



The John A. Hartford
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REPORT

In Support of Family Caregivers: A Snapshot of Five States

by Jennifer Afill, Julia Burgdorf, and Jennifer Wolff
Johns Hopkins Bloomberg School of Public Health

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Foreword

The coming years will bring drastic changes in the composition of the U.S. population. Not only will we be more racially and ethnically diverse, but, as the baby boom generation ages, we will have many more very old and frail people among us.

The aging of America will be experienced first and foremost in the families who love, support, and care for older relatives and friends. Along with adapting our health care delivery and financing systems to respond to the needs of an increasingly older population, we will need to promote the broader public policy goal of supporting family members and through them, our communities.

So how can public policies support families in their roles as caregivers? We at The John A. Hartford Foundation and the Milbank Memorial Fund believe that to address this question—as with many other pressing public issues—there is much to be learned from the responses of leading state governments. States, after all, are closer to the population they serve than the federal government and thereby able to respond in ways that meet the particular needs of their residents.

With this in mind we commissioned a team of researchers from Johns Hopkins University to identify and examine a diverse set of states that have developed policies that support family caregivers. We invited the researchers to ask: In what kind of environment were these policies developed? What have these states done and how did they do it? And what are lessons for other policymakers?

The report that follows captures the lessons garnered from states that range geographically and culturally from Maine to Hawaii. The report underscores the importance of considering community context, of being attentive to the experiences of caregivers and caregiving, and of persistence in policy adjustments. It gives examples of how attention to these elements is reflected in resulting state policies.

An implication is that these elements are foundational for considering family caregiving issues and precede concerns that often arise about financing additional services. Stakeholders in Washington state, for instance, have long worked to build a community-based system for long-term services and supports. Only since this report was written have lawmakers there passed landmark legislation, the Long-Term Care Trust Act, to establish a fund that residents can use to support family caregivers.

We believe the lessons from these states can inform the policies of other states as well as the federal government. The health of older adults in this country and the families who love and care for them depends in large part on our ability to learn and act together.

Sincerely

Terry Fulmer, PhD, RN, FAAN

President

The John A. Hartford Foundation

Christopher F. Koller

President

The Milbank Memorial Fund

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Introduction

Family and unpaid caregivers play a foundational role in the care of older adults with complex health needs and disabling conditions by assisting with a wide range of household, self-care, and medical tasks that are necessary for health, function, and community living. In the United States, an estimated 18 million family caregivers—mostly spouses and adult children—provide help to 9 million community-living older adults with disabilities.^{1,2} Of these, about half of caregivers help older adults who are “high-need,” defined as having two or more self-care limitations or dementia, placing them at greater risk for role-related challenges.^{1,3} We recognize that many support aging family members who do not have disabling conditions. Public funds are mainly used to support family caregivers who provide care for health or function reasons. State funds are typically focused on populations with a relatively high degree of impairment, which will be the focus of this report.

According to the Congressional Budget Office, family caregivers produce 80% of the total economic value of community-based long-term services and supports for older adults.⁴ Rapid demographic changes including an aging population, greater workforce participation among women, and declining fertility threaten the future availability of family caregiver support.² The caregiving role can be demanding.^{5,6} Caregivers may experience physical, financial, and emotional challenges due to caregiving while balancing work and other family responsibilities.² Serving as a caregiver has been found to have significant economic and health consequences, including foregone wages as well as effects on health and well-being.^{2,6}

Numerous factors limit family caregivers’ access to supportive services. Family caregivers often do not identify as caregivers, instead viewing their contributions as part of their relationship as a spouse, adult child, relative, or friend. Additionally, the system of available supports and services is fragmented, since health care and social services often operate in silos with different funding sources, information systems, eligibility requirements, and distinct workforces with variable training and skills.⁷ Although a number of local, state, and federal programs directly target or indirectly influence the well-being of family caregivers, these programs are financed through a fragmented patchwork of services and are uneven in availability. Because these programs are typically modest in size and funding, they are generally symbolic in the magnitude of assistance afforded to family caregivers.² Previous findings from randomized controlled trials indicate that comprehensive, tailored support can be effective in alleviating role-related strain of caregiving, but few models have been disseminated widely.^{2,3}

The complexity and heterogeneity of family caregiving arrangements pose unique considerations in conceptualizing and evaluating the success of supportive efforts. Because family caregiving can be defined on the basis of varied characteristics of persons receiving care, providing care, or the nature of assistance being provided, defining a target population who

would most benefit from policy change is not straightforward. The criteria (e.g., types or intensity of help or underlying care needs) or circumstances (e.g., by age or relationship between caregiver and receiver) that trigger eligibility for supports or benefits is variable across programs, populations, and context. As caregiving results from impaired function of another person, available supports to family caregivers through health insurance programs such as Medicare, Medicaid, and the Department of Veterans Affairs are generally evaluated in relation to outcomes of the “care recipient” (e.g., nursing home entry, hospitalization). This raises questions about whether outcomes of caregiver support strategies should encompass those of the care recipient, caregiver, or both. Most care delivery systems lack data infrastructure to identify and monitor family caregivers in routine care (e.g., in the electronic health record, in assessments for home and community-based services). As a result, it is often not feasible to determine who relies on a caregiver, the identity of their caregiver, what tasks they perform, or the caregiver’s capacity to provide care. Evaluating the effects of supports within and across current systems of care is therefore often difficult. The tension between pursuing supports that benefit outcomes of the care recipient (e.g., through reductions in nursing home entry or becoming eligible for Medicaid) versus outcomes of the caregiver (e.g., improved well-being, reduced financial strain) is a critical consideration. Because most efforts to support caregivers have a disease-specific population (e.g., dementia caregivers), insured population (e.g., veterans, state Medicaid beneficiaries), or program (e.g., the National Family Caregiver Support Program), interest in evaluating best practices in population-based caregiver support is only now emerging.

In January 2018, Congress passed the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act to establish a national strategy to acknowledge and assist family caregivers. This legislation sets forth the possibility of developing a coherent and coordinated plan for policy initiatives, data infrastructure, and supportive programs to better address the needs of caregiving families.⁸ Fundamental to the success of such a national plan will be the integration of evidence-based services and supports across health care organizations, social service agencies, and employers. However, a stand-alone national plan is not enough. The national strategy developed under the RAISE Family Caregivers Act must accommodate, extend, and reinforce the efforts of states and local communities. Since understanding how states have developed and implemented supportive programs could help efforts related to the RAISE Family Caregivers Act, as well as those of individual states and local communities, we undertook this project to assess state program development for family caregiver support.

This report uses a case-study approach to identify common themes and lessons from selected states that have pursued policies and programs to better support family caregivers. Working with subject-matter experts, we identified five geographically and politically diverse states that were distinguished by operating one or more programs for family caregiver support through state-funded programs, state units on aging, and/or Medicaid.

Key informants were referred to the study team by state leaders, and tailored interview guides were developed for each stakeholder. We probed the history and evolution of related programs, including structure, design, staffing, financing, and oversight; the approach to program evaluation and monitoring; the relevance of environmental and contextual factors; and evidence of programmatic success. Key informants were state officials, policy leaders working on aging and caregiver services, and directors of programs related to aging and disability services. Evaluation of programmatic outcomes and comprehensive input from all relevant stakeholders, implementers or otherwise, about the programs' effectiveness was outside the scope of this report.

The report is structured in three sections. First, we provide an overview of state demographic characteristics, legislative policies, and service delivery programs that most directly affect family caregivers, including those in the five states that are profiled. We briefly summarize foundational aging network and Medicaid programs that are supported by federal and state funding. To highlight variability in service delivery expenditures, we present national estimates of spending for institutional and community-based long-term services and supports alongside those for each of the five states. Next, we profile each state, drawing on evidence from national and state reports, state aging plans, and interviews with 26 key informants (Appendix A). In each profile, we emphasize novel programs and circumstances given unique state context. Finally, we conclude our report by synthesizing common themes that emerged from key informant interviews and policy implications that may be relevant to broader state and national efforts.

