



50 UNIFIED STATE STRATEGY

FEBRUARY 2021

FROM MOMENTUM TO MOVEMENT:

DEVELOPING A UNIFIED STRATEGY
TO SUPPORT FAMILY CAREGIVERS
ACROSS THE NATION

A PROJECT OF:



National Alliance for Caregiving

FOREWORD

By C. Grace Whiting, J.D., President and CEO, National Alliance for Caregiving

When the Founding Fathers debated the U.S. Constitution, the Tenth Amendment was added to bookend a heated debate on state versus federal powers. Plainly stated, the Tenth Amendment reinforced the “truism” that any powers not given to the federal government lay squarely with the U.S. states.*

Even today, and despite of the attention paid to Washington D.C. and its corresponding “inside-the-Beltway” chatter, it is the states – with the federal government – who manage the public health of the American people.** The global coronavirus pandemic in 2020 has made clear what those in our field have known for decades: when our public institutions fail to protect our health and wellbeing, it is the friend and family members who care for us that hold the line.

This report builds on the organizing principle that the family is the basic unit of society – and that society, in turn, must recognize and support family caregivers. The federal government has recognized this critical role of caregivers through its RAISE Family Caregivers Advisory Council, through the VA Caregiver Support Program, and through the use of Medicaid’s home- and community-based services waivers to provide self-directed care through a family caregiver. The global community has begun to recognize the role of caregivers, with global convenings by the World Dementia Council, the Global Coalition on Aging, and the International Alliance of Carer Organizations, among others.

Now is the perfect opportunity for individual states to take leadership – within the ecosystem of federal and global efforts – to continue to build momentum for caregiver supports. We believe that caregiving is core to the nation’s public health, and that states can learn from each other how best to support the diverse and dynamic population of more than 53 million family caregivers of people across the lifespan.

We hope that this report will catalyze your community to address caregivers’ needs and better support them as America ages. We also invite you to be partners in this movement—and encourage you to reach out to the NAC team at www.caregiving.org.

Kind regards,



C. Grace Whiting, J.D.
President/CEO

*See Linda R. Monk, “State Powers.” *Constitution USA with Peter Sagal*, PBS, available at <https://www.pbs.org/tpt/constitution-usa-peter-sagal/federalism/state-powers>; see also Steven Schwinn, “The ACA and the Tenth Amendment.” *SCOTUSblog* (August 2011), available at <https://www.scotusblog.com/2011/08/the-aca-and-the-tenth-amendment/>.

**See American Bar Association, “Two Centuries of Law Guide Legal Approach to Modern Pandemic.” *Your ABA April 2020*, available at <https://www.americanbar.org/news/abanews/publications/youraba/2020/youraba-april-2020/law-guides-legal-approach-to-pandemic/>.

ACKNOWLEDGMENTS

The National Alliance for Caregiving is proud to present “From Momentum to Movement: Developing a Unified Strategy to Support Family Caregivers Across the Nation”. This report and corresponding convenings were supported by funding from EMD Serono, Inc., and made possible through the contributions and direction of the following caregiving advocates and subject-matter experts.

Author

Karen L. Marshall, J.D., Director, Advocacy and Engagement, NAC

Contributing Editors

Michael Reese Wittke, M.P.A., Vice President, Research and Advocacy, NAC

C. Grace Whiting, J.D., President/CEO, NAC

Charlotte Davidson, Strategic Communications Manager, NAC

Lisa O’Neill, D.B.H., M.P.H., 2019–20 Health and Aging Policy Fellow, Clinical Assistant Professor, Medicine, Associate Director of Research & Education, University of Arizona Center on Aging

Lauren Tokarewich, M.L.S., Special Projects Associate, NAC

Project Advisors

Della Sanchez, LMSW, AL Cares Support for Caregivers, Coordinator, South Alabama Regional Planning Commission/Area Agency in Aging

Donna Benton, Ph.D., USC Leonard Davis School of Gerontology

Gary Simon, State President, AARP Hawaii

Pam Oliason, Program Specialist, Idaho Commission on Aging, Idaho Caregiver Alliance

Jennifer Eastman, M.B.A., MD Department of Disabilities, Maryland Commission on Caregiving Chair

Dorinda A. Adams, LMSW, State of Maryland Department of Human Services

Spencer Blalock, LCSW, Co-Chair, Mississippi Family Caregiver Coalition

Jane Mahoney, Greater Wisconsin Agency on Aging Resources, Wisconsin Governor’s Task Force on Caregiving



TABLE OF CONTENTS

| | |
|-----------|---|
| 02 | Acknowledgments |
| 02 | Foreword |
| 04 | Introduction |
| 05 | In A Nutshell: A Strategic Process And Core Policy Domains To Develop State Caregiving Plans |
| 06 | Aligning The Caregiving Policy Landscape |
| 08 | How System Barriers Impact America's Family Caregivers |
| 11 | A Better Way: Building On The Progress Of The Alzheimer's And Dementia Community |
| 13 | Addressing Caregiver Needs In The Midst Of A Global Pandemic |
| 13 | Methodology For Developing This Report |
| 14 | Global Policy Alignment |
| 15 | Federal Policy Alignment |
| 17 | Strategies To Advance A State Caregiving Plan |
| 20 | Inventory Of Existing State Caregiving Plans |
| 21 | Core Policy Domains For State Caregiving Strategies |
| 22 | Recommendation 1: Identify System-Wide Caregiver Entry Points And Utilize Assessments To Direct Access To Caregiver Services And Supports |
| 23 | Recommendation 2: Expand Caregiver Education And Training To Support Caregiver Well-Being |
| 24 | Recommendation 3: Support Financial Security And Caregiver-Friendly Workplaces |
| 26 | Recommendation 4: Expand Respite And Strengthen The Network Of Services Supporting Caregivers |
| 27 | Recommendation 5: Foster Person-And Family-Centered Care And Shared Decision-Making |
| 28 | State Caregiving Plan Case Studies |
| 28 | Developing a Plan for Alabama Caregivers |
| 29 | Developing a Plan for California Caregivers |
| 30 | Developing a Plan for Idaho Caregivers |
| 31 | Developing a Plan for Maryland Caregivers |
| 32 | Developing a Plan for Wisconsin Caregiver |
| 33 | Moving The Field Forward |
| 34 | The National Caregiver Advocacy Collaborative |

INTRODUCTION

More than 53 million people living in the United States care for a family member, friend, or neighbor with a health care need or functional disability. One of the biggest challenges facing these family caregivers¹ is coordinating care across siloed systems of support. Despite emerging efforts to align caregiving supports, a five year comparison of data from AARP and NAC shows that care coordination and maintaining personal health has become even more difficult for family caregivers.²

According to that research, a third (31 percent) of all caregivers of adults in 2019 reported it was “very difficult” or somewhat difficult” to coordinate care, compared to just 23 percent of all caregivers five years earlier. This difficulty is universal, across all age groups under 75, all genders, and all income groups, among other variables. Meanwhile, the 2019 data from NAC and AARP also shows that 23 percent of caregivers reported that “caregiving has made their health worse,” compared to 22 percent five years earlier.

Coordinating care while supporting the caregiver’s own health and well-being, across various pathways has reached a critical point as the COVID-19 pandemic has added new challenges to navigating various systems. Many caregivers report not having any access to respite care; others face an increasing threat of social isolation as existing emotional support structures shut down during the pandemic.³ Such outcomes are often heightened among caregivers who co-reside with their care recipients.⁴ Caregivers who do not live in the same household as their care recipient face issues related to gatekeeping, where they are excluded from shared or supported decision-making or must support a friend or family member over a tablet, telephone, or other communicative device.⁵

To address these needs, the National Alliance for Caregiving (NAC) has continued to build the case that caregiving is core to the nation’s public health. This report intends to align the work of state caregiving advocates with national efforts, such as the RAISE Family Caregivers Act, and global efforts from groups such as the International Alliance of Carer Organizations, the World Dementia Council, and public-private partnerships, such as the Embracing Carers initiative.

With input from family caregiving advocates in more than 21 states, and policy analysis of existing global, federal, and state efforts, this report recommends a process for developing state-level caregiving strategies, addresses core policy priorities in key person-centered domain areas, and offers case studies illustrating how to execute the process and adapt these strategies to address caregiver needs at the community level. The report is intended to guide states that have yet to form caregiving task forces, those that have newly formed caregiving task forces, and those that have existing state caregiving plans to collectively elevate caregiving policy priorities that contribute to a national infrastructure.

This effort articulates a unified caregiving strategy that aligns with global and national efforts to improve the lives of family caregivers with services and supports that aid caregiving across the lifespan. This is an emerging focus for the field of caregiving to bridge siloes and recognize caregiving not just as an eldercare or childcare issue, but rather as a lifelong process from infancy to older adulthood.⁶ This work aims to support the federal RAISE Family Caregiving Advisory Council’s mandate to identify actions that communities and other stakeholders can take in support of a national family caregiving strategy.⁷

¹National Alliance for Caregiving and AARP. (2020). *Caregiving in the United States 2020*. <https://doi.org/10.26419/ppi.00103.001>. Available at <https://www.caregiving.org/caregiving-in-the-us-2020/> and <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html>. For purposes of this report, the term family caregiver aligns with the RAISE Family Caregiver’s Act’s definition and refers to “an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation.” RAISE Family Caregivers Act of 2018, P.L. No: 115-119 (Jan. 22, 2018). However, it should be noted that in addition to adults, an estimated 3.4 million children under 18 may also have a caregiving role within their household. In the international context, the term “carer” is often used to refer to family caregivers.

²See note 1. See also National Alliance for Caregiving and AARP. (2015.) *Caregiving in the United States 2015*. Available at https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Executive-Summary-June-4_WEB.pdf.

³Liu, C., Fabius C.D., Howard, V.J., Haley, W.E., & Roth, D.L. (2020). Change in social engagement among incident caregivers and controls: Findings from the Caregiving Transitions Study. *Journal of Aging and Health*. <https://doi.org/10.1111/jgs.16726>. Rosalynn Carter Institute for Caregiving, October 2020. Available at <https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020-10-22-20.pdf>; The University of Pittsburgh. (2020, July). *Effects of COVID-19 on family caregivers: A community survey*. https://ucsur.pitt.edu/files/center/covid19_cg/COVID19_Full_Report_Final.pdf.

⁴Litwin, H., Stoeckel, K.J., & Roll, A. (2014). Relationship status and depressive symptoms among older co-resident caregivers. *Aging & Mental Health*, 18(2): 225-31. doi:10.1080/13607863.2013.837148.

⁵Wright, D.R. (2020). Memorandum regarding nursing home visitation - COVID-19. Centers for Medicare and Medicaid Service. <https://www.cms.gov/files/document/qso-20-39-nh.pdf>. Kent, E. E., Ornstein, K.A., & Dionne-Odom, J.N. (2020). The family caregiving crisis meets an actual pandemic. *Journal of Pain and Symptom Management*, 60(1): e66-e69. doi:10.1016/j.jpainsymman.2020.04.006.

