District Statutes, and City and County Laws,” National Partnership for Women & Families, updated May 2019, <http://www.nationalpartnership.org/our-work/resources/economic-justice/paid-sick-days/paid-sick-days-statutes.pdf>.
- 145 Local jurisdictions with paid sick days include 7 cities in California (San Francisco, Oakland, San Diego, Berkeley, Emeryville, Santa Monica, and Los Angeles); Seattle, Tacoma, and Spokane, Washington; Washington, DC; New York City and Westchester County, New York; Eugene and Portland, Oregon; Philadelphia and Pittsburgh, Pennsylvania; Montgomery County, Maryland; Duluth, Minneapolis, and St. Paul, Minnesota; Chicago and Cook County, Illinois; Austin, Dallas, and San Antonio, Texas; and 13 cities in New Jersey (Jersey City, Newark, Irvington, Passaic, East Orange, Patterson, Trenton, Montclair, Bloomfield, Elizabeth, Plainfield, Morristown, and New Brunswick).
- 146 This Illinois law defines *family* broadly to include an employee’s child, stepchild, spouse, domestic partner, parent, stepparent, in-law, sibling, grandchild, or grandparent.
- 147 This Georgia law applies to employees who work 40 or more hours per week for a business with 25 or more employees. In this law, *family member* is defined as a child, spouse, grandchild, grandparent, parent, or other dependent. The law sunsets on July 1, 2020.
- 148 This New Mexico law applies to both public- and private-sector employees who have accrued sick leave. In this law, *family member* is defined as the eligible employee’s spouse, domestic partner, parent, grandparent, great-grandparent, child, foster child, grandchild, great-grandchild, sibling, niece, nephew, or aunt or uncle. See: <https://www.billtrack50.com/BillDetail/1000079>.
- 149 In addition to the District of Columbia, states that have expanded the federal provisions of the FMLA for family caregivers include California, Colorado, Connecticut, Hawaii, Maine, Minnesota, New Jersey, New York, Oregon, Rhode Island, Vermont, Washington, and Wisconsin. Massachusetts allows unpaid leave for family members’ routine medical appointments. See: Feinberg, *Breaking New Ground*.
- 150 Koryn M. McHone, “New York City Protects Caregivers under Expanded Law,” *The National Law Review*, Western Springs, IL, January 6, 2016, <http://www.natlawreview.com/article/new-york-city-protects-caregivers-under-expanded-law>.
- 151 Effective 2016. See: <http://www.longtermscorecard.org>. No current data source is available to track laws protecting caregivers from employment discrimination.
- 152 Other states have created task forces, working groups, and coalitions related to respite care, Alzheimer’s disease, or LTSS that also address family caregiving issues.
- 153 Guardianship reforms include increased court monitoring and oversight, required standards and training for guardians, creation of and funding for public guardianship, increased coordination between state courts and guardianship stakeholders, and the encouragement of less-restrictive alternatives to guardianship, where appropriate.
- 154 In total, 46 states, the District of Columbia, and territories have enacted the Uniform Adult Guardianship Protective Proceedings Jurisdiction Act, providing uniformity across the states. Since 2015, Louisiana, Georgia, and North Carolina (all in 2016); US Virgin Islands (2017); and Wisconsin (2018) have enacted the law. See: <http://www.uniformlaws.org/home>.
- 155 The Uniform Guardianship, Conservatorship and Other Protective Arrangements Act (UGCOPPA) was approved by the Uniform Law Commission in July 2017. The UGCOPPA updates current state law to provide for a more person-centered approach to guardianship. It aims to ensure that guardians have the training and tools they need, and that state courts are providing ample information, guidance, and oversight in guardianship cases. Maine (2018) and Washington State (2019) adopted the comprehensive act in whole, and New Mexico (2018 and 2019) adopted certain sections of the act. See: <https://www.americanbar.org/content/dam/aba/administrative/crsj/committee/ABA-UGCOPAA-presentation-2-28-18.pdf>.