Setting the Stage:

Overview of State Demographic Characteristics

The family caregiving policy landscape is affected by a variety of demographic, geographic, political, and economic factors including the service delivery environment, payment policies, and capacity of the health care workforce to provide long-term services and supports. The five states profiled range in total population from 1.3 million in Maine to 7.3 million in Washington, with variability in age distribution, socioeconomic status, and rurality. Maine has the oldest age distribution, with approximately 32 residents ages 65 and older for every 100 working-age adults, whereas Washington had the lowest ratio with 24 residents age 65 and older for every 100 working-age adults. Life expectancy ranges from 76 years in Tennessee to 81 in Minnesota and Hawaii. The racial and ethnic composition of states also varies widely; more than nine in 10 Maine residents are white and non-Hispanic, in comparison with less than one in four Hawaiians.

Table 1: Demographic Characteristics of States Profiled

	USA	WA	MN	HI	TN	ME
Total Population	323,127,515	7,288,000	5,519,952	1,428,557	6,651,194	1,331,479
Aged 18-64, %*	62.8%	61.6%	61.4%	61.7%	61.5%	62.8%
Aged 65+, %*	15.2%	14.8%	15.0%	17.1%	15.7%	19.3%
Aged 85+, %*	2.0%	1.8%	2.2%	2.7%	1.7%	2.4%
Aged 65+ Living Alone, %†	10.4%	9.8%	10.4%	9.2%	10.2%	12.4%
Aged 65+ Below Poverty, %†	9.3%	7.9%	7.4%	7.7%	9.7%	8.9%
Urban and Rural‡+						
-Urban, %	80.7%	84.0%	73.3%	91.9%	66.4%	38.7%
-Rural, %	19.3%	16.0%	26.7%	8.1%	33.6%	61.3%
Race and Ethnicity†						
-White, Non-Hispanic, %	62.0%	70.4%	81.3%	22.4%	74.5%	93.7%
-Black, Non-Hispanic, %	12.3%	3.5%	5.6%	1.7%	16.7%	1.2%
-Asian, Non-Hispanic, %	5.2%	7.7%	4.5%	37.0%	1.6%	1.1%
-Hispanic or Latino, %	17.3%	12.1%	5.1%	10.0%	5.0%	1.5%
Title III Minority Clients, % §	28.5%	17.2%	7.8%	74.9%	22.6%	5.0%
Average Life Expectancy, y ¶	78.9	79.9	81.1	81.3	76.3	79.2
Age Dependency Ratio #	24.6	23.6	24.4	27.78	25.5	31.5

* U.S. Census Bureau. American Community Survey 2016 1-year estimate.⁹

† U.S. Census Bureau. American Community Survey 2016 5-year estimate.¹⁰

‡ U.S. Census Bureau. Census 2010.¹¹

§ Administration on Aging: Aging Integrated Database (AGID) 2016.¹²

¶ Kaiser Family Foundation.¹³

The ratio is a proportion of older adults ages 65+ per 100 working-age adults ages 18-64.

Legislative Policies Supporting Family Caregivers

The five states profiled in this report pursued diverse legislative policies that impacted long-term services and supports, health care, and workplace leave, all of which affect family caregivers. These policies illustrate legislative options available to states, some of which fit within a broader policy context. For example, the federal Family and Medical Leave Act of 1993 entitles working Americans to 12 weeks of job-protected leave to manage serious personal illness, bond with a new child, or care for a sick family member. But, it is limited to those working full-time for large employers and who have been employed for 12 months or longer. Several states (including all five of our profiled states) have expanded these provisions by lowering employer size requirements, expanding the definition of “family” to include other relatives, or increasing flexibility of sick-leave policies. Washington is one of a

handful of states that has approved paid family medical leave, allowing workers to take up to 12 weeks of paid leave to provide care for a relative with a serious illness.¹⁶ Thirty-seven state legislatures, including four of the states examined here, have passed the Caregiver Advise Record and Enable (CARE) Act, which requires hospitals to identify and document the presence of a caregiver, notify the caregiver when the patient will be discharged from the hospital, and provide resources and training to caregivers who will perform medical tasks.^{14,17}

Table 2: Federal and State Policies Affecting Caregivers and Older Adults

	USA	WA	MN	HI	TN	ME
Federal Policies*						
Older Americans Act	1965	Yes	Yes	Yes	Yes	Yes
Medicare Hospice Benefit	1982	Yes	Yes	Yes	Yes	Yes
Family and Medical Leave Act	1993	Yes	Yes	Yes	Yes	Yes
National Family Caregiver Support Program	2000	Yes	Yes	Yes	Yes	Yes
Lifespan Respite Care Program	2006	Yes	Yes	Yes	Yes	Yes
VA Caregiver Support Program	2010	Yes	Yes	Yes	Yes	Yes
NAPA	2011	Yes	Yes	Yes	Yes	Yes
State Policies						
CARE Act Passed†	37 states	2016	2017	2017	Introduced	2015
Paid Family Medical Leave‡	7 states	2018	No	Introduced	No	Introduced
FMLA Expansions:‡						
-Lowered Employer Size	8 states	Yes	Yes	No	No	Yes
-Expanded “Family” Definition	14 states	No	No	Yes	No	Yes
-Flexible Sick Leave	16 states	Yes	Yes	Yes	No	Yes

Abbreviations: FMLA, Family and Medical Leave Act; NAPA, National Alzheimer’s Project Act; VA, Veterans Affairs.

Source: * National Academies of Sciences Engineering and Medicine (U.S.). Committee on Family Caregiving for Older Adults. Families caring for an aging America.² † AARP¹⁴ ‡ National Partnership. “Lowered Employer Size” requires smaller private-sector employers (with fewer than 50 employees) to provide job-protected family and medical leave. “Expanded ‘Family’ Definition” covers family members beyond the employee’s spouse, parent, son, or daughter as defined by FMLA for job-protected family leave. “Flexible Sick Leave” allows private sector workers to use accrued sick time to care for a sick relative.¹⁵

Service Delivery Programs

1. Programs Funded by the Older Americans Act

The Administration for Community Living serves as the central administrator for a range of home- and community-based services and supports for older adults, including support to family caregivers, that are authorized by the Older Americans Act (OAA).¹⁸ Enacted in 1965, the OAA has enabled states to provide social support services for older adults through a network of local Area Agencies on Aging (AAAs), with each state granted funds based on the number of older adults living in the state. Nearly 75% of Administration for Community Living funding is directed to OAA Title III programs for older adults, such as nutrition, transportation, case management, adult day care, personal care, chore services, and access assistance (Table 3).¹⁹ Nutrition, including congregate and home-delivered meals for older adults, comprises the largest spending category in all five states profiled and nationally.