⁶Administration for Community Living. (2018). *Administration for Community Living Supports for Family Caregiving Across the Lifespan*. Available at https://agid.acl.gov/Resources/DataOutputs/NFCSP_Brief.pdf.

⁷Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017, P.L. 115–119, 132 Stat. 23 (2018) (as amended by Pub. L. 116–131, title I, §122(b), (c), 134 Stat. 248 (2020)).

IN A NUTSHELL: A STRATEGIC PROCESS AND CORE POLICY DOMAINS TO DEVELOP STATE CAREGIVING PLANS

This report offers a six step strategic process to guide states that have not yet created a statewide strategy to support caregivers across the lifespan:

- 1** Establish and maintain a formally recognized task force of family caregiving stakeholders.
- 2** Assess the needs of family caregivers statewide as well as the availability and capacity of existing services and supports to address those needs.
- 3** Learn from the successes and challenges of other states.
- 4** Develop a statewide strategy (i.e., a plan) with specific policy recommendations addressing family caregivers' needs across the lifespan in key person-centered domain areas:



Caregiver Entry Points and Assessments



Caregiver Education, Training, and Well-being



Financial Security and Caregiver-Friendly Workplaces



Respite and Caregiving Service Delivery



Person- and Family-Centered Care/Shared Decision-Making

- 5** Engage stakeholders in the design, adoption, and ongoing evaluation of the implementation.
- 6** Establish measurable goals for implementing the state plan that will guide the periodic evaluation of plan progress and, as appropriate, modification of the plan over time.



This report is intended to serve as a tool to facilitate the engagement of family caregivers, caregiving advocates, lawmakers, and other public and private stakeholders.

ALIGNING THE CAREGIVING POLICY LANDSCAPE

The 20th century ushered in a focus on person- and family-centered health and social care models⁸ that provide patients and their families with choices over where and how services are provided. With movements by many states toward “consumer-directed” options for personal care services under Medicaid and grants to states from the Robert Wood Johnson Foundation to develop “Self Determination” and “Cash and Counseling” programs during the 1990s, as well as authority under the Deficit Reduction Act of 2005 and the Affordable Care Act of 2010, self-directed care options for Medicaid services emerged under state plans and waivers.⁹ Meanwhile, several decades of advocacy moved toward community-based models of care that would allow people to live independently and with dignity in their homes for as long as possible. The U.S. Supreme Court’s decision in *Olmstead v. L.C.* cemented this community-based movement toward more community-based care by requiring that states avoid unnecessary segregation of persons with disabilities and ensure that they receive services in the most integrated settings appropriate to their needs.¹⁰

As care delivery has increasingly shifted to include more non-institutional settings, family support with health and medical tasks has become more common and complex.¹¹ Medical/nursing tasks that were once limited to hospitals and nursing homes and performed by professionals are increasingly performed in the home with assistance from a family caregiver.¹² But, while family caregivers help improve patient outcomes and lower hospitalization rates,¹³ caregiving impacts—often negatively—fundamental facets of the individual caregiver’s life, including work, interpersonal relationships and social interactions, and mental and physical health.¹⁴

The intersection between caregivers’ individual needs and the public health needs of community members has given rise to the notion that family caregiving has potential health consequences that must be addressed in order to sustain the vital, foundational role that friends and families collectively play in health and social systems of care. At its core, a health and human services system that adequately sustains caregivers in promoting public health:

- expands caregivers’ access to services and supports;
- invests in evidence-informed caregiver research;
- protects caregivers’ financial security;
- includes caregivers as vital members of the health and human services system; and
- enhances caregivers’ health and well-being.¹⁵

Yet, the data suggests that many caregivers may take on this role without having adequate and affordable services and supports in place.¹⁶

As policymakers and advocates articulate policy recommendations to support caregivers globally, nationally, and at state and local levels, there is evolving attention towards bridging siloed systems to deliver long-term services and supports for care coordination across the lifespan.¹⁷ A unified strategy for establishing caregiver support infrastructure, similar to the successful support infrastructure for Alzheimer’s and dementia care established through passage of the National Alzheimer’s Project Act and BOLD Act, is needed to coordinate efforts and to support the caregiving role across the nation and the lifespan.



⁸Jolley, J., & Shields, L. (2009). The evolution of family-centered care. *Journal of Pediatric Nursing* 24(2), 164-70. doi:10.1016/j.pedn.2008.03.010; Rawson, J. & Moretz, J. (2016) Patient- and family-centered care: A primer. *Journal of the American College of Radiology* 13. doi.org/10.1016/j.jacr.2016.09.003.

⁹The Self-Determination programs evolved into Medicaid-funded home community-based services waiver programs, while the Deficit Reduction Act authorized the home and community-based services and self-directed personal assistance services state plan options, and the Affordable Care Act authorized the “Community First Choice” state plan option. *Self Directed Services. Centers for Medicare and Medicaid Services.* Last visited 11/30/2020 at <https://www.medicare.gov/medicaid/long-term-services-supports/self-directed-services/index.html>.

¹⁰United States Department of Justice, Civil Rights Division. *Olmstead: Community integration for everyone. Americans with Disabilities Act.* Last visited 11/30/2020 at <https://www.ada.gov/olmstead/>.

¹¹National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America.* The National Academies Press. <https://doi.org/10.17226/23606>.

¹²Reinhard, S. & Feinberg, L. (2015). *The escalating complexity of family caregiving: Meeting the challenge.*

¹³Skufkal, L. (2019, February). *Primary care providers’ experiences with family caregivers.* AARP Research. <https://doi.org/10.26419/res.00273.001>.

¹⁴See note 9.

¹⁵National Alliance for Caregiving Core Advocacy Principles. Available at: <https://www.caregiving.org/advocacy/>.

¹⁶See note 1.

¹⁷Roman, Courtney, et.al. *Strengthening Family Caregiving Programs and Policies through Collaboration: Lessons from Six States.* Center for Health Care Strategies. September 2020. Available at: https://www.chcs.org/media/FCG-Brief_092820_FINAL.pdf.

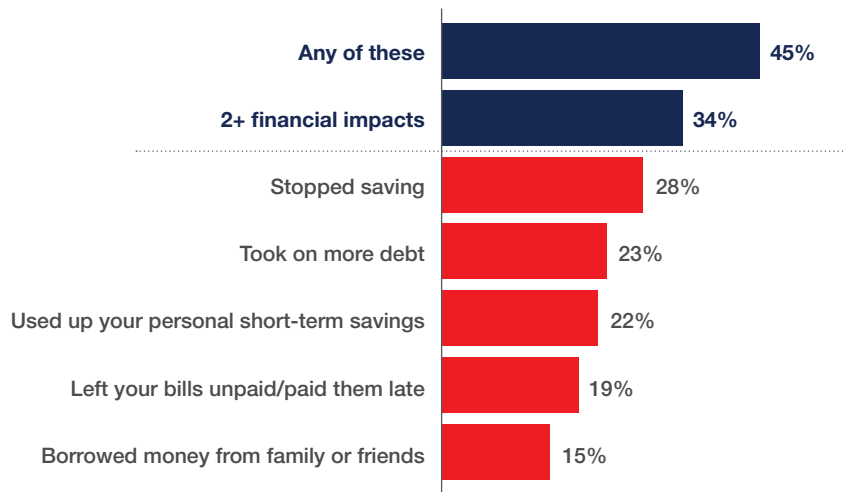
How Providing Care Impacts Caregivers' Financial Security

The economic effects of family caregiving can result in financial strain with substantial short- and long-term financial consequences across demographic groups.¹⁸ Data from AARP shows that 78 percent of caregivers incur out-of-pocket expenses related to caregiving.¹⁹ Family caregivers may cover these out-of-pocket expenses, which average \$7000 per year,²⁰ by incurring more debt or diminishing or exhausting short- or long-term savings. At the same time, caregiving may impact their capacity to work, potentially resulting in lost income and lost credit toward Social Security retirement benefits.

About half of caregivers have experienced at least one financial impact as a result of caregiving and over one-third of caregivers have two or more financial impacts, such as stopping or exhausting short- or long-term savings or taking on more debt.²¹ Most commonly, 28 percent of caregivers have stopped saving, while 23 percent have taken on more debt. Both financial impacts could have longer-term repercussions on caregivers' financial security, especially if the caregiving situation lasts a long time. Caregivers ages 18 to 49 report 2.1 financial impacts, on average, which is more than those ages 50 to 64 (1.5) who, in turn, report more impacts than caregivers ages 65 and older. One out of three caregivers ages 50 to 64 report dipping into savings, which could jeopardize their long-term financial security since they will have less opportunity to build savings as they approach their retirement years.

Caregiving in the U.S. 2020: Top Financial Impacts as a Result of Caregiving

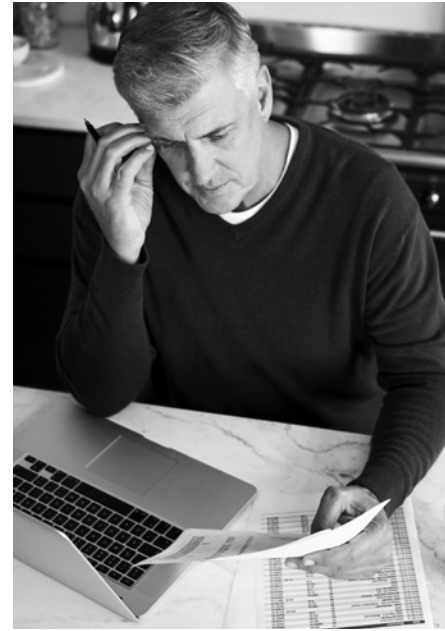
As a result of providing care to your [relation], have you ever experienced any of these financial things?



2020 Base: Caregivers of Recipient Age 18+ (n=1392)

Note: Respondents may select more than one response; results add to great than 100 percent.

National Alliance for Caregiving and AARP. Caregiving in the United States 2020. Washington, DC: NAC and AARP. May 2020. <https://doi.org/10.26419/ppi.00103.001>. Available at <https://www.caregiving.org/caregiving-in-the-us-2020/> and <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html>.



Data from AARP shows that 78 percent of caregivers incur out-of-pocket expenses related to caregiving.¹⁹

¹⁸See note 1.

¹⁹Rainville, Chuck, et al. Family Caregivers Cost Survey: What They Spend & What They Sacrifice: Family Caregiving and Out-of-Pocket Costs: 2016 Report. AARP. November 2016. Available at: https://www.aarp.org/content/dam/aarp/research/surveys_statistics/tc/2016/family-caregiving-costs.doi.10.26419-2Fres.00138.001.pdf

²⁰See note 19.

²¹See note 1.

Although caregivers are not necessarily gaining financial ground against out-of-pocket caregiving costs, most caregivers' time is stretched between caregiving and employment. Sixty-one percent of caregivers are employed while also caregiving. The majority (61 percent) have also experienced at least one work-related impact, such as going in late, taking time off to accommodate care, or leaving the workforce. Caregivers increasingly report having workplace benefits, such as paid family leave (39 percent in 2020, up from 32 percent in 2015) and paid sick days (58 percent in 2020, up from 52 percent in 2015), which is likely an effect of a greater number of large employers and state and local governments taking action on paid leave.²² But, while 39 percent of caregivers report being salaried, over half of employed caregivers are paid hourly. Caregivers paid hourly more often report lower incomes, fewer workplace benefits, and working fewer hours than salaried caregivers.