- 156 In 2006, the Uniform Law Commission approved a revised UPOAA. It includes a presumption that the document is “durable.” A durable power of attorney must be completed while an individual is competent. It remains valid even if the person becomes incapacitated and unable to make decisions for herself or himself. See: <https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=6b70eddf-53b2-093b-6da0-e1b245255e00&forceDialog=0>.
- 157 Centers for Connected Health Policy, *State Telehealth Laws and Reimbursement Policies Report, Spring 2019*, https://www.cchpca.org/sites/default/files/2019-05/cchp_report_MASTER_spring_2019_FINAL.pdf. (National Telehealth Policy Resource Center, 2019).

- 158 “Infographic, State Telehealth Laws and Reimbursement Policies, Spring 2019,” Centers for Connected Health Policy, <https://www.cchpca.org/sites/default/files/2019-05/50-State%20Infograph%20Spring%202019%20FINAL.pdf> (2019).
- 159 Interstate licensure compacts are agreements among states that allow for certain health professions to apply for an expedited licensure to be able to practice within surrounding states. See: Centers for Connected Health Policy, *State Telehealth Laws*.
- 160 The Long-Term Care Trust Act requires eligible workers to pay into the program with a premium of 0.58 percent of their wages starting in 2022, with benefits beginning in 2025. For example, a worker earning \$50,000 a year would pay about \$24 a month to this program. Self-employed workers and independent contractors can opt into the program. Starting in 2025, eligible individuals (those who need help with three or more activities of daily living such as bathing or dressing) will receive a lifetime benefit up to \$36,500 to use for long-term care services at home, in the community, and in nursing homes. The new law also allows reimbursement to unpaid family caregivers. See: <https://www.agingwashington.org/member-resources/annual-advisory-council-gatherings/long-term-care-trust-act-fact-sheet/>.
- 161 The 18-month initiative is led by the Center for Health Care Strategies with funding from The John A. Hartford Foundation, Milbank Memorial Fund, May and Stanley Smith Charitable Trust, and the Gordon and Betty Moore Foundation.
- 162 Massachusetts Alzheimer’s and Dementia Act, <https://malegislature.gov/Bills/190/H4116>.
- 163 The National Study of Caregiving excludes family caregivers of nursing home residents.
- 164 Freedman and Spillman, “Disability and Care Needs.”
- 165 The first two rounds of the NSOC were funded by the Assistant Secretary for Planning and Evaluation in the US Department of Health and Human Services. The third round was funded by the National Institute on Aging. See: <https://www.nhats.org/scripts/QuickLinkNSOC.htm>.
- 166 In 2015, 24 states (Alabama, Florida, Hawaii, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maine, Maryland, Mississippi, Nebraska, New Jersey, New York, Oregon, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming) used the revised BRFSS Caregiver Optional Module. In 2016, it was used by 19 states (Arizona, Arkansas, California, Colorado, Connecticut, Georgia, Minnesota, Missouri, Montana, Nevada, New Jersey, New York, North Dakota, Ohio, Oregon, South Dakota, Tennessee, Texas, and Utah), the District of Columbia, and Puerto Rico. In 2017, 12 states (Alaska, Hawaii, Kansas, Maryland, Michigan, New Jersey, New Mexico, New York, Oklahoma, Oregon, Rhode Island, and Utah) administered the Caregiver Module. In 2018, 5 states (Georgia, New Jersey, New York, Ohio, and Oregon) used the Caregiver Module. Three states (New Jersey, New York, and Oregon) administered the Caregiver Module annually between 2015 and 2018. See: <https://www.cdc.gov/aging/healthybrain/brfss-faq-caregiver.htm>.
- 167 The Family Caregiving Institute is funded by the Gordon and Betty Moore Foundation. See: <https://health.ucdavis.edu/nursing/familycaregiving/index.html>.
- 168 The new center is named for former Senator Elizabeth Dole and is known as The Elizabeth Dole Center of Excellence. See: <https://www.hsrp.research.va.gov/centers/dole/default.cfm>.

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