Since 2000, the National Family Caregiver Support program (NFCSP) has provided approximately \$150 million annually in grants to state units on aging as Title III-E of the OAA^{20,21} for five core services: information services, access assistance, counseling, training, respite care, and supplemental services.²⁰ Nearly 200,000 caregivers were touched by the NFCSP in 2016.¹² The NFCSP is the first of its kind that provides grants to states for the sole purpose of providing supports and services for family caregivers. States have considerable flexibility in design and implementation of OAA programs, including the NFCSP. Each state is unique in how it has approached developing its service delivery infrastructure, statewide information databases, directory of service providers, and collaboration between their state unit on aging (SUA) and their AAAs.²² Today, the aging network comprises 56 SUAs, 655 AAAs, 243 Indian tribal and native Hawaiian organizations, and thousands of service providers and volunteers that are funded through a match of federal and state dollars approaching \$2 billion annually.^{12,19,23}

Table 3: State Expenditures on Older Adults and Caregivers by ACL Service FY16 (\$ thousands)

	USA	WA	MN	HI	TN	ME
Older Adult Expenditures	\$3,671,096	\$31,538	\$30,030	\$15,022	\$36,911	\$11,432
- Personal Care, %*	20.0%	1.3%	4.5%	16.8%	15.0%	1.0%
- Nutrition, %†	42.0%	53.0%	72.2%	35.4%	39.7%	55.2%
- Adult Day Care, %	2.8%	1.0%	0.0%	2.6%	0.4%	9.4%
- Case Management, %	6.8%	2.2%	0.0%	9.5%	9.0%	0.3%
- Transportation, %‡	6.3%	5.8%	6.4%	14.1%	4.6%	0.9%
- Access Assistance, %§	7.0%	22.6%	10.2%	10.9%	5.0%	26.5%
- Other Services, %¶	15.0%	14.0%	6.6%	10.8%	26.2%	6.8%
Caregiver Expenditures	\$198,547	\$11,994	\$2,926	\$919	\$3,434	\$1,516
- Counseling, %	14.7%	7.6%	35.0%	30.6%	2.4%	38.1%
- Respite, %	47.4%	34.7%	46.2%	35.3%	63.3%	31.4%
- Supplemental, %	7.3%	7.1%	0.0%	12.6%	7.7%	0.0%
- Cash and Counseling, %	0.8%	0.0%	0.7%	0.0%	0.1%	0.0%
- Access Assistance, %	21.7%	45.9%	14.1%	12.0%	23.7%	24.7%
- Information Services, %	8.1%	4.6%	3.9%	9.5%	2.8%	5.8%

Abbreviations: ACL, Administration for Community Living; FY, fiscal year;

* “Personal Care” includes activities of daily living assistance, chores, and homemaking.

† “Nutrition” includes home-delivered meals, congregate meals, and nutrition education and counseling.

‡ “Transportation” includes providing or arranging for medical and nonmedical travel.

§ “Access assistance” includes information and assistance, outreach, and health promotion.

¶ “Other services” includes cash and counseling and legal services.

Source: Administration on Aging: Aging Integrated Database (AGID) State Performance Report 2016.¹²

Recent reports that have examined state variability in social service spending have highlighted the importance of tailoring services to meet the unique needs of each state’s local context and population.²⁴ Diverse state allocation of Title III funding illustrates states’ varied approaches to prioritizing older adult and family caregiving issues. For example, Maine and Washington spend proportionally more than three times the national average on access assistance (26.5% and 22.6% versus 7.0% nationally) while Hawaii and Tennessee devote proportionately more to case management (9.5% and 9.0% versus 6.8% nationally). For distribution of funding related to caregiver services, Washington devotes nearly half of caregiver program spending to access assistance (45.9%)—nearly twice that of the next closest state profiled in this report (Maine, at 24.7%). Tennessee directs almost two-thirds of spending to respite (63.3%), which is nearly one-third higher than that of the next highest state profiled in this report (Minnesota, at 46.2%). Nationally, respite (47.4%), access assistance (21.7%), and counseling (14.7%) comprise the largest categories of NFCSP spending.

2. Programs Funded by Medicaid

Medicaid is the largest purchaser of long-term services and supports (LTSS) nationally, exceeding \$100 billion in 2016.²⁵ More than 5 million people, 45% of whom are age 65 or older, receive LTSS through state Medicaid programs.²⁶ Medicaid covers a continuum of long-term services and supports, from home- and community-based services to institutional care in a nursing facility. Rebalancing Medicaid to enable persons with disabilities to remain living in the setting of their choice has been a longstanding priority.^{27,28} Nearly half (45.2%) of Medicaid spending for older adults is devoted to home- and community-based services nationally, but there is notable variability across states. Among states profiled, Washington and Minnesota spend about 70 cents of every dollar on Medicaid long-term services and supports on home- and community-based services, making them among the most highly rebalanced states nationally (Table 4).²⁶ Although Medicaid provisions are limited by care-recipient eligibility criteria, several state-level Medicaid policies directly impact family caregivers from the standpoint that services effectively benefit caregivers by providing case management, homemaker/home health aide/personal care services, adult day care, and respite care.

Table 4: Medicaid Expenditures on LTSS for Older Adults FY16 (\$ millions)

	USA	WA	MN	HI	TN	ME
Spending, \$	\$103,578	\$2,198	\$3,031	\$400	\$1,398	\$427
- Institutional Care, %	54.8%	28.8%	30.1%	74.0%	65.5%	72.0%
- HCBS, %	45.2%	71.2%	69.9%	26.0%	34.5%	28.0%

Abbreviations: LTSS, long-term services and supports; HCBS, home- and community-based services; FY, fiscal year.

Source: Medicaid Expenditures for Long-Term Services and Supports in FY 2016, May 2018.²⁶

Historically, most Medicaid-funded LTSS have been delivered in institutional settings, but rebalancing efforts have incrementally shifted care to the community in recent years. This evolution has been supported by introducing new waiver authorities that afford states flexibility in the approach to delivering and financing services. The states profiled in this report are diverse in how they have structured Medicaid and LTSS (Table 5). The focus on rebalancing and reducing fragmentation in service delivery has led a growing number of states to rely on managed long-term services and supports (MLTSS) to integrate financing of health care and LTSS through a private health plan responsible for delivering both types of services. The number of states with operating MLTSS plans has increased from six in 2009 to 22 in 2017.^{29,30} The 1915(b) and 1915(c) waiver authorities allow states to target specific services to select populations, whereas 1115 demonstration waivers afford flexibility to re-structure statewide benefits. State plan programs such as Community First Choice 1915(k) afford supplemental community-based services to beneficiaries who meet an institutional level of care. The Money Follows the Person demonstration grant provides incentives to transition Medicaid enrollees from institutions back into the

community³¹ and the Testing Experience and Functional Tools grant seeks to incorporate health information technology in Medicaid person-centered care planning.³²

State-level Medicaid policies may indirectly affect family caregivers through more effective coordination of care and home- and community-based supports that facilitate greater independence and quality of life for persons with disabilities, thereby reducing caregiving-related responsibilities among family caregivers. State-level Medicaid policies may also directly benefit caregivers through caregiver assessment and referrals to supportive services, such as respite care. The personal care optional benefit allows family members to be hired as paid caregivers, though training, certification, and restrictions on who may be hired varies from state to state. State Medicaid programs may also regulate policies related to uniform caregiver assessment, training requirements, and hiring limitations.

Table 5: State Medicaid Policies Affecting Older Adults and Caregivers

	WA	MN	HI	TN	ME
Statewide MLTSS*	No	Yes	Yes	Yes	No
1915(b4) Waiver for Older Adults†	No	Yes	No	No	Yes
1915(c) HCBS Waiver for Older Adults†	Yes	Yes	No	No	Yes
1915(k) Community First Choice Statewide Program†	Yes	Yes	No	No	No
1115 Demonstration Waiver for Older Adults†	Yes	Yes	Yes	Yes	No
Money Follows Person Grant†	Yes	Yes	Yes	Yes	Yes
Testing Experience and Functional Tools Grant†	No	Yes	No	No	No
Mandatory Worker Training for Consumer Directed Services‡	Yes	Yes	No	Yes	No
Spouses May Be Hired Under Consumer Direction‡	No	No	Yes	No	No

Abbreviations: MLTSS, managed long-term services and supports; HCBS, home- and community-based services.

Source: * National Association of State United for Aging and Disabilities State of the States in Aging & Disability: 2017 Survey of State Agencies.²⁹ † Medicaid.gov. ‡ Key informant interviews.