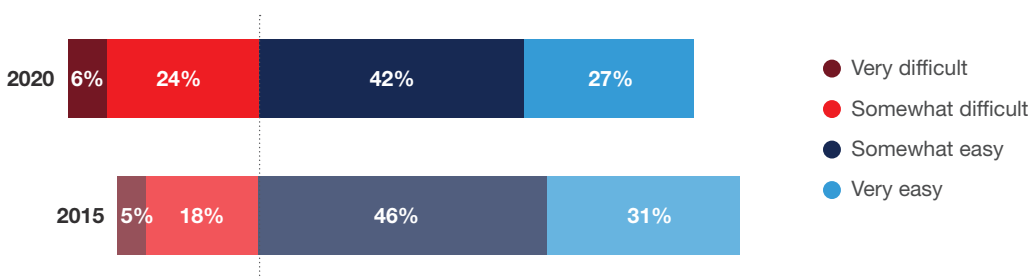


When caregivers experience work-related impacts, they more often face financial impacts (2.9 on average) and are twice as likely to report high financial strain (35 percent). Research shows that without adequate supports to defray the costs of care, caregivers are straining to balance the financial consequences of caregiving with supporting the nation's system of long-term services and supports.²³

Most caregivers' time is stretched between caregiving and employment.

Caregiving in the U.S. 2020: Ease of Coordinating Care

(If responsible for coordinating) Please think about all of the health care professionals or service providers who give/gave care or treatment to your [relation]. How easy or difficult is/was it for you to coordinate care between those providers?



2020 Base: Caregivers Involved in Care Coordination for Recipient Age 18+ (n=1200)

2015 Base: Caregivers Involved in Care Coordination for Recipient Age 18+ (n=1042)

Note: Respondents are rounded and don't know/refused responses are not shown; results may not add up to 100 percent.

National Alliance for Caregiving and AARP. Caregiving in the United States 2020. Washington, DC: NAC and AARP. May 2020. <https://doi.org/10.26419/ppi.00103.001>. Available at <https://www.caregiving.org/caregiving-in-the-us-2020/> and <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html>.

²²National Alliance for Caregiving and AARP. (2020). Executive Summary Caregiving in the United States 2020. <https://doi.org/10.26419/ppi.00103.001>. Available at https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Executive-Summary-June-4_WEB.pdf.

²³See note 22.

²⁴See note 1.

HOW SYSTEM BARRIERS IMPACT AMERICA'S FAMILY CAREGIVERS

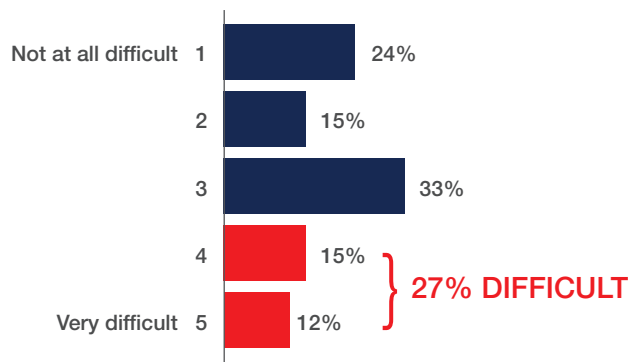
For many family caregivers, the challenges navigating health and long-term service and support systems in the United States have become increasingly difficult.²⁴ Compared to research conducted in 2015, caregivers in 2020—before the pandemic—had at least some difficulty in coordinating care between various providers.

Nearly a third of caregivers of adults find it difficult to find affordable services in their community, such as delivered meals, transportation, or in-home health services that could help them with care. Since 2015, women in particular and those who care for someone more than 21 hours a week find it increasingly hard to find support services. Those in rural areas, those between 18 and 49, and those in the same household as the person receiving care also tend to have a harder time finding services, especially those that are affordable. Likewise, caregivers managing medical complexity—such as in high-intensity care situations or when caring for someone with a mental/behavioral health issue—often report higher difficulty getting the help that they need.



Caregiving in the U.S.: Affordability of Services in Recipient's Area

How difficult is/was it to get affordable services in your [relation]'s local area or community that could help/would have helped you care for your [relation], like delivered meals, transportation, or in-home health services?



2020 Base: Caregivers of Recipient Age 18+ (n=1392)

Note: Respondents are rounded and don't know/refused responses are not shown; results may not add up to 100 percent.

National Alliance for Caregiving and AARP. Caregiving in the United States 2020. Washington, DC: NAC and AARP. May 2020. <https://doi.org/10.26419/ppi.00103.001>. Available at <https://www.caregiving.org/caregiving-in-the-us-2020/> and <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html>.

A majority of caregivers also reported needed more training and information (62%). Topics of interest include help keeping the person in their care safe at home (26%), help managing the caregiver's own stress (26%), and help with managing forms, paperwork, and service eligibility (25%). While more than half of caregivers go to a doctor or health professional first for sources of help or information (55%), many also rely on government agencies (19%), the Internet or social media (19%), or nonprofits working in aging, caregiving, or other social services (14%). One in five "never got help or information" (20%) that they needed to support themselves or the person in their care.

Nearly a third of caregivers of adults find it difficult to find affordable services in their community, such as delivered meals, transportation, or in-home health services that could help them with care.

These research findings are not surprising, given the fragmented federal landscape to provide services to caregivers:

| GOVERNMENT PROGRAM | PROGRAM FUNCTION | NUMBER OF CAREGIVERS SUPPORTED |
|---|---|---|
| National Family Caregiver Support Program (NFCSP), Older Americans Act (OAA) | <p>NFCSP grantees provide five types of services to caregivers of adults:</p> <ul style="list-style-type: none"> • information to caregivers about available services; • assistance to caregivers in gaining access to the services; • individual counseling, organization of support groups, and caregiver training; • respite care; and • supplemental services, on a limited basis. | <p>700,000 Caregivers</p> <p>Based on FY2014 service data (the most recent year available)</p> |
| RAISE Family Caregiving Advisory Council, Administration for Community Living, HHS | <p>The RAISE Council, under the leadership of the Secretary for Health and Human Services, will develop a national family caregiving strategy. The strategy will identify actions that communities, providers, the government, and others are taking and may take to recognize and support family caregivers.</p> | <p>N/A – No direct impact on caregivers as this is a strategic initiative.</p> |
| Lifespan Respite Care Program | <p>The Lifespan Respite Care program gives competitive grants to agencies to provide a coordinated system of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs.</p> | <p>Data unclear; competitive grants of up to \$200,000 have been awarded to 37 states and DC as of 2018.</p> |
| VA Caregiver Support Program, U.S. Department of Veterans Affairs | <p>The U.S. Department of Veterans Affairs (VA) provides two caregiver programs: The Program of General Caregiver Support Services for caregivers of Veterans of all eras, and the Program of Comprehensive Assistance to Family Caregivers for those caring for eligible Veterans with service-connected conditions.</p> | <p>Between 2010 and 2018, roughly 37,000 caregivers received services.</p> |
| Medicare Program, Center for Medicare and Medicaid Services, Health and Human Services | <p>Medicare Advantage plans may have a respite care benefit available to caregivers to give them a break from supporting activities of daily living. Under the Special Supplemental Benefits for the Chronically Ill program, plan benefits may also include access to companion care, marital counseling, family counseling, paid caregivers of children, or programs that can help address isolation and improve emotional and/or cognitive function. Under Traditional Medicare, some CPT (or “billing”) codes may allow a provider reimbursement for services provided to a family caregiver.</p> <p>In general, all of the services are for the benefit of the Medicare beneficiary or patient – the caregiver is a secondary beneficiary, creating potential fraud and abuse issues for Medicare providers per guidance at the Office of Inspector General.</p> | <p>Unclear; family caregivers are not clearly delineated in the Medicare claims data.</p> |
| Medicaid Program, Center for Medicare and Medicaid Services, Health and Human Services | <p>Caregivers may be eligible to participate in the self-directed care program and receive financial support for care provided through the Home and Community Based Waiver Programs under section 1915 (various). HCBS waiver programs are for the benefit of the Medicaid beneficiary or patient, meaning that the caregiver’s role is to support patient outcomes rather than address their own needs.</p> | <p>Unclear; family caregivers are not clearly delineated in the Medicaid claims data.</p> |
| Employer Best Practices, Various Federal, State/ Local Laws | <p>Guidance from EEOC (Equal Employment Opportunity Commission) that covers best practices and discrimination related to family responsibilities discrimination includes both parental leave, eldercare, and caring for people with disabilities; this guidance summarizes a number of federal laws that may impact caregivers at work.</p> | <p>Unclear, as there is currently no systematic way to capture the impact of workplace programs on family caregivers.</p> |

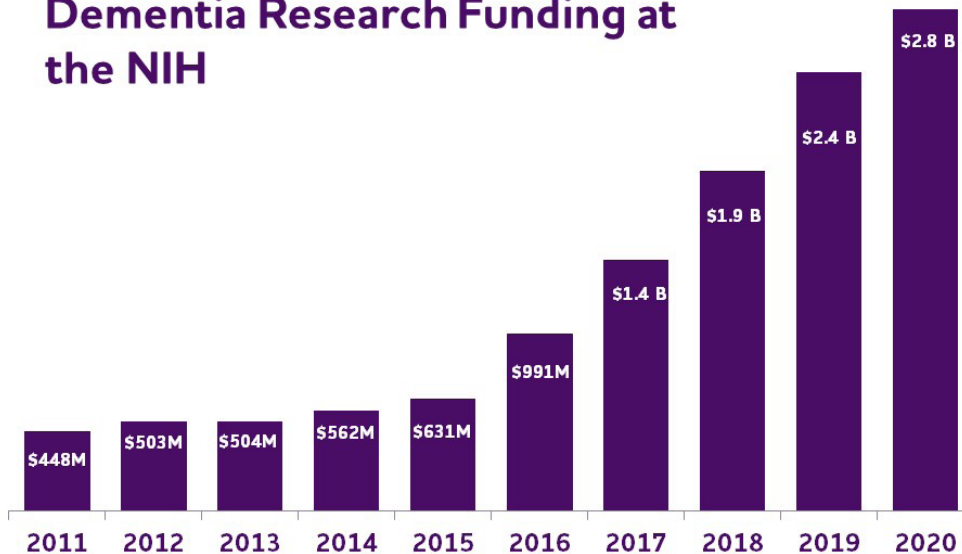
A BETTER WAY: BUILDING ON THE PROGRESS OF THE ALZHEIMER'S AND DEMENTIA COMMUNITY

After fragmented efforts to tackle Alzheimer's and related dementias, patient advocates, caregivers, researchers, policymakers, and others came together to spur the passage of the National Alzheimer's Project Act (NAPA) in 2011.²⁵ Following its mandate to establish the National Alzheimer's Project and create and maintain an integrated national plan to overcome Alzheimer's disease. In May 2012, the U.S. Department of Health and Human Services (HHS) unveiled the initial National Plan to Address Alzheimer's Disease.²⁶ This plan galvanized advocates, researchers, and others to work towards the goal of preventing and effectively treating Alzheimer's disease by 2025 and focused ongoing efforts to improve research funding to make this possible.

