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EXECUTIVE SUMMARY FOR POLICYMAKERS

In Support of Family Caregivers: A Snapshot of Five States

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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.^{1,2} 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.³ We recognize that many Americans 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 and will be the focus of this report.

Facing the reality of caregiving today, states are building family caregiving into their service delivery systems—both to support caregivers and extend care to the aging population. This report gives the broad state policymaker audience insights into a handful of states that have advanced policies and programs in support of family caregivers.

Despite conceptual appreciation of the importance of recognizing and addressing the needs of caregiving families, little is known about best practices in state and federal policy.

At the federal level, lawmakers are paying attention. 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.

Fundamental to the success of such a national program will be the integration of evidence-based services and supports across health care organizations, social service agencies, and employers. However, a standalone 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.

States have long led the way in community-based innovations to support aging adults with disabilities and the families who are involved in their care. As states vary widely in demographic characteristics, legislative priorities, and service delivery environments, understanding how states have approached programmatic support for family caregivers could inform state and national policymaking in this area.

This report draws attention to what some states are doing—both with federal investments and state innovation—so that interested states can jump-start or learn from these efforts. The five states described here—Washington, Hawaii, Maine, Minnesota, and Tennessee—were selected because they were identified as having pursued unique policies and programs to better support family caregivers.

Key Components Found in All Five States

Important similarities were found in the motivation and approach of all five states in their work in support of family caregiving.

- Stakeholders in all states were motivated by the foundational role of family caregivers to achieve 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.

Common Themes and Considerations for State Policymakers

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 a given innovative approach and said that scaling strategies statewide takes longer. Smaller-scale pilot testing of innovative approaches affords time to perfect new delivery models before expanding these programs statewide.

- 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 at Home pilot programs are generally funded for a three- to five-year period, laying the foundation for subsequent incremental scaling, such as the Live Well screening assessment now used statewide by the aging network and grantees.
- Now in its fourth year, funding from a coalition of external foundations has allowed the Tri-State Learning Collaborative on Aging, which serves Vermont, New Hampshire and Maine, to develop a strong base of grassroots stakeholders, a series of coordinated programming activities, and time to plan for long-term sustainability.

Assess caregivers' experience. Caregiver assessment refers to a systematic process of gathering information from the caregiver 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 unique individual situation. Assessing and addressing the needs of family caregivers serves as the basis of evidence-based,

tailored intervention² and has been a longstanding priority in public policy.^{4,5} Although confusion regarding meaning, scope, and approach has historically impeded programmatic adoption,^{5,6} key informants in all of the states that were profiled 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.⁷ Evidence that the use of statewide caregiver assessment delayed utilization of Medicaid long-term care services was identified as contributing to Washington state'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.⁸

Increase awareness and visibility of caregivers. Caregiver lack of self-identification was widely stated as impeding use of supportive services. Key informants reported that caregivers are generally most concerned with accessing services to benefit the person they assist and, therefore, are reticent to seek services on their own behalf. While increasing awareness was a widely stated objective, stakeholders discussed the importance of targeting efforts to those most in need of services (e.g., through caregiver assessment) to ensure the efficient use of scarce resources.

- 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 mainstreaming caregiving through raising awareness of activities that constitute caregiving and transforming the ecosystem of support by reshaping discourse and promoting community collaboration and engagement.⁹
- Hawaii's launch of the Kupuna Caregivers Program received national media attention and was successful in generating statewide demand for support.

Other state activities did not specifically involve public awareness but provided opportunities for convening and sharing of ideas—for example, through the Tri-State Learning Collaborative on Aging.

Harness the aging network and support cross-sector integration of service delivery. Key informants in all five states identified challenges to integrating care across service delivery providers and settings. Efforts to bridge silos and promote higher-quality, higher-value care was recognized as requiring attention to a range of organizational and cultural factors, financing arrangements, and information systems, all of which vary considerably by state. Many stakeholders spoke to the value and importance of harnessing the local expertise and flexibility of the aging network.

Although the aging network was uniformly acknowledged as being under-resourced, stakeholders commented on its deep knowledge and expertise in the unique needs, circumstances, and challenges of local communities. In each of the states, the aging network was found to play an important role in supporting vulnerable subpopulations not eligible for Medicaid-funded services and in bolstering availability of services in rural areas and for other hard-to-reach populations.

- In Washington and Minnesota, organizational co-location of the state unit on aging and Medicaid long-term support administration enabled efficiencies through coordinated staffing by enhancing staff knowledge of service offerings and improving the efficiency and appropriateness of service referrals and care planning.
- 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 AAAD and managed care plan staffs has helped ensure that Medicaid's Managed Long Term Services and Supports are in sync with the local service delivery environment and generate appropriate referrals for community services.

Conclusion

This is a time of unprecedented population aging. The extension of life is a great accomplishment that has enabled more older Americans to actively participate and contribute to a wide range of family, community, and professional endeavors. However, population aging will also 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 number of older Americans with severe disability 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.¹⁰ There is a pressing need for a more coherent, coordinated, and rational approach to addressing the needs of caregiving families.

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 the state and local service delivery environment. 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 related to programmatic objectives and outcomes for caregivers, older adults, and state and budgetary considerations.

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 undertaken by states in the area of family caregiver support and the relevance of lessons for future policy directions on both the state and national scale.

Supporting Family and Unpaid Caregivers: Lessons for State Policymakers

- Take time to test new approaches; there is value in sustained incrementalism.**
Innovations in services such as transportation, educational webinars, or help at work require flexible funding and iterative development, refinement, and pilot testing.
- Assess caregivers' experience.**
Services should be tailored to the individual.
- Increase awareness and visibility of caregivers.**
Caregivers may not identify themselves as people who need services.
- Harness the potential of the aging network.**
Comprised of state and local agencies, the network provides services and supports to older adults.
- Support cross-sector integration at the local level, while recognizing challenges.**
It is important to integrate financing, information systems, and service delivery to coordinate across health plans and service providers.

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