State Profiles

In the following section, we profile each of the five states. For each state, we describe high-level information about demographic factors, state geography, the history and evolution of programs, workforce issues, and the service delivery context. We highlight how the state has built upon federal and state legislation and funding through the Older Americans Act and Medicaid to enhance family caregiver support. For each state, we spotlight at least one novel program that stands out for leveraging available infrastructure and strengths to address the needs of older state residents and their family caregivers. For each program, we summarize the connection between state context and programmatic goals and describe emerging evidence of outcomes, if available.

Hawaii

Hawaii Spotlight: Kupuna Caregivers Program

Hawaii State Context	Program Goal and Structure	
<ul style="list-style-type: none"> • Highly urban, densely populated • Racially and ethnically diverse • Family-oriented culture • Multigenerational housing • Working “sandwich generation” caregivers • Lowest percentage of older adults living alone 	<ul style="list-style-type: none"> • <i>Goal:</i> Allow working family caregivers to remain in the workforce and delay or divert Medicaid or nursing home entry for older adults • <i>Structure:</i> Built upon existing Kupuna Care program for older adults, created a program funded by state statute and motivated by advocacy and personal stories 	<ul style="list-style-type: none"> • Offers up to \$70/day for adult day services • Eligible caregivers must work >30 hours/week, care for adult >60 who meets Kupuna Care eligibility criteria • Launched January 2017 with \$600,000 in funding from state legislature (funding doubled in 2018)

Among states profiled, Hawaii stands out for its diversity, multigenerational and family-oriented culture, and supplemental state funding for economically vulnerable older adults at-risk of Medicaid or nursing home entry and their working caregivers. Nearly three in four clients served by Title III programs in Hawaii are members of a racial or ethnic minority subgroup (74.9%).¹² Hawaii also is unique in having the lowest percentage of older adults living alone (9.2% vs. 10.4% nationally). Key informants noted the prominence of multi-generational housing and that strong cultural norms and expectations of family support are a barrier that limits family caregivers from accessing supportive services.

Hawaii attracted considerable attention for the January 2018 launch of the Kupuna Caregivers program, which offers financial support to working family caregivers. The Kupuna Caregivers program is an outgrowth of its state-funded Kupuna Care program, which seeks to support community-living older adults with significant disabilities (near nursing-home level of care) who are not eligible for Medicaid but are at risk for both nursing home and Medicaid entry. The Kupuna Care program is administered through the Hawaii state aging network and has an annual operating budget of \$4.9 million that is devoted to core services (similar to Title III services) that support community living.

Kupuna Caregivers is a state legislatively backed program that provides working family caregivers with a subsidy of up to \$70 per day to be applied toward adult day services. To be eligible, family caregivers must be employed 30 hours or more per week and provide care to an adult 60 years or older who meets Kupuna Care eligibility criteria. The program was motivated by the state legislature’s recognition of the need to better support family caregivers who are often pivotal to community living for persons with disabilities and an appreciation of the demands placed on sandwich generation working adults caring for both aging parents and minor children, often all under one roof. The concept of “Oha-na,” or familial bonds and cooperation, is strong in Hawaii and has prompted policy efforts to support the family unit as an entity. In its first year (2017), the program was funded at \$600,000 and provided support to about 90 recipients. Funding the program has been

doubled by the state to \$1.2 million, though the benefit may be reduced to \$70 per week due to funding limitations.³³

“I don’t think there was one testimony against [Kupuna Caregivers]. We’ve all been in the situation of caring for a loved one or knowing someone who has. A lot of advocates came out, people who left their jobs to take care of a family member saying, ‘This would have helped me stay employed.’”

—Hawaii key informant interview

Hawaii is unique in emphasizing choice and autonomy in the ability to self-direct who serves as individual providers within Medicaid. Since 2009, Hawaii has allowed any family member, including spouses, to serve as paid personal care attendants. Hawaii has sought to maximize freedom and flexibility in hiring individual service providers and imposes minimal training and background check requirements, due in part to its culture and family orientation.

“We have always allowed family members be caregivers, we never asked any questions about that...I would say 90% to 95% [of providers under self-direction] are family members on the Medicaid side.”

—Hawaii key informant interview

Hawaii’s Medicaid program performs a comprehensive assessment for Medicaid clients every six months using a homegrown assessment that incorporates questions of caregivers to assess and address burnout, although this information is not electronically captured or systematically monitored at the state level.

Maine

Maine Spotlight: Tri-State Learning Collaborative on Aging

<p>Maine State Context</p> <ul style="list-style-type: none"> • Most of population lives in rural areas • Majority white non-Hispanic population • Fiercely independent: many older adults live alone • Lack of affordable housing • Caregiving shortage due to full employment of direct-care workforce 	<p>Program Goal and Structure</p> <ul style="list-style-type: none"> • <i>Goal:</i> Strengthen community practices to support healthy aging through shared learning and collaborative partnerships in similar rural states (Maine, Vermont, New Hampshire) to support older adults and family caregivers • <i>Structure:</i> Interstate network to support volunteer and professional connections 	 <p>TRI-STATE LEARNING COLLABORATIVE ON AGING</p> <ul style="list-style-type: none"> • Convenes representatives from state units on aging, local foundations, community leaders, providers, advocates, and researchers • Hosts monthly topical webinars, electronic forums, issue-based calls • Stimulates volunteer initiatives
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Maine stands out for strong cross-sector partnerships between the Maine Council on Aging, a state-level nonprofit initiative to improve services for older adults, the state transportation and housing agencies, and well-organized, robust local volunteer networks. Key informants noted that Maine has the oldest and most rural population of any state—and that residents are fiercely independent. A lack of affordable and contemporary housing stock, shortage of direct-care workers, and full employment have contributed to a “perfect storm” of population aging with waiting lists for affordable senior housing and constraints on access and delivery of long-term services and supports.

Maine has pursued several strategies to address these challenges, prioritizing housing, workforce, and transportation. Maine allocates more than half (53.8%) of its Title III budget to home-delivered and congregate meals and spends more than three times the national average on access assistance. For Title III-E, Maine prioritizes caregiver counseling and respite and access assistance. In addition to respite services that are provided through a 1915(c) waiver and a state-funded home care program, Maine has a state-funded respite program run by the AAAs that offers up to \$3,800 per year for caregivers of low-income older adults with dementia.

“Over the last couple years, at the community level, people are stepping up to initiate change and be creative....Each community is different, and like everything else, it will become a question of sustainability.”

—Maine key informant interview

The Maine Council on Aging is part of the Tri-State Learning Collaborative on Aging, a shared rural learning collaborative of individuals and community organizations in Maine, New Hampshire, and Vermont. The Tri-State Collaborative convenes officials from each state unit on aging, a coalition of seven local foundations, community leaders, providers, advocates, and researchers with the goal of identifying effective processes and tools to support aging in place in rural communities. Now in its fourth year, the Tri-State Collaborative facilitates monthly topical and technical webinars, regional in-person events, electronic forums, and issue-based calls. Key informants report that activities related to family caregivers have been particularly well-attended and widely endorsed as useful among participants for enabling a forum for sharing experiences and peer-to-peer education and knowledge about respite, transportation, and workplace supports.

“[The Tri-State Learning Collaborative on Aging] focus on grassroots approaches and solutions is what is so helpful to community groups struggling with the same issues.”

—Maine key informant interview

Given Maine’s predominantly rural population, geographic dispersion and transportation challenges were highlighted as contributing to social isolation among older adults and limiting access to food and services. The Maine Council on Aging has partnered with state agencies responsible for transportation and housing. The Maine housing administration pro-

vides up to \$3,800 in tax credits for home modifications for older adults, and the Tri-State Learning Collaborative has spurred volunteer initiatives engaged in home modification. The Maine Council on Aging is leading efforts to create a model accessory dwelling ordinance and is promoting the home-share models found in Vermont to match people willing to share homes. The Maine 2025 Public Transit Plan includes specific provisions for older adults by supporting volunteer transportation networks and the 1915(b4) Non-emergency Transportation Waiver.