Building on milestones created in the federal plan, advocates pushed for more than \$2 billion in new funding for research and dementia care support at the National Institutes of Health. Funding reached \$2.4 billion by 2019, less than ten years after the implementation of the initial national plan.²⁷



Alzheimer's and Related Dementia Research Funding at the NIH



See Alzheimer's and Dementia Research. Alzheimer's Impact Movement (AIM), Alzheimer's Association. Last Accessed 10/28/20 at <https://alzimpact.org/issues/research>.

Yet, these efforts did not happen in isolation. The national efforts to address the needs of the Alzheimer's and related dementia community built on corresponding state and global efforts. Notably, the Centers for Disease Control and Prevention launched a public health approach to dementia as described in the Healthy Brain Initiative Road Map Series.²⁸ The initial Healthy Brain Initiative road map was published in 2007²⁹; additional public efforts have continued since the initial road map, including the most recent conceptual framework to guide state and local public health partnerships to tackle dementia from 2018-2023 and the corresponding Road Map for Indian Country.²⁹

The national efforts to address the needs of the Alzheimer's and related dementia community built on corresponding state and global efforts.

²⁵National Alzheimer's Project Act. P.L. 111-375. January 4, 2011. Available at <https://www.congress.gov/111/plaws/pub/375/PLAW-111pub375.pdf>.

²⁶See Office of the Assistant Secretary for Planning and Evaluation (ASPE), National Alzheimer's Project Act (NAPA), at <https://aspe.hhs.gov/national-plans-address-alzheimers-disease>.

²⁷See Alzheimer's and Dementia Research. Alzheimer's Impact Movement (AIM), Alzheimer's Association. Last accessed 10/28/20 at <https://alzimpact.org/issues/research>.

²⁸"Road Map for State and Local Public Health." Alzheimer's Disease and Healthy Aging Program. Centers for Disease and Control Prevention (CDC). Last accessed 10/28/20 at <https://www.cdc.gov/aging/healthybrain/roadmap.htm>.

²⁹Centers for Disease Control and Prevention and the Alzheimer's Association. (2007). *The healthy brain initiative: A national public health road map to maintaining cognitive health*. Alzheimer's Association. <https://www.cdc.gov/aging/pdf/TheHealthyBrainInitiative.pdf>.

³⁰Alzheimer's Association and Centers for Disease Control and Prevention. (2018). *Healthy brain initiative, state and local public health partnerships to address dementia: The 2018-2023 road map*. Alzheimer's Association. <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>.

National public health initiatives were informed by the work of global advocates, such as the World Dementia Council when it convened for the G8 Dementia Summit in London in December 2013. This global convening resulted in a declaration of G8 nations to create a multi-national response to dementia in a shared commitment to accelerate efforts to find effective treatments and cures for the disease. Global partners set the goal of identifying a cure or disease-modifying medicine for dementia by 2025, a milestone that was adopted by the U.S. in its national Alzheimer's plan. As described by the World Dementia Council, the global commitment shaped national efforts, including the United Kingdom's efforts to establish the Dementia Discovery Fund and global efforts, such as the World Health Organization's focus on dementia beginning in 2015 and culminating in the WHO Global Action Plan on the Public Health Response to Dementia in 2017.



Just as the global plan informed national efforts, state efforts to address Alzheimer's disease and related dementia informed best practices for the federal plan. In partnership with the Alzheimer's Foundation of America, NAC identified core components of state Alzheimer's plans and provided cases studies to inform the ongoing creation of state Alzheimer's plans in a 2014 white paper, *From Plan to Practice: Implementing the National Alzheimer's Plan in Your State*.³³ As described in the paper, state plans are a core component of an effective, coordinated public health response:

"Successful state plans need consistent efforts to be effective, including keeping stakeholders engaged and oversight to ensure implementation of plan recommendations and action steps. In addition, state plans need to be frequently revisited to measure progress and consider new recommendations that identify gaps in plans.

All plans, including those already in motion, should articulate performance metrics to ensure actions steps are fulfilled and the plan is progressing. If the plan is not effective, states should determine how to modify the implementation, or even the plan if need be. **In short, state plans must be living documents where progress is constantly being measured and recommendations are continually updated.**

For states that have not yet implemented plans, even simple plans, such as coordinating state and local resources and targeting services, can have a profound positive impact on the community. For example, dementia training for first responders will ensure greater degrees of community safety during emergencies or national disasters that could require evacuations of vulnerable populations in nursing homes, assisted living residences or hospitals.

Adoption of a state plan will galvanize stakeholders and allow them to hold state and local officials accountable for implementation of recommendations and achieving certain benchmarks. Advocates for family caregivers and direct care providers can use the state plan to motivate state and local policymakers to effectuate legislation and regulation that enhance access to care services while removing barriers to implementation of innovative care models."

In fact, since 2007, a majority of states (49), the District of Columbia, and Puerto Rico have published State Alzheimer's Plans. These state plans offer several advantages in mounting a response to the threat of Alzheimer's disease and related dementias, by galvanizing state legislatures and state agencies to address the needs of local communities, by establishing accountability for policymakers and by identifying opportunities for advocates to address state-specific needs.³⁴

State plans are a core component of an effective, coordinated public health response.

³¹See "History." World Dementia Council: *Leading the Global Action Against Dementia*. Available at <https://worlddementiacouncil.org/about-us/history>.

³²See World Health Organization. *Global Action Plan on the Public Health Response to Dementia, 2017 – 2025*. ISBN: 978-92-4-151348-7. Available at https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/.

³³National Alliance for Caregiving and Alzheimer's Foundation of America. (2014, July). *From Plan to Practice: Implementing the National Alzheimer's Project Act*. <https://www.caregiving.org/wp-content/uploads/2014/10/AlzheimersStatePlans-7-21-14.pdf>.

³⁴Alzheimer's Impact Movement. (2020, March). *Fact sheet: State Alzheimer's disease plans*. Alzheimer's Association. Last Accessed 10/28/20 at <https://alzimpact.org/media/serve/id/5d23af19258fb>.

ADDRESSING CAREGIVER NEEDS IN THE MIDST OF A GLOBAL PANDEMIC

This report builds upon NAC's efforts, including its role as Secretariat for the International Alliance of Carer Organizations (IACO), its work to align the caregiving community through engagement with the RAISE Family Caregiving Advisory Council, and its 2019 Annual Conference of Caregiver Advocates to help unify caregiver advocates representing various jurisdictions under a common strategy for recognizing and supporting family caregivers' diverse needs. This report further builds on that work by developing a model family caregiving strategy aligned with key global, national, state, and local caregiving health and social care priorities.

The COVID-19 pandemic has rendered the need to address family caregiving from a public health perspective more relevant and more important than ever. The pandemic has amplified the vital roles family caregivers play in supporting the continuity of care outside of traditional health and long-term care settings,³⁵ as well the challenges they face in ensuring that continuity in the absence of a national caregiver support infrastructure across the lifespan. Caregiver responses to community surveys on the impacts of the pandemic reveal that they are experiencing increased emotional stress, caregiving responsibilities, job and financial insecurity, while also receiving less support in their roles.³⁶ Now is the time to align and leverage the work of policymakers and caregiving advocates occurring globally, nationally, and at the state and community levels to strengthen and expand such infrastructure to support caregivers.

Following examples of strategies that have been translated into public health support infrastructures or formally articulated into policy priorities globally, nationally, or at the state level, this report offers a common framework to help address the needs of caregivers. Developed in consultation with state and local caregiving advocates across the nation, the following framework advances a unified strategy to address caregiving across the lifespan by (i) identifying family caregiving policy priorities across core person-centered domain areas to be adapted to address community-level needs, and (ii) presenting a process, with state case studies, to guide states in establishing and building upon statewide, formal plans aimed at anchoring a nationwide caregiver support infrastructure.

METHODOLOGY FOR DEVELOPING THIS REPORT

Building upon discussions about the economic and health impacts of family caregiving on society-at-large at NAC's 2017 National Conference of Caregiver Advocates, NAC's 2018 white paper, *From Insight to Advocacy: Addressing Family Caregiving as a National Public Health Issue*³⁷, urged caregiver advocates, health systems, and policymakers to consider the public health implications of caregiving. Ninety-seven percent of primary care providers agree that family caregivers play a significant role in patient care, leading to improved patient outcomes, lower hospital readmission rates, and higher patient satisfaction.³⁸ When supported with policies such as paid family leave that make it easier to take time off from work, caregivers may also help reduce nursing home utilization, and thereby Medicaid spending, according to a 2017 study.³⁹ Although there is increasing acknowledgement of the positive impacts of family caregivers' knowledge-sharing on patient outcomes in health care systems and the estimated \$470 billion economic value of their unpaid contributions to the system of long-term services and supports, the value they bring to these systems can come at the expense of their own physical, emotional, and financial health.⁴⁰ Caregivers' continued ability to fill the growing gap between the number of individuals requiring care and the number of individuals (including health care professionals) available to provide that care depends on how they are integrated in formal care systems and supported in their roles.⁴¹

The pandemic has amplified the vital roles family caregivers play in supporting the continuity of care outside of traditional health and long-term care setting.

³⁵Wong-Cornall, C., Parsons, J., Sheridan, N., Kenealy, T., & Peckham, A. (2017). Extending "continuity of care" to include the contribution of family carers. *International Journal of Integrated Care*, 17(2):11. doi:10.5334/ijic.2545.

³⁶See note 4.

³⁷National Alliance for Caregiving. (2018, January). *From insight to advocacy addressing family caregiving as a national public health issue*. https://www.caregiving.org/wp-content/uploads/2020/05/From-Insight-to-Advocacy_2017_FINAL.pdf.

³⁸Skufca, L. (2019, February). Primary care providers' experiences with family caregivers. *AARP Research*. <https://doi.org/10.26419/res.00273.001>.

³⁹Arora, K. & Wolf, D.A. (2018). Does paid family leave reduce nursing home use? The California experience. *Journal of Policy Analysis and Management*, 37(1), 38-62. www.doi.org/10.1002/pam.22038.

⁴⁰In 2017, the estimated economic value of the care provided by unpaid family and friends in the U.S. was approximately \$470 billion, exceeding total out-of-pocket spending on health care and total Medicaid spending on long-term services and supports. Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019, November). *Valuing the invaluable 2019 update: Charting a path forward*. Washington, DC: AARP Public Policy Institute, available at www.aarp.org/valuing.

⁴¹National Academies of Sciences, Engineering, and Medicine. 2016. *Families caring for an aging America*. Washington, DC: The National Academies Press. doi: 10.17226/23606.