Minnesota

Minnesota Spotlight: Live Well at Home

<p>Minnesota State Context</p> <ul style="list-style-type: none"> • Geographically dispersed • Strong academic and community partnerships • Highly rebalanced Medicaid long-term services and supports • Co-located Medicaid agency and state unit on aging • Robust local funding for Area Agencies on Aging 	<p>Program Goal and Structure</p> <p><i>Goal:</i> Expand capacity of long-term services and support by stimulating innovation with grant funding to pilot test promising local programs</p> <p><i>Structure:</i> Funded by state statute, awarded by a call for proposals from the Minnesota Department of Human Services</p>	 <ul style="list-style-type: none"> • Enable local organizations to test strategies for supporting older adults and caregivers in the community • Launched in 2001, has provided grants to over 700 organizations thus far • Annual budget \$8 million (\$485,000 for caregiver programs)
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Minnesota is notable for strong academic and community partnerships, leveraging a mix of foundation and state funds to support innovation and prioritizing grassroots community initiatives to address gaps in local service delivery. Minnesota has encouraged local agencies to pursue creative services tailored to their communities. In Minnesota, local funds for AAAs are seven times greater than state funds and 1.4 times greater than federal funds.³⁴ The Minnesota state unit on aging and Medicaid authority are co-located in the Minnesota Department of Human Services and work in tandem to coordinate services across geographic regions, populations, and managed long-term services and supports plans.

Minnesota's Live Well at Home program provides grant funding to local organizations to pilot test strategies to support older adults and caregivers in the community. The Live Well at Home grants are awarded by a call for proposals from the Minnesota Department of Human Services, and the resulting projects are highly diverse. Projects can range from opening a new adult day center to piloting new models of service delivery (e.g., digital transportation coordination) or organizing a volunteer network.

Launched in 2001, the Live Well at Home program currently has an annual budget of nearly \$8 million, of which \$485,000 is specifically set aside for family caregiver supports. More than 700 organizations have received grants through the program thus far, with project duration ranging from six months to five years. In piloting these small-scale projects, the state has gained valuable insight into practical aspects of rolling out a successful program. One key informant noted that new programs need at least three to five years to show results and become sustainable.

“Sometimes you’re trying something out and it doesn’t work, but you always learn something from the grantee. These [Live Well] grants give you that flexibility...it’s so unusual in government to be allowed to take risks, to have seed money to do this type of work.”

—Minnesota key informant interview

A major objective of Minnesota’s Live Well at Home program has been to identify private-pay clients who are at risk of “spend down” (depleting economic resources and enrolling in Medicaid) and then streamline access to community-based services to enable them to age in place. With funding from the state unit on aging, Minnesota partnered with researchers from the University of Minnesota to develop and pilot test a consumer-directed approach to efficiently target at-risk private-pay persons with a multicomponent diversion service program.³⁵ This effort led to the development of a seven-item Live Well at Home screening program that includes a family of screening instruments specific to older adults and family caregivers. These screening instruments are used by AAAs to guide individuals to appropriate services. The screening instruments have also been used to assess the impacts of Live Well grants (e.g., through pre-post comparisons), as a required element of awards. Although Minnesota collects the Live Well rapid-screen data statewide through program reporting and the LinkAge database, these data have not yet been used to formally monitor statewide progress.

Minnesota assesses home- and community-based services capacity through a biannual survey and has found the most common service gaps are related to chore, nonmedical transportation, and respite services—most notably in rural geographic areas and for immigrant populations. With grant funding from the Live Well at Home program, the state has partnered with Chicago REST (Respite Education Support Tools; www.restprogram.org) as an interim solution to increase availability of respite care. Minnesota’s Powerful Tools for Caregivers, an in-person self-education program for caregivers, is available through most AAAs.

Caregiver self-identification was noted by key informants as an impediment to uptake of caregiver supportive services. With funding from the Schultz Foundation, the state worked closely with the Amherst H. Wilder Foundation to develop a public relations campaign to increase awareness of family caregiving. The initial program was developed in the St. Paul area and subsequently expanded statewide and has since been adopted by other states and communities.³⁶

“Caregivers are focused on getting resources for the older adult, and it’s harder to get them to seek resources for themselves.”

—Minnesota key informant interview

Minnesota Medicaid uses a standardized state-specific assessment for person-centered care planning. The assessment is performed by lead agencies (counties, tribes, and managed care organizations under contracts with the department that include long-term care consultation responsibilities). Lead agencies use MnCHOICES, a face-to-face long-term care consultation assessment, which includes an optional caregiver module that queries caregiving activities and burden. The caregiver assessment allows assessors to identify the needs and appropriate services and supports for caregivers to be addressed by the care plan. Key informants indicated that the tool is administered as a standardized interview as opposed to a checklist. Minnesota is one of nine states to receive a grant from the Centers for Medicare and Medicaid Services to pilot health information technology innovations in Medicaid long-term services and supports, including creation of untethered personal health records. An early lesson from this effort has been the importance of ensuring that personal health records have the capacity for both individuals with long-term services and supports needs and their family caregivers to be able to legitimately access information about individuals’ health, function, and care plans, such that family caregivers are provided their own identity credentials.

Tennessee

Tennessee Spotlight: TennCare Managed Long-Term Services and Supports

<p>Tennessee State Context</p> <ul style="list-style-type: none"> • Long history with managed care in Medicaid • One in 10 older adults live in poverty • Less rebalanced long-term services and supports • Dedicates most Title III funding to caregiver respite 	<p>Program Goal and Structure</p> <p><i>Goal:</i> Accelerate the pace of shifts toward community-based long-term services and supports</p> <p><i>Structure:</i> Enlist managed care organizations in assessing and supporting family caregivers, enlist Area Agencies on Aging in providing local service provider information</p>	 <ul style="list-style-type: none"> • The Tennessee Medicaid bureau of TennCare is the first to enroll all Medicaid beneficiaries with disabilities in managed care <ul style="list-style-type: none"> ◦ 40,000 individuals are enrolled in managed long-term services and supports • Eliminated wait lists for home- and community-based services for the older adult population • Successfully mandated all plans have a caregiver assessment as part of intake visits that meets statewide criteria
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Tennessee stands out as the first state to enroll all Medicaid beneficiaries with disabilities in managed long-term services and supports (MLTSS) plans. The state is also notable for mandating that MLTSS plans assess family caregivers and for deliberately incorporating programmatic partnerships between MLTSS providers and its state aging network. Tennessee has a long history of partnering with managed care plans to support Medicaid beneficiaries with disabilities dating back to the early 1990s. Key informants stated that the decision to move toward reliance on MLTSS plans statewide was motivated by this history, a desire to expand access to home- and community-based services, and the opportunity to rebalance the system while improving care quality and coordination. By 2015, TennCare—the state Medicaid agency—had enrolled 1.4 million individuals across three statewide managed care plans encompassing long-term services and supports, with about 40,000 individuals enrolled in MLTSS.

Prior to the implementation of Tennessee’s CHOICES MLTSS program, Tennessee administered several waiver programs to provide home- and community-based services to older adults and adults with physical disabilities. Since TennCare introduced CHOICES in 2010, the state has experienced increases in participant-direction and eliminated waiting lists for its home- and community-based services programs for these populations.³⁷ Tennessee provides incentives to promote self-direction in MLTSS, with the managed care plans required to offer self-direction to all program participants.

“We started by requiring a family caregiver assessment and requiring, if needs were identified as a part of that assessment, that those needs were addressed as a part of the planning process.”

—Tennessee key informant interview

Since 2014, Tennessee has required that MLTSS plans incorporate caregiver assessment in the face-to-face intake process to identify and address the needs of the caregiver. Key informants noted the introduction of this requirement was due in part to recommendations of a governor-led taskforce on aging that noted the importance of prioritizing caregiver supports as well as other national policy initiatives. While the state does not prescribe a specific assessment tool to be used by the plans, several elements of the annual assessment are mandated. Elements of the mandated caregiver assessment include questions regarding: caregiver health and well-being, stress and burden, need for training or support, willingness and ability to provide care, and employment status.

“[The AAAs] have our hand on the pulse of the community-based systems....that’s an ingredient that most Area Agencies bring to the table across the country.”

—Tennessee key informant interview

Tennessee has taken an integrative approach to case management, where AAAs perform initial intake assessment and initiate Medicaid financial applications, the Medicaid bureau

of TennCare determines eligibility, and individuals select or are assigned to a managed care plan that subsequently assumes responsibility for developing the service delivery plan. Key informants noted that the aging network and managed care plans regularly communicate about the availability and capacity of supportive services in quarterly meetings.

Washington State

Washington State: Programmatic Caregiver Assessment

<p>Washington State Context</p> <ul style="list-style-type: none"> • Relatively young population • Rebalanced Medicaid long-term services • Long history of state legislative support of family caregivers • Co-located state unit on aging and Medicaid agencies 	<p>Program Goal and Structure</p> <p><i>Goal:</i> Systematically gather data on caregiver needs to make the case to state legislature for funding</p> <p><i>Structure:</i> Washington State Department of Social and Health Services piloted the Tailored Caregiver Assessment and Referral (TCARE) program (2008-2010) before scaling statewide—now funded by state statute</p>	<p></p> <ul style="list-style-type: none"> • The Washington State Health Care Authority Apple Health (Medicaid) program transformed long-term services and supports using caregiver data collected by the Washington State Department of Social and Health Services • State evaluation found caregivers who completed assessment program were 20% less likely to use Medicaid • Efforts supported 1115 demonstration waiver geared toward serving “pre-Medicaid” at-risk population
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Among states profiled, the Washington State Health Care Authority Apple Health (Medicaid) program has the most rebalanced system of long-term services and supports, and supporting family caregivers has been core to its community orientation. Washington stands out for reliance on an evidence-based caregiver assessment throughout its aging network, a coordinated approach to integrating the delivery of Title III and Medicaid-funded services, and the use of data and evidence to justify scaling innovative strategies. Motivated by strong advocacy and evidence from programmatic evaluations, the Washington state legislature has incrementally increased state funding for family caregiver support programs over the course of several decades.³⁸ State funding accounted for 80% of an estimated \$14 million devoted family caregiver supports in 2016 (the remaining 20% was Title III funding from the National Family Caregiver Support Program).³⁹ The state unanimously passed the CARE Act in 2016, and in 2020 will become one of seven states with a paid leave policy to care for a sick relative.⁴⁰ Key informants highlighted the importance of conveying to their state legislature the evidence that supporting family caregivers can delay or divert entry into Medicaid.⁴¹

“The legislature over 30 years has been consistently aware, in a bipartisan way, that caregiving is a huge issue, that caregivers do important work, and that they ultimately save the state money given the economic value of what they’re doing in terms of keeping their loved one at home.”

—Washington key informant interview

In Washington, Title III services, state-funded caregiver supports, and Medicaid LTSS, are co-located within the Aging and Long-Term Support Administration of the Department of Social and Health Services. Reliance on the aging network to case manage both Medicaid and non-Medicaid clients has enabled programmatic efficiencies across Title III, Medicaid, and state funding streams. This level of integration has streamlined access to services by ensuring that case managers possess deep understanding of available programs to facilitate appropriate service referrals.

The current landscape of family caregiver supports has evolved through incremental and purposeful testing and scaling of effective strategies. The state deliberately pilots and refines new programs before implementing those that are successful statewide. For example, Washington’s Lifespan Respite Program started as a grant-funded grassroots effort in 2002 and has since been expanded with an emphasis on supporting caregivers who do not meet the financial requirements for existing programs but who are at risk and unable to pay for needed respite care services.

Over the course of three years (2008–2010), Washington piloted, refined, and scaled the Tailored Caregiver Assessment and Referral (TCARE) caregiver assessment program⁴² through its Aging and Long-Term Support Administration. The use of a single, standardized assessment tool to identify and address specific challenges through an individualized care plan has allowed the state to allocate scarce resources to caregivers most in need of support. State evaluations concluded that statewide deployment of TCARE was associated with reductions in enrollees accessing Medicaid-funded long-term services for the first time.⁴¹ Building on this statewide evaluation of TCARE, Washington pursued and was awarded an 1115 Medicaid demonstration waiver to experiment with expanding access for unpaid family caregivers of persons who are at risk of spend down or “pre-Medicaid.”⁴³ In an era of rapid MLTSS expansion, Washington is the only state in which MLTSS plans have withdrawn. State informants attributed MLTSS withdrawal to the heavy focus on community-based care delivery and its efficient in-house case management.²⁹

“We’re doing what a managed care company would do, but we’re doing it through our AAAs, and our programs are the workhorse.”

—Washington key informant interview

Due to an appreciation of the increasing complexity of care needs of people served in community settings, Washington has sought to build capacity through training of personal care attendants. In Washington, paid providers working in home care agencies, assisted living, adult family homes, or in self-directed programs must complete 75 hours of basic training to be certified as a home care aide. However, there are exceptions: paid providers who are parents or adult children of the client are exempt from the higher level of training and must complete 35 hours of training. Paid attendants other than respite providers and limited services providers must complete 12 hours per year of continuing education. The state has partnered with the Service Employees International Union to ensure the workforce has the skills and capacity to meet the changing needs and demands of more individuals being served in the community. In 2018, the state launched an online platform, [CarinaCare.com](https://www.carinacare.com), to facilitate culturally sensitive matching between Medicaid clients and paid personal care providers and to allow paid providers to increase hours of work and help individuals who are self-directing their care needs to identify new or additional workers.

Common Themes and Considerations for State Policymakers

We profiled five geographically and politically diverse states that have pursued novel approaches to supporting family and unpaid caregivers of older adults. Demographic factors, state geography, workforce issues, service delivery context, and the history and evolution of programs were found to shape how each state has approached the structure and financing of long-term services and supports, including support for family caregivers. Maine is addressing geographic dispersion, access, and workforce challenges through cross-sector efforts with transportation and housing agencies and through grassroots organization of volunteer networks. Hawaii's family-oriented, multigenerational culture stimulated supplemental state funding for financial support of working "sandwich-generation" caregivers with an emphasis on choice and flexibility in Medicaid consumer direction. Tennessee has drawn on its history of managed care by innovating in partnership with private managed long-term services and supports plans to create state mandates related to assessment of family caregivers. Minnesota has capitalized on local energy and innovation by providing seed funding to pilot test promising local programs to support older adults and family caregivers. Washington is systematically acting on assessments of family caregivers to drive efficient use of long-term services and supports and collaborative efforts across service delivery.

Although the structure and orientation to service delivery were highly variable by state, important similarities emerged with respect to motivation and approach to support of family and unpaid caregivers. The forces behind statewide changes and policy leadership varied from individual champions at state units on aging, AAAs, and Medicaid agencies to the efforts led by coalitions of volunteers and advocates, and state legislators—but stakeholders in all states were motivated by the foundational role of family caregivers to achieving sustainable and robust systems of community-based long-term services and supports for older adults. In all states, personal stories, coordinated advocacy, and data-driven evidence

helped propel family caregiving onto the legislative policy agenda. All states directed supplemental state funding to community-based supports for targeted subgroups of family caregivers of individuals with disabilities at high risk of institutionalization or entry into Medicaid. Here, we synthesize common themes from key informant interviews and discuss considerations and implications for states seeking to advance programmatic innovation in family caregiver support.