In 2020, NAC convened its National Caregiver Advocacy Collaborative, a network of state and national interdisciplinary leaders, experts, and influencers dedicated to building upon shared experiences and expertise to improve the lives of family caregivers.⁴² Using core goals driving international policy discussions and specific actions to be taken in the federally-mandated development of a national caregiving strategy, the Collaborative prioritized person-centered policy domains that should form the foundation of a unified strategy to guide the development of formal caregiving plans in each state. NAC then convened a group of state-level advocates involved in the development of and/or implementation of existing statewide caregiving plans that were officially mandated or endorsed by resolution to obtain insight on how these groups convened their task forces, as well as the specific policy recommendations they developed for their communities under each domain area. These insights were reported back to the Collaborative in periodic meetings and webinars focused on specific policy domains in order to obtain further input in developing this guidance.



In addition to the lived experiences of family caregivers and insights from caregiving advocates, this project also reviewed and identified additional initiatives on the global and federal levels to address the growing need of family caregivers. These initiatives are summarized below.

GLOBAL POLICY ALIGNMENT

In 2017, the International Alliance of Carer Organizations (IACO), a multinational coalition working to build a global understanding and respect for the vital role of carers,⁴³ partnered with the Embracing Carers™ movement, a global initiative to recognize caregivers' role in the health ecosystem, to describe common policy goals across nations. The resulting *2017 Carer Report: Embracing the Critical Role of Caregivers Around the World* identified four core aims for supporting unpaid carers, including “activating policy by identifying and advancing legislative action among policymakers, governments and international public health organizations.”⁴⁴

The National Caregiver Advocacy Collaborative prioritized person-centered policy domains that should form the foundation of a unified strategy to guide the development of formal caregiving plans in each state.

To further facilitate policy discussions among advocates around the world, IACO published a blueprint to address the needs of unpaid carers through:⁴⁵



Legislation



Financial support



Working arrangements



Pension credits



Respite care



Information and training

⁴²National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. The National Academies Press. <https://doi.org/10.17226/23606>.

⁴³International Alliance of Carer Organizations. *Fostering international action for carers*. Last accessed 10/29/2020 at https://internationalcarers.org/about-us/carers/media/infographics/us/Merck%20GaA%20Embracing%20Carers_White%20Paper%20Flattened.pdf.

⁴⁴Embracing Carers. (2017, October). *Carer report: Embracing the critical role of caregivers around the world*. https://www.embracingcarers.com/content/dam/web/healthcare/corporate/embracing-carers/media/infographics/us/Merck%20GaA%20Embracing%20Carers_White%20Paper%20Flattened.pdf.

⁴⁵International Alliance of Carer Organizations. *Global state of care*. Last accessed 10/28/2020 at <https://internationalcarers.org/wp-content/uploads/2018/11/IACO-EC-GSoC-Report-FINAL-10-20-18-.pdf>

FEDERAL POLICY ALIGNMENT

On the national level, bipartisan efforts have emerged to recognize and support family caregivers' and their families' needs over the past decade. In addition to the legislation outlined below, the current and two most recent presidential administrations have prioritized expansion of services and supports that help caregivers. In 2011, Centers for Medicare and Medicaid Services (CMS) defined Medicaid's home and community setting criteria for services and supports delivered under the Community First Choice State Plan Option authorized under the Affordable Care Act of 2010.⁴⁶ In 2020, the Department of Veterans Affairs launched the expansion of the Program of Comprehensive Assistance for Family Caregivers (PCAFC) to caregivers of eligible Veterans of earlier eras pursuant to the VA Mission Act of 2018.⁴⁷ As of 2021, presidential priorities related to caregiving are expected to include a proposed \$775 billion caregiving plan aimed at improving delivery of home- and community- based care, strengthening the caregiving workforce and establishing tax and Social Security credits for unpaid family caregivers, among other initiatives.⁴⁸



The RAISE Family Caregivers Act of 2018

Congress acted in 2017 to identify measures that government, communities, and providers—among other stakeholders—may take to recognize and support family caregivers across the U.S. **The Recognize Assist Include Support and Engage (RAISE) Family Caregivers Act of 2018**⁴⁹ directed the Secretary of Health and Human Services (HHS) to establish a Family Caregiving Advisory Council.

The RAISE Family Caregiving Advisory Council is charged with supporting the development and execution of a national caregiving strategy with recommendations to promote the following actions:

- Promoting greater adoption of person- and family-centered care in all health care and long-term service and support settings, with the person and the family caregiver at the center of care teams
- Involving care recipients and family caregivers in assessment and service planning (including care transitions and coordination)
- Expanding information, education, training supports, referral, and care coordination
- Increasing respite options
- Improving financial security and workplace issues.

The Council is comprised of members representing family caregivers, older adults with long-term services and support needs, individuals with disabilities, health care and social service providers, long-term services and supports providers, employers, paraprofessional workers, state and local officials, accreditation bodies, veterans, and other relevant experts and advocates in family caregiving. The Council also includes nonvoting, federal members representing the Centers for Medicare & Medicaid Services, the Administration for Community Living, the Department of Veterans Affairs, and other relevant federal agencies or departments overseeing the labor and workforce, economy, government financial policies, community services, and other impacted populations. The Council's preliminary report to Congress is expected in early 2021.

The current and two most recent presidential administrations have prioritized expansion of services and supports that help caregivers.

⁴⁶Centers for Medicare & Medicaid Services. *Final Rule. Medicaid Program; Community First Choice Option.* 42 CFR Part 441. May 7, 2012. Available at: <https://www.medicare.gov/sites/default/files/2019-12/cfc-final-regulation.pdf>.

⁴⁷Department of Veterans Affairs. *Final Rule. Program of Comprehensive Assistance for Family Caregivers Improvements and Amendments Under the VA MISSION Act of 2018.* 85 FR 46226. July 31, 2020. Available at: <https://www.federalregister.gov/documents/2020/07/31/2020-15931/program-of-comprehensive-assistance-for-family-caregivers-improvements-and-amendments-under-the-va>.

⁴⁸Plan to Create a 21st Century Caregiving and Education Workforce. Available at: <https://joebiden.com/caregiving/#>.

⁴⁹RAISE Family Caregivers Act of 2018, P.L. 115-119. January 22, 2018. <https://www.congress.gov/bill/115th-congress/house-bill/3759>.

The BOLD Act of 2018

In 2018, Congress also passed the **Building Our Largest Dementia Infrastructure for Alzheimer's Act (BOLD)** authorizing a uniform public health infrastructure across the country to, among other goals, increase early detection and diagnosis and support of dementia caregiving.⁵⁰

The BOLD Act increases nationwide implementation of the Centers for Disease Control and Prevention Healthy Brain Initiative's road maps⁵¹ by authorizing CDC to:

- establish Alzheimer's and Related Dementias Public Centers of Excellence;
- provide cooperative agreements to public health departments; and
- increase data collection, analysis, and timely reporting of data related to Alzheimer's, cognitive decline, caregiving, and health disparities.

In 2020, CDC awarded BOLD Act grants to three Public Health Centers of Excellence (PHCOE) to identify, translate, and disseminate promising research findings and evidence-informed best practices addressing social determinants of health and to use a nationwide systematic public health uptake by state, local, tribal, and other public health programs. Over \$2.5 million was awarded to the University of Minnesota to establish a PHCOE focused specifically on dementia caregiving.⁵²

The National Alzheimer's Plan

The National Alzheimer's Plan requires input from a public-private Advisory Council on Alzheimer's Research, Care, and Services and is guided by three principles:

- Optimizing existing resources, and improving and coordinating ongoing activities;
- Supporting public-private partnerships; and
- Transforming how public and private sectors approach Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD).

Among other challenges presented by AD/ADRD, the National Plan was designed to address the need for services and supports for family members and other unpaid caregivers who provide care for people living with AD/ADRD as well as the major implications (e.g., symptoms of depression) caregiving can have on caregivers, families, and population health.⁵³ An ongoing action under the plan is the regular convening of a National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers. A working group of family caregiver stakeholders participating in the 2020 Summit recommended that research:

- actively engage the participation of diverse and under-represented family caregivers in aims, goals, and outcomes, and identify family caregiver characteristics for measurement in representative real-world studies to determine those most likely to benefit from specific, programs, services, and supports.
- be conducted to support preparing, training, rewarding, and certifying medical and social service professionals to work effectively with family caregivers.
- be conducted to develop and test information, approaches, and strategies to help family caregivers with nutritional, functional, and early palliative and hospice care for people with advanced dementia.
- identify effective approaches to educate families and health professionals on managing co-existing multi-morbidities or lifelong disabilities.
- identify, test, and develop strategies to reduce negative financial, emotional, social, and physical impacts on family caregivers and for best practices in preventive and coping measures for specific caregiver health vulnerabilities.
- be conducted on current and proposed policies including those addressing shared family health decisions, employee family leave, and financial, health, and safety barriers for family caregivers with limited capacity for home care or access to quality affordable alternatives to care at home.⁵⁴

The BOLD Act increases nationwide implementation of the Centers for Disease Control and Prevention Healthy Brain Initiative's road maps.⁵¹

An ongoing action under The National Alzheimer's Plan is the regular convening of a National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers.

⁵⁰Building Our Largest Dementia Infrastructure for Alzheimer's Act, P.L. 115-406. December 18, 2018. <https://uscode.house.gov/statutes/pl/115/406.pdf>.

⁵¹See HBI State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map, available at <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>; HBI Road Map for Indian Country, available at <https://www.cdc.gov/aging/healthybrain/pdf/HBI-Road-Map-for-Indian-Country-508.pdf>.

⁵²<https://www.cdc.gov/aging/funding/phc/index.html>

⁵³National Plan to Address Alzheimer's Disease: 2019 Update. U.S. Department of Health and Human Services. Available at: <https://aspe.hhs.gov/system/files/pdf/262601/NatiPlan2019.pdf>.

⁵⁴Family Caregiver Stakeholder Group. Family Caregiver Recommendations: Dementia Care Virtual Summit Meeting. Research Summit on Dementia Care. July 2020. Available at <https://aspe.hhs.gov/system/files/pdf/263836/FamilyCareRecom20.pdf>.



STRATEGIES TO ADVANCE A STATE CAREGIVING PLAN

The following strategic process for establishing and advancing state caregiving plans aims to provide new opportunities for state and community-level caregiving advocates to engage in initiatives that address the needs of caregivers across the lifespan within the policy landscape of each respective state. Specifically, state- and community-level advocates are encouraged to develop and adopt strategies to improve the lives of and expand services and supports for family caregivers through participation among state agencies, state legislators, executive offices, and private sector leaders. Development of state-level strategies to address caregiver needs will ultimately provide a roadmap to expand the support infrastructure for family caregivers across the nation.

Below are recommended process steps to establish and advance a state caregiving plan, developed with a view to the existing process in states with caregiving plans, the process to develop a national strategy, and efforts in countries around the globe.