Take time to test new approaches; there is value in sustained incrementalism. The importance of flexible funding and iterative development, refinement, and pilot testing of innovative approaches were identified as pivotal to deliberative capacity building and systems change. Stakeholders spoke to the need for a minimum of three to five years to test an innovative approach and noted that scaling strategies statewide takes longer. With strong legislative support and supplemental state funding, Washington’s rebalanced system has evolved over more than three decades with foundational programs related to caregiver assessment and respite initiated as local pilot efforts before scaling. Minnesota’s Live Well pilot programs are generally funded for three to five years, laying the foundation for subsequent incremental scaling, such as the Live Well screening assessment, which is now used statewide by the aging network and grantees. Funding from a coalition of external foundations has allowed the Maine Tri-State Learning Collaborative, now in its fourth year, to develop a strong base of grassroots stakeholders, a series of coordinated programming activities, and time to plan for long-term sustainability. Smaller-scale pilot testing of innovative approaches affords time to refine and perfect new delivery models and maximize successful deployment when expanding these programs statewide.

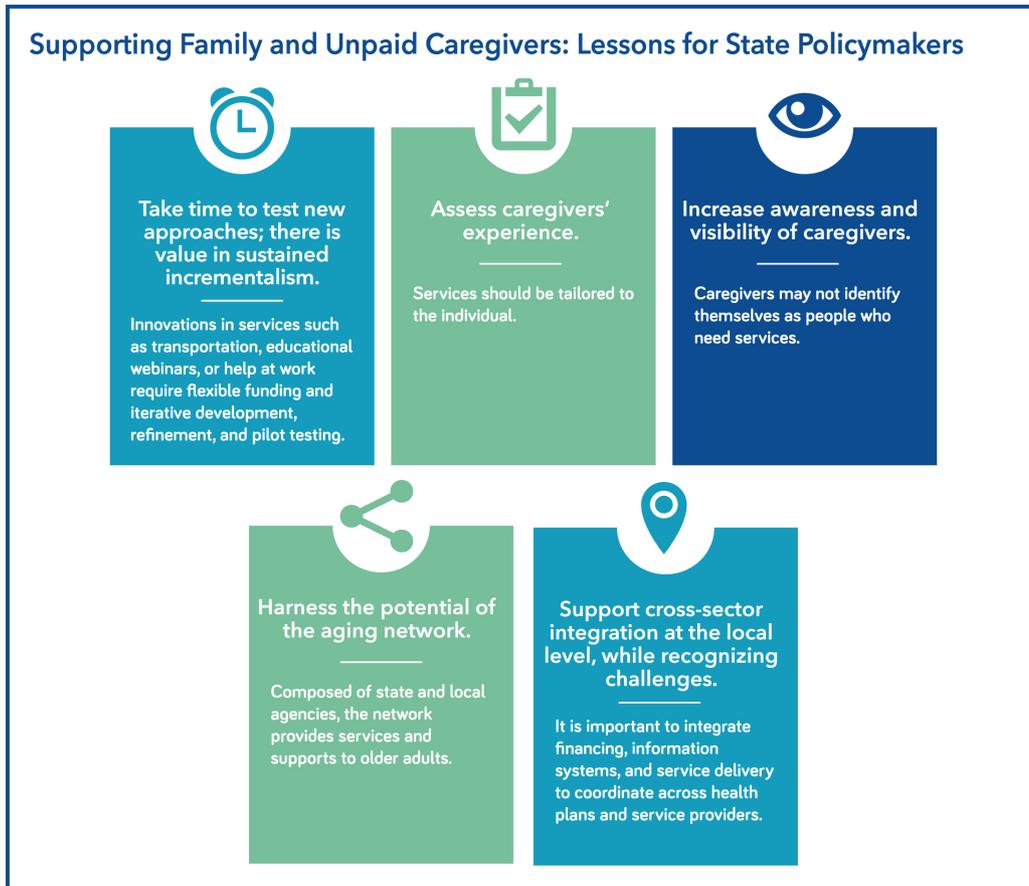
Assess caregivers’ experience. Caregiver assessment refers to a systematic process of gathering information from caregivers to understand their needs, strengths, and resources and how these factors affect care provision. Caregiver assessment recognizes that caregiving circumstances are highly diverse and that tailoring service interventions or initiating appropriate referrals requires an understanding of each individual situation. Assessing and addressing the needs of family caregivers serves as the basis of evidence-based, tailored intervention² and have been longstanding priorities in public policy.^{44,45} Although confusion regarding meaning, scope, and approach has historically impeded programmatic adoption,^{45,46} we found key informants were familiar with the concept and objectives of caregiver assessment. Each of the five states included elements of caregiver assessment within their aging network (Washington, Hawaii, and Minnesota) or Medicaid program (Hawaii, Maine, and Tennessee). Washington’s aging network stood out for its emphasis on the selection of an evidence-based caregiver assessment program and pursuing formal evaluation of the effects of deploying caregiver assessment at a systems level.⁴¹ Evidence that the use of statewide caregiver assessment delayed utilization of Medicaid long-term care services was identified as contributing to Washington’s Medicaid Alternative Care transformation initiative to support unpaid caregivers of at-risk individuals who are eligible for Medicaid but not using Medicaid-funded supports.⁴⁷

Increase awareness and visibility of caregivers. Caregiver lack of self-identification was widely stated as reducing use of supportive services among caregivers who might most benefit. Key informants reported that caregivers are generally most concerned with accessing services to benefit the person they assist and often are reticent to seek services on their own behalf. Prompted by this realization, Minnesota and Washington have adopted a statewide caregiver awareness campaign developed by the Amherst H. Wilder Foundation. The campaign seeks to increase self-identification by raising awareness of activities that constitute caregiving and transforming the ecosystem of support by reshaping discourse and promoting community collaboration and engagement.³⁶ Other state activities did not specifically involve a public awareness campaign but provided opportunities for convening and sharing of ideas, for example, through Maine's Tri-State Learning Collaborative. Hawaii's launch of Kupuna Caregivers received national media attention and was successful in generating statewide demand for support. While increasing awareness broadly aids in sustaining public and legislative support for family caregivers, targeting those most in need of services while effectively deploying scarce resources must be considered.

Support the aging network. Despite variability in the distribution of funded services and structure and strength of connections to service delivery organizations, the aging network was foundational to the success of innovative caregiver support programs in all five states we profiled. Key informants in each state discussed the deep knowledge and expertise that the aging network brings in addressing the unique needs, circumstances, and challenges of local communities. Although the aging network was acknowledged as being under-resourced, stakeholders commented on its pivotal role in supporting vulnerable subpopulations not eligible for Medicaid-funded services and in bolstering availability of services in rural areas and for hard-to-reach populations. For example, Washington has capitalized on the flexibility of the aging network to secure greater state funding to serve those at risk of Medicaid entry such as with the 1115 waiver authority.

Expect challenges in cross-sector integration. Key informants in all five states identified challenges in cross-sector integration of financing, information systems, and service delivery. In Washington and Minnesota, organizational co-location of the state unit on aging and Medicaid long-term support administration enabled efficiencies through coordinated staffing, which facilitated greater knowledge among staff about the range of service offerings and enabled the initiation of appropriate service referrals and care planning. Similarly, Tennessee's reliance on Area Agencies on Aging and Disabilities (AAADs) to conduct in-person functional and eligibility assessments for Medicaid, paired with regularly scheduled joint quarterly meetings between the AAADs and managed care plans staffs has helped ensure that MLTSS plans are familiar with the local service delivery environment and generate appropriate referrals for community services. Moving forward, efforts to bridge silos of care and promote higher-quality, higher-value care at the local level will require greater attention

to collaborative organizational, financial, and information systems, as well as local expertise to bridge variability in eligibility and available services for Medicaid and non-Medicaid clients.



Conclusion

This is a time of unprecedented population aging. The increases in life expectancy that allow more older Americans to actively participate in wide-ranging family, community, and professional endeavors are a great accomplishment. However, population aging is expected to exert a profound effect on the capacity of care delivery organizations and the budgets of federal and state government entitlement programs. As the leading edge of the baby boomers reach very old age in the decades to come, the numbers of older Americans living longer and requiring assistance with daily living will increase. Over the same period, the available pool of family members who are now the dominant source of assistance to community-dwelling older adults with disabilities is expected to contract.⁴⁸ There is a pressing

need for a more coherent, coordinated, and rational approach to addressing the needs of family caregivers.

States have been effective in their efforts to strengthen home- and community-based supports for older adults. This report finds that family caregivers are integral to such efforts. The states profiled in this report leveraged wide-ranging funding streams, organizational resources, programmatic expertise, and creative strategies to harmonize information, staff, and organizational infrastructure that were relevant to the geographical and cultural context of their state and local service delivery environments. Notable similarities were evident in the emphasis on investments to enhance home- and community-based long-term services and supports for populations that were at risk for institutionalization and/or Medicaid entry. In each of the states, successful efforts had been incrementally developed and refined, with a focus on sustainability. All of the states grappled with the necessity of prioritizing constrained resources and tradeoffs about programmatic objectives and outcomes for caregivers, older adults, and state and budgetary considerations.

This report focuses on state efforts to support family caregivers through long-term services and supports and social service programs, but its conclusions interrelate with a wider set of efforts to address the emotional, physical, and financial consequences of caregiving.⁴⁹ For example, the labor force impacts of caregiving and evidence of the benefits of longer and more generous workplace leave⁵⁰ have led to state and national paid family leave policy proposals gaining momentum.^{51,52} Evidence of the foundational role assumed by family caregivers in navigating health system demands has stimulated attention and efforts to more explicitly recognize, understand, and support family caregivers as partners in family-centered care delivery.² Families have been described as the primary social agent in the cultivation of health,⁴⁹ and efforts to support family caregivers are aligned with the broader movements to address nonmedical factors relating to the environments in which people live, work, and age.⁵³⁻⁵⁵ Conceptualizing and defining the success of coordinated population-based strategies to support the nation's caregiving families will be a critical element in policies to support aging Americans in the decades to come. Our report speaks to the important work being done by states in family caregiver support and the relevance of lessons for future policy directions on both the state and national scale.

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APPENDIX A: Key Informants

Hawaii

Caroline Cadirao

Program Specialist, Kupuna Caregivers
Hawaii State Department of Health

Madi Silverman

Project Director
Hawaii Department of Human Services/
Med-Quest Division

Maine

Elizabeth Gattine

Senior Policy Associate
University of Southern Maine
Muskie School of Public Service

Len Kaye

Director, Center on Aging
University of Maine

Betsy Sawyer-Manter

Chief Executive Officer
Maine AAA SeniorsPlus
EIM Care Coordination

Jessica Maurer

Executive Director
Maine Council on Aging

Louise Olsen

Research Analyst
University of Southern Maine
Muskie School of Public Service

Holly Zielinski

Chief Operating Officer
Maine AAA SeniorsPlus
EIM Care Coordination

Minnesota

Julie Angert

Research Analysis Specialist
Aging & Adult Services Division
Minnesota Department of Human Services

Mary Olsen Baker

Manager of Quality Assurance & Information
Unit
Minnesota Department of Human Services

Clancy Ferris

Family Caregiving Program Coordinator
Minnesota Department of Human Services

Tom Gossett

Testing Experience and Functional Tools
Grant Business Project Manager
Minnesota Department of Human Services

Jacqueline Peichel

State Program Administrator Manager
Minnesota Department of Human Services

Libby Rossett-Brown

Human Services Program Consultant
Minnesota Department of Human Services

Jeanine Wilson

Self-Directed Services Supervisor
Minnesota Department of Human Services

Tennessee

Aaron Bradley

Director
East Tennessee Area Agency on Aging and
Disability

Patti Killingsworth

Assistant Commissioner and Chief of
Long-Term Services and Supports
Tennessee Bureau of TennCare, Long-Term
Services and Supports

Dottie Lyvers

Special Projects Manager
East Tennessee Area Agency on Aging
and Disability

Lisa Pullem

CHOICES LTSS Program
East Tennessee Area Agency on Aging
and Disability

Washington**Susan Engels**

Office Chief, State Unit on Aging
Home & Community Services Division,
Aging & Long-Term Support Administration
Washington State Department of Social and
Health Services

Karen Fitzharris

Duals Director
Home & Community Services Division,
Aging & Long-Term Support Administration
Washington State Department of Social and
Health Services

Stacy Graff

Program Manager for Individual Providers
Home & Community Services Division,
Aging & Long-Term Support Administration
Washington State Department of Social and
Health Services

Hilari Hauptman

Caregiver Support Program Manager
Home & Community Services Division,
Aging & Long-Term Support Administration
Washington State Department of Social and
Health Services

Lorrie Mahar

Office Chief, Unit of Training, Communica-
tion, Development & Quality
Home & Community Services Division,
Aging & Long-Term Support Administration
Washington State Department of Social and
Health Services

Brad McFadden

Program Manager
Home & Community Services Division,
Aging & Long-Term Support Administration
Washington State Department of Social and
Health Services

Bea Rector

Director
Home & Community Services Division,
Aging & Long-Term Support Administration
Washington State Department of Social and
Health Services

APPENDIX B: Glossary and Acronyms

Access assistance is a service that navigates caregivers through the complex network of supports and services available to them.

Caregiver assessment is defined by the systematic process of gathering information about a caregiving situation to identify: 1) the specific problems, needs, strengths, and resources of the family caregiver, and 2) the ability of the caregiver to contribute to meeting the needs of the care recipient.

Counseling and training can include support groups, individual counseling, or training to perform caregiving-related tasks.

Information services include increasing public awareness of the types of caregiver resources available in each community or improving a local agency's website to provide accurate and up-to-date information.

Respite services are short-term breaks for caregivers where a paid or volunteer personnel assists with caregiving tasks in the home, community, or a specialized facility.

Supplemental services can be used to provide home modifications like raised toilet seats or grab bars, chore services, transportation, or emergency response technology.

AAA	Area Agency on Aging
CARE Act	Caregiver Advise Record and Enable Act
HCBS	Home- and community-based services
LTSS	Long-term services and supports
MLTSS	Managed long-term services and supports
NFCSP	National Family Caregiver Support Program
OAA	Older Americans Act
RAISE Act	Recognize, Assist, Include, Support, and Engage Family Caregivers Act
REST	Respite Education Support Tools
SUA	State Unit on Aging
TCARE	Tailored Caregiver Assessment and Referral

The Authors

Jennifer Afill is a research program coordinator at the Roger C. Lipitz Center for Integrated Health Care in the Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health. She earned her BA in public health and writing seminars from the Johns Hopkins University and works as a researcher to improve service delivery in primary care and medical oncology. Her research focuses on applied studies and policies directed at better supporting older adults and family caregivers within systems of care.

Julia Burgdorf is a PhD candidate in health services research at Johns Hopkins Bloomberg School of Public Health. Her research focuses on the intersection of family caregiving and home-based models of care for older adults, analyzing how these sources of care interact to determine outcomes and utilization. Ms. Burgdorf has previously worked as a researcher and consultant for post-acute and long-term care providers. She is a graduate of Cornell University.

Jennifer Wolff, PhD, is the Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management and director of the Roger C. Lipitz Center for Integrated Health Care at the Johns Hopkins Bloomberg School of Public Health. Dr. Wolff's research focuses on the care of older persons with complex health needs and disabilities and applied studies to better support them within systems of care delivery.