Strategic Process

1. Establish and maintain a formally recognized task force of family caregiving stakeholders.

Most of the caregiving plans highlighted in this report were established as a result of a mandate from the state Governor's office or Legislature, which directed the development of a task force charged with studying caregivers' needs and access to services and supports, as well as making policy recommendations. Others ensured formal recognition from a state-level entity once a strategy was developed by a credible and interdisciplinary group of respected stakeholders and experts. The absence of an official governmental mandate does not preclude state-level advocates and stakeholders from embarking upon the process of establishing a plan with recommendations. For instance, stakeholders who were members of the Idaho Caregiver Alliance organized their effort and developed a plan without a legislative mandate or executive order.⁵⁵

Building formality into the planning process bolsters credibility and can foster the implementation of established recommendations. Formality can also help garner funding for research, administrative support, and dissemination. At a minimum, state-level advocates should convene a defined group of public and private stakeholders for a specified period with the objective of developing a written report with specific recommendations to be submitted to state officials and policymakers for endorsement, adoption, and implementation. Processes and timelines for reaching consensus, issuing preliminary (if any) and final recommendations, and obtaining public input (if any) should be set as early as possible in the task force's tenure.

Development of state-level strategies to address caregiver needs will ultimately provide a roadmap to expand the support infrastructure for family caregivers across the nation.

⁵⁵Idaho's Legislature did, however, pass a resolution recognizing and endorsing their effort.

2. Assess the needs of family caregivers statewide as well as the availability and capacity of existing services and supports to address those needs.

A state task force should analyze what data is already available or data that needs to be obtained focused on caregivers' strengths and barriers, as well as the supports and services currently available. Systemic knowledge about available services is preferably conducted by health care and/or social service professionals, or compiled from relevant sources, to help the task force identify any gaps in services or populations whose needs are not being addressed.

3. Learn from the successes and challenges of other states.

Through efforts such as the strategies recommended in this paper, state programs that help inform the work of the RAISE Family Caregiver Advisory Council via the RAISE Family Caregiver Resource and Dissemination Center,⁵⁶ the Center for Health Care Strategies, Inc.'s learning collaborative,⁵⁷ and the Long-Term Services & Supports State Scorecard,⁵⁸ state advocates learn from and build upon each other's work, ultimately strengthening networks of caregiving supports in their own communities and across the nation.

4. Develop a statewide strategy (i.e., a plan) with specific policy recommendations to address family caregivers' needs across the lifespan in core person-centered domain areas.

The caregiving strategy, or plan, developed by the task force should aim to both inform policymakers as well as public and private stakeholders about the evidence-base for specific caregiving services and supports. Established recommendations should offer applicable guidance and models for delivering and paying for services and supports for caregivers of those with chronic conditions, mental health impairments, and limitations due to disability. The task force's work should take into consideration steps that contribute to the development of a national caregiving infrastructure by addressing policy domains aligned with recommendations that have been advanced globally, nationally, and at state and local levels.

Established recommendations should offer applicable guidance and models for delivering and paying for services and supports for caregivers of those with chronic conditions, mental health impairments, and limitations due to disability.

POLICY DOMAINS

Key policy recommendations that have been advanced globally, nationally, and at state and local levels typically fall into the following categories:



Caregiver Entry Points and Assessments



Caregiver Education, Training, and Well-being



Financial Security and Caregiver-Friendly Workplaces



Respite and Caregiving Service Delivery



Person- and Family-Centered Care/Shared Decision-Making

⁵⁶National Academy for State Health Policy. The RAISE family caregiver resource and dissemination center. <https://www.nashp.org/policy/chronic-and-complex-populations/the-raise-family-caregiver-resource-and-dissemination-center/>.

⁵⁷Roman, C., Soper, M.H., Ralls, M., & Torralba, G. (2020, September). Strengthening family caregiving programs and policies through collaboration: Lessons from six states. Center for Healthcare Strategies, Inc. <https://www.chcs.org/resource/strengthening-family-caregiver-programs-and-policies-through-collaboration-lesson-from-six-states/>.

⁵⁸AARP (2020). Long-term services and supports state scorecard. <https://www.longtermscorecard.org/>.

Although multi-jurisdictional alignment informs and advances the national conversation on caregiver services and supports, state advocates should thoughtfully consider and adapt these recommendations to their community needs, staying cognizant of which actors will ultimately play a role in implementation and the state's authority (or lack thereof) to modify existing programs (e.g., programs accessed by virtue of the care recipient which are not controlled by the state). For instance, policies may have challenges overcoming lack of political will in some states as compared to others. Advocates need not adopt a one-size-fits-all approach to supports and services and may find a more productive process by focusing on recommendations that build on general consensus among the group.

State caregiving plans should also incorporate recommendations from statewide initiatives, especially any disease and condition-specific plans, such as the state's Alzheimer's plan, as appropriate.⁵⁹



5. Engage stakeholders in the design, adoption, and ongoing evaluation of the implementation.

States that have successfully convened task forces and issued plans have included representation from public, private, and non-profit sectors in their task forces, including professionals in academia, experts in health and social service delivery across the lifespan, and caregiving advocates with lived experience. In recruiting stakeholders, states should consider qualities such as subject matter expertise (e.g., from respite programs and providers that may have access to and insight on relative data), technical expertise (e.g., academic institutions with the capacity to conduct or access existing bodies of relevant research), and capacity to provide other resources (e.g., capacity to provide administrative support to the task force). Task force composition should reflect a range of expertise to address both the health and human services and financial challenges facing caregivers. Public- and private-sector stakeholders should also look for opportunities to include family caregiver liaisons in statewide advisory councils, programs, and initiatives that advise issues affecting family caregivers.

6. Establish measurable goals for implementing the state plan that will guide the periodic evaluation of plan progress and, as appropriate, modification of the plan over time.

To date, state caregiving task forces have been established with specific sunsets for their work. Some states, however, have been able to achieve significant progress implementing their recommendations by including specific, measurable goals that guide stakeholders and advocates in adoption and implementation efforts after the task force concludes. For example, upon convening, the California Task Force on Family Caregiving set a goal of recommending at least four legislative proposals, including the creation of a “master plan on aging.” California’s Governor later issued an executive order calling for the plan’s creation. Multiple members of the caregiving task force were part of the plan’s advisory committee which enabled them to advance some of the work of the prior task force.

Public- and private-sector stakeholders should also look for opportunities to include family caregiver liaisons in statewide advisory councils, programs, and initiatives that advise issues affecting family caregivers.

⁵⁹See note 24.

INVENTORY OF EXISTING STATE CAREGIVING PLANS

The following states have developed formal caregiving task forces and plans as of October 2020:

Alabama*

California*

Delaware*

Idaho*

Hawaii

Kentucky

Maryland*

Minnesota

Mississippi*

New Mexico

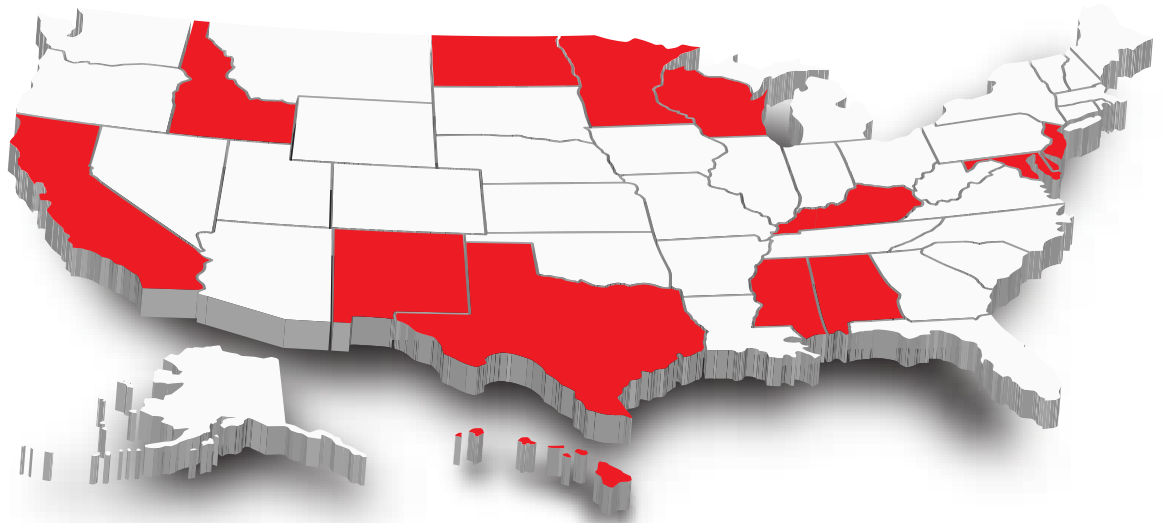
New Jersey^{*60}

North Dakota⁶¹

Texas

Wisconsin*

An asterisk (*) denotes a plan with a task force composition or policy focus across the lifespan.



⁶⁰A report is also forthcoming from the caregiving task force established by the New Jersey State Legislature. https://www.njleg.state.nj.us/2016/Bills/A1500/1463_11.

⁶¹North Dakota's state legislature commissioned a university-led caregiving study which included recommendations.



CORE POLICY DOMAINS FOR STATE CAREGIVING STRATEGIES

As described in the methodology section above (“How This Report Was Developed”), the following framework presents the core elements of a united, nationwide strategy with flexibility for states to adopt and adapt elements, as appropriate, to meet community needs. It is intended to serve as a tool to facilitate the engagement of family caregivers, caregiving advocates, lawmakers, and other public and private stakeholders. One or more broad recommendations are offered for each policy domain followed by examples of specific recommendations featured in existing state plans.

We identified five policy domains aligned with multi-jurisdictional family caregiving policy priorities and encompassing best practices in caregiver support.

CORE POLICY DOMAIN RECOMMENDATIONS



Recommendation 1: Identify system-wide caregiver entry points and utilize assessments to direct access to caregiver services and supports.



Recommendation 2: Expand caregiver education and training to support caregiver well-being.



Recommendation 3: Support financial security and caregiver-friendly workplaces.



Recommendation 4: Expand respite and strengthen the network of services supporting caregivers.



Recommendation 5: Foster person- and family-centered care and shared decision-making.



RECOMMENDATION 1: IDENTIFY SYSTEM-WIDE CAREGIVER ENTRY POINTS AND UTILIZE ASSESSMENTS TO DIRECT ACCESS TO CAREGIVER SERVICES AND SUPPORTS.

States should define and implement caregiver assessments for use across state agencies and, when possible, in coordination with other entry points within health care settings, social services, and the private sector for purposes of informing and coordinating services for individual caregivers and programs that impact them. These assessments should be standardized so that information can be compared across state agencies that (a) deliver services and supports to anyone over the age of 18 with a serious condition or disability or any older adult who relies on assistance for ADL's or IADL's from a family caregiver or (b) directly serve family caregivers, allowing for secure data-sharing across agencies.

Aligning with the National Academy of Sciences' 2016 recommendation that the federal government "[e]xpand the data collection infrastructures within the U.S. Departments of Health and Human Services, Labor, and Veterans Affairs to facilitate monitoring, tracking, and reporting on the experience of family caregivers,"⁶² NAC's 2018 white paper observed that "routine assessments of the status of caregivers help public health professionals understand the effects of efforts to support families as America ages."⁶³ Caregiver assessment principles and guidelines were developed as early as 2005 when the National Consensus Development Conference for Caregiver Assessment responded to increased recognition of the value of systematic assessment of family caregivers' needs in health care and in home- and community-based long-term care (LTC) settings.⁶⁴ As part of a comprehensive evaluation of the National Family Caregiver Support Program in 2012, the Administration for Community Living compiled examples of assessment tools used by State Units on Aging (SUAs) serving caregivers under the program, but did not endorse specific tools.⁶⁵

Today, standards are included, to varying degrees, in the U.S. Department of Veteran Affairs' Program of General Caregiver Support Services (VA Directive 1152(1)), the Supporting Older Americans Act, P.L. No: 116-131 (reauthorizing and funding certain programs under the Older Americans Act), and evidence-based care programs, such as TCARE and BRI Care Consultation. However, state agencies often lack standardized statewide assessment instruments for caregivers across the lifespan or means of utilizing and sharing assessment data across agencies. While existing agencies and caregiving resource centers at the state level may assess caregivers to at least some extent, they do not necessarily have funding available to oversee statewide standardization⁶⁶ and modernization⁶⁷ efforts.

Below are examples of specific recommendations from existing state strategies or plans:

- 1.1 Modernize and standardize data collected in caregiver assessments in order to understand service utilization of services, support individualization of services, reduce service fragmentation, and track any evolving needs and unmet needs of the caregiving population.
- 1.2 Adopt and implement recommendations for caregiver assessments from the National Consensus Development Conference for Caregiver Assessment, including:
 - "embracing family-centered perspectives, inclusive of the needs and preferences of both the care recipient and the family caregiver",⁶⁸



⁶²See note 9.

⁶³National Alliance for Caregiving. (2018, January). From insight to advocacy addressing family caregiving as a national public health issue, p. 8. https://www.caregiving.org/wp-content/uploads/2020/05/From-Insight-to-Advocacy_2017_FINAL.pdf.

⁶⁴Family Caregiver Alliance. (2006). Caregiver assessment: Principles, guidelines and strategies for change: Report from a National Consensus Development Conference, 1. <https://www.caregiver.org/national-consensus-report-caregiver-assessment-volumes-1-2>. AARP's Public Policy Institute has more recently issued policy and practice considerations on assessing family caregivers' needs. Feinberg, L. & Houser, A. (2012). Assessing family caregiver needs: Policy and practice considerations. AARP Public Policy Institute. Last visited 10/31/2020 at https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/caregiver-fact-sheet-AARP-ppi-ltc.pdf.

⁶⁵Administration for Community Living. (2012). SUA resource library: State caregiver assessments. <https://acl.gov/sites/default/files/programs/2016-11/State-Caregiver-Assessment.pdf>.

⁶⁶For purposes of this framework, "standardization" refers to collection of data in a manner that aggregates the data across settings. Standardization may be accomplished by using a common assessment tool for programs providing caregiver support across different settings. See Feinburg, L. (2002). The state of the art: Caregiver assessment in practice settings. Family Caregiver Alliance. <http://www.rosalynnecarter.org/wp-content/uploads/2019/05/Caregiver-Assessment-2002-FCA.pdf>.

⁶⁷For purposes of this framework, "modernization" means the alignment of assessment practices with current goals and outcomes.

- ensuring assessments result in a plan of care, developed in collaboration with the caregiver, resulting in a provision of services and intended measurable outcomes;
- multidimensional, periodically updated assessments;
- reflecting culturally competent practice;
- assessors with specialized knowledge and skills;
- government and other third-party payers recognizing and paying for caregiver assessments as part of care for older adults and adults with disabilities.

1.3 Remove barriers to coordinating assessment while ensuring secure record-sharing across state organizational units.



RECOMMENDATION 2: EXPAND CAREGIVER EDUCATION AND TRAINING TO SUPPORT CAREGIVER WELL-BEING.

States should ensure family caregivers are prepared to safely perform care coordination and any necessary medical/nursing tasks by providing easily accessible information, education, and training that is tailored to their caregiving situations and delivered in culturally competent and evidence-informed ways.

Although a myriad of supports and services may be available to caregivers from various public and private sources within their communities, caregivers often lack a centralized source to help them distill and locate the information and resources they need. Assistance navigating resources is available to participants in the National Family Caregiver Support Program (NFCSP).⁷⁰ The NFCSP helps connect caregivers with services from volunteer and private agencies.⁷¹

Seventy-four percent of caregivers served by the NFCSP reported that the services they received helped them continue providing care, and eighty-eight percent of the individuals served reported that the services helped them become better caregivers.⁷² Although some states have statewide caregiver resource centers that could similarly function as centralized sources of information and resources for caregivers across the lifespan in their communities, they may lack funding to maintain and update resources for caregivers in their states to experience similar outcomes.

Just as caregivers experience difficulty finding and navigating resources, agencies often experience difficulty spreading the word about services to caregivers. Some advocates indicate that funding restraints on marketing hinder their ability to deliver programs at capacity. Their program budgets often exclude funding for marketing programs and services based, at least in part, on assumptions that social media is a free, viable advertising option. However, not all caregivers are active on social media and those that do use the platform and need services do not necessarily identify themselves as caregivers or know that they may be eligible for services and supports. Funding to advertise programs and services on social media and other platforms would improve their outreach efforts.

Below are examples of specific recommendations from task forces:

2.1 Centralize state systems for accessing information, including funding opportunities, for state resource centers that support family caregivers, modeling the Administration for Community Living's collection of data under the National Family Caregiver Support Program.

2.2 Provide caregivers with access to up-to-date, tailored, or individualized caregiving resources, education, and training that is specific to their needs and provided in culturally competent ways,



Caregivers often lack a centralized source to help them distill and locate the information and resources they need.

⁶⁸ See note 64.

⁶⁹ Advocates should be cognizant that states may lack authority to collect data on federal programs for federal beneficiaries.

⁷⁰ The NFCSP, which is authorized by Title III E of the Older Americans Act, provides grants to states and territories to fund a number of supports that help families care for older adults at home for as long as possible. NFCSP services are available to adult caregivers for individuals age 60 and over, adult caregivers for people with Alzheimer's disease and related disorders and adults age 55 and over providing care to children under 18 or adults with disabilities.

⁷¹ Administration for Community Living. (2019). National Family Caregiver Support Program. Last accessed 10/31/2020 at www.acl.gov/programs/support-caregivers/national-family-caregiver-support-program.

⁷² See note 70.

including ensuring that health and social service providers can provide education at critical points (e.g., at diagnosis, during care transitions).

2.3 Identify and provide access to evidence-based caregiver programs throughout the state.

2.4 Increase public awareness about caregiving and help caregivers self-identify by utilizing social media, events, and venues, and identifying public and private funding and/or partnerships to target ongoing awareness campaigns to individuals who do not necessarily self-identify as caregivers, are unaware of their eligibility for support, or hesitant to approach formal services.

2.5 Ensure state statutory definitions of “functional disability” include “serious mental illness” and implement and fund training programs for family members—that include caregivers of those with mental illness—that include education, support, and peer mentorship (following NAMI’s successful Peer-to-Peer model).⁷³



RECOMMENDATION 3: SUPPORT FINANCIAL SECURITY AND CAREGIVER-FRIENDLY WORKPLACES.

Public and private stakeholders should take collective action to protect the financial security of caregivers in the workforce by promoting flexible working schedules, paid leave, and other job protections, and also to protect caregivers’ financial security—regardless of employment status—through supports that help reduce out-of-pocket spending and establish and preserve personal and retirement savings (e.g., financial education, legal assistance, and tax credits).

Caregiving can have substantial financial consequences for the individual providing care, both in terms of its impact on earnings and its out-of-pocket costs.⁷⁴ As may be expected, states have different appetites for enacting specific employment laws and tax measures that may benefit caregivers, particularly if there is a perception that employers would oppose such policies. Ultimately, state-level advocates should recognize that their local political climate may impact the success of their recommendations.

State-level advocates should also be cognizant that, although legislative and regulatory initiatives, including leave policies, are important, they should not be the exclusive means of protecting the financial security of family caregivers. Advocates and stakeholders should also use state caregiving plans as opportunities to acknowledge the economic value of family caregivers⁷⁵ and their desire to remain engaged with their jobs,⁷⁶ as well as to promote a variety of solutions for caregiver assistance. For instance, Hawaii’s Kūpuna Caregivers Program helps caregivers who work a minimum number of hours outside of the home pay for long-term care services, thereby helping them remain employed while also providing direct care to qualified individuals. In addition, state caregiving task forces should consider publishing data and recommendations on flexible work schedules as relatively low or no cost ways to help caregivers balance their jobs and caregiving responsibilities without necessarily taking extended leave from work.⁷⁷

In addition to guiding lawmakers, plans developed by state caregiving task forces can be used to inform and leverage employer efforts to build caregiver-friendly workplaces, similar to how the Maryland Commission on Caregiving has cultivated relationships with various stakeholders, including major state employers who view the Commission as a resource for obtaining helpful information for its caregiver employees. Connecting employers with such resources also engages the private sector in implementation of other policy priorities by providing a convenient, accessible venue for caregivers—namely working caregivers—to obtain education and support.

⁷³National Alliance on Mental Illness. NAMI peer-to-peer. <https://www.nami.org/Support-Education/Mental-Health-Education/NAMI-Peer-to-Peer>.

⁷⁴MetLife Mature Market Institute, National Alliance for Caregiving, Center for Long-Term Care Research and Policy at New York Medical College. (2011, June). *The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents*. Available at: <https://www.metlife.com/mmi/research/caregiving-cost-working-caregivers.html#key%20findings>. Rainville, C., Skufca, L., & Mehegan, L. (2016, November). *Family Caregiving and Out-of-Pocket Costs: 2016 Report*. AARP. Available at: <https://www.khi.org/assets/uploads/news/14680/family-caregiving-cost-survey-res-ltc.pdf>.

⁷⁵See note 40.

⁷⁶Gastfriend, J. (2014). *No one should have to choose between caregiving and work*. Harvard Business Review. <https://hbr.org/2014/07/no-one-should-have-to-choose-between-caregiving-and-work>. Hawai’i Family Caregiver Coalition. (2019). *Aging and Disability Issues: A Guide for Hawai’i’s Legislators, Organizations and Citizens 2019*. <https://hccoalition.org/index.php/education-resources/>.

⁷⁷See California Task Force on Family Caregiving. (2018). *Picking up the pace of change in California: A report from the California Task Force on Family Caregiving*. https://secureservercdn.net/198.71.233.135/159.a31.myftpupload.com/wp-content/uploads/2018/07/USC_CA_TFFC_Report_Digital-FINAL.pdf (citing findings in a 2016 Associated Press NORC Center for Public Affairs Research long term care poll that 72 percent of adults age 40 or older would find time away from work or the ability to adjust their work schedules help to providing ongoing living assistance). Time away from work affords employees opportunities to recharge and experience improved productivity, lower stress and better mental health. Achor, S. & Gielan, M. (2016). *The data-driven case for vacation*. Harvard Business Review. <https://hbr.org/2016/07/the-data-driven-case-for-vacation>. Workplace policies like flexible work schedules help working caregivers, who might otherwise exhaust their available leave to attend to caregiving responsibilities, experience the same benefits and improved productivity as their non-caregiving colleagues.

Below are examples of specific recommendations from task forces to support working family caregivers from task forces:

3.1 (For Employers) Adopt policies to support working caregivers (e.g., offer flexible working schedules to help employees balance their jobs with providing care to a child, family member with a persistent health condition, or parent aged 65 and older; offer paid leave for family caregivers to take time off work for caregiving responsibilities; and offer informational resources on financial and legal assistance).

3.2 (For Lawmakers) Provide tax credits to employers offering a minimum number of weeks of paid leave to family caregivers.

3.4 (For Lawmakers) Extend job protections, found in the FMLA, and paid family leave to working caregivers.

3.6 (For Lawmakers and Employers) Increase the number of weeks over which paid leave is provided from six to twelve weeks annually.

3.7 (For Employers and State Labor Agencies) Expand public education programs about paid leave eligibility and availability, including ensuring culturally appropriate awareness campaigns.

3.8 (For Lawmakers) Make long-term care more affordable for working caregivers by providing financial assistance for adult daycare, assisted transportation and other services that help caregivers continue to work outside the home and earn retirement benefits.

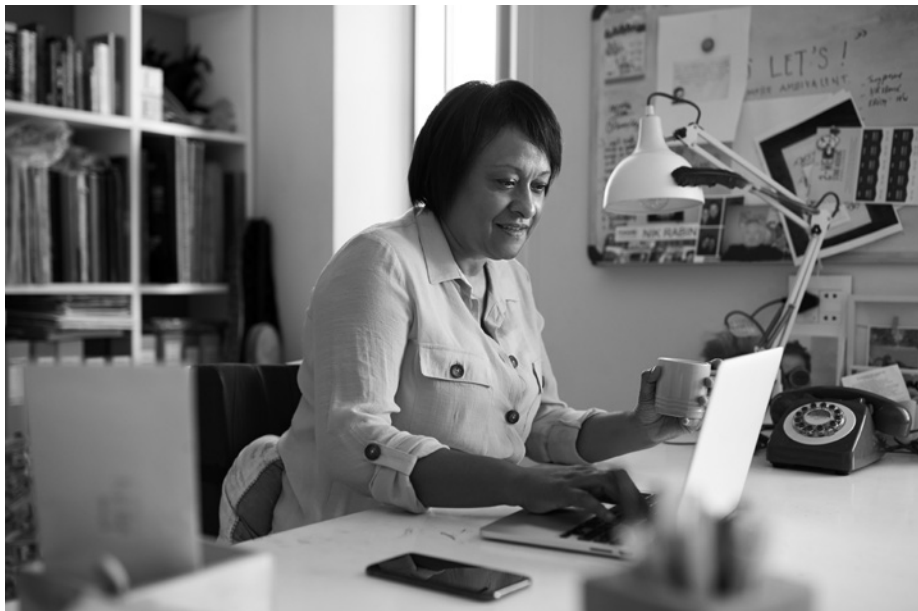
Below are examples of specific recommendations from task forces to support financial security regardless of employment status:

3.9 Study the financial impacts of caregiving and the extent to which the role contributes to an increased risk of poverty and long-term financial insecurity for the state's caregivers.

3.10 Provide statewide tax credits for out-of-pocket costs related to caregiving, such as housing costs, home modifications, respite, medical costs, and other household expenses incurred from providing care to a friend or family member.

3.11 Make state tax credit eligibility criteria more accessible for middle-income caregivers than federal criteria.⁷⁸

3.12 Establish a long-term care insurance program⁷⁹ to cover family costs related to community-based services, such as adult day care, chore services, home-delivered meals, personal care, respite care, and transportation.



Employers should adopt policies to support working caregivers.

⁷⁸At the time of the California Task Force on Family Caregiving's report, federal tax credit eligibility required that the income of the relative receiving care not exceed \$4050 and that the family member pay 50 percent of the older adult's expenses, while either cohabitating with the care recipient or satisfying other relationship criteria. Since California's family caregivers spent an average of \$7000 per year on out-of-pocket costs related to caregiving, the task force recommended covering more of caregivers' costs by establishing a minimum credit of \$5000 per year. California Task Force on Family Caregiving, *Picking up the Pace of Change in California: A Report from the California Task Force on Family Caregiving*, July 2018. Available at https://secureservercdn.net/198.71.233.135/159.a31.myftpupload.com/wp-content/uploads/2018/07/USC_CA_TFFC_Report_Digital-FINAL.pdf.

⁷⁹E.g., Washington's 2019 Long-Term Care Trust Act, available at: <http://lawfilesexet.leg.wa.gov/biennium/2019-20/Pdf/Bills/House%20Passed%20Legislature/1087-S2.PL.pdf>.



RECOMMENDATION 4: EXPAND RESPITE AND STRENGTHEN THE NETWORK OF SERVICES SUPPORTING CAREGIVERS.

States should increase access to affordable caregiving services and supports and also collect data to plan and develop a stronger infrastructure for a qualified direct care workforce and non-medical volunteer respite services in order to help alleviate caregiving strain and prevent burnout.

State recommendations related to respite and caregiving service delivery generally focus on leveraging new and existing resources and programs effectively. Expanding respite delivery is a recurring priority in state plans that have emerged. States have subsequently implemented that priority by leveraging and building their respite network through grants and cooperative agreements under the federally funded Lifespan Respite Program. The program is intended to improve the delivery and quality of respite services available to families across age and disability spectrum by facilitating coordination between programs, reducing duplication of efforts, and assisting in the development of respite care infrastructure at the state and local level.⁸⁰ Some state advocates have indicated that the process of applying for Lifespan Respite Program positioned them to strengthen access to respite even if they did not receive funding (i.e., by helping them assess state resources, identify partnerships, and strategically plan respite delivery).

Another priority area is expanding data collection infrastructure to determine the number of individuals with long-term chronic mental or physical health diagnoses and their caregiving needs. However, states do not necessarily need to establish new data collection infrastructures to help them identify gaps in and plan future service delivery. States can potentially use data from the Behavioral Risk Factor Surveillance System (BRFSS) to plan and inform their service delivery as BRFSS collects and stores data from health-related telephone surveys about health-related risk behaviors, chronic health conditions, and use of preventive services of more than 400,000 adults per year in all 50 states, the District of Columbia, and three U.S. territories.⁸¹

Examples of specific state task force recommendations:

- 4.1 Use data collection infrastructure to determine the number of individuals with long-term chronic mental/physical health diagnoses and the number of caregivers in order to plan adequate services and supports that meet capacity.
- 4.2 Equip and expand the network of individuals who assist family caregivers to understand, arrange, and access affordable services and supports that help caregivers provide complex care tasks.
- 4.3 Increase affordability of respite services, specifically by:
 - a) Strengthening the respite care workforce throughout the state, including rural areas.
 - b) Supporting the state Lifespan Respite Network to provide caregiver training and person-centered voucher respite.



States should increase access to affordable caregiving services and supports.

⁸⁰The Lifespan Respite Program was established in 2006 to provide, supplement, or improve access and quality of respite care services through coordinated systems of accessible, community-based respite care services for family caregivers of children or adults of all ages with special needs. Lifespan Respite Care Act of 2006, Pub. L. 109-442, 120 Stat. 3291(2006) (codified as 42 USC 201 note).

⁸¹Center for Disease Control and Prevention (CDC). (2014, May). About BRFSS. <https://www.cdc.gov/brfss/about/index.htm>.



RECOMMENDATION 5: FOSTER PERSON-AND FAMILY-CENTERED CARE AND SHARED DECISION- MAKING.

States should support integration of family- and person-centered approaches that recognize caregiver autonomy in care settings and in health care policy (at the individual and community level).

The nation has begun to recognize the essential role that unpaid friend and family caregivers play in supporting individuals with ongoing health and assistance needs. People living with various health conditions along with their friends and family members are essential partners in the delivery of health care. The person receiving care and the persons providing care offer complementary insights into the way that disease and disability impacts families and informal social structures. Yet, informal support systems are not sufficient to support the many Americans with care needs.

Policymakers need pathways that will encourage businesses, entrepreneurs, community partners, think tanks, and incubators to find sustainable solutions to support and augment the support provided by family caregivers across the lifespan and the vital roles they play in shaping regulatory decision-making, and health care delivery. State task forces can help facilitate pathways through specific recommendations for interagency collaboration, data collection to inform service gaps or adoption of model legislation. For instance, the year after the Mississippi Caregiver's Task Force recommended adoption of legislation similar to the Caregiver Advise Record Enable Act, the state enacted legislation to support family caregivers at hospital discharge.

Below are specific examples from state plans:

- 5.1** Encourage collaboration among state agencies to providing person- and family-centered services as a unified approach to deliver care.
- 5.2** Establish a statewide task force to review the prevalence of caregivers who are no longer available to care, putting the dependent in their care at risk of hospitalization or worsening health outcomes.
- 5.3** Recognize caregivers as members of the interdisciplinary care team, especially in hospital-to-home care transitions through the ongoing expansion and implementation of the state Caregiver Advise Record Enable (CARE) Act to support family caregivers performing medical/nursing tasks following hospital discharge (or enhance the CARE Act, where enacted, and provide guidance to hospitals on implementing the CARE Act) while working with stakeholders e.g., hospital associations to improve implementation.



The person receiving care and the persons providing care offer complementary insights into the way that disease and disability impacts families and informal social structures.

STATE CAREGIVING PLAN CASE STUDIES

CASE STUDY: DEVELOPING A PLAN FOR ALABAMA CAREGIVERS⁸²



Step 1: Establish and maintain a task force.

The Alabama State Legislature passed Senate Joint Resolution 73 in 2015, establishing a task force to study caregiving in the state, to identify policies, resources, and programs available to support family caregivers, and to suggest “innovative, creative means to support family caregivers and assist them in providing the needed in-home support for care recipients.”

Step 2: Assess the needs of caregivers and the capacity of existing services and supports.

The Alabama Caregiver Task Force informed its work by reviewing nationally-available data related to caregiving and the needs of caregivers.⁸³ The task force also completed a Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis during its first meeting and collaborated to gather resources and information, including caregiver focus groups conducted by the Alabama Department of Senior Services (ADSS) and the University of Alabama Research Institute on Aging, as well as surveys distributed to faith-based leadership via the Alabama Lifespan Respite Network (Alabama Respite).

Step 3: Develop a state plan for family caregivers across the lifespan.

The task force met quarterly during its first year and ultimately finalized a white paper with policy recommendations in 2017. Grant funding from the Administration on Community Living/ Administration on Aging helped fund the white paper.

Examples of Alabama’s policy recommendations include:



Expanding data collection infrastructures to determine both the number of individuals with long-term chronic mental/physical health diagnoses and the number of caregivers in Alabama, and to inform future planning and advocacy for adequate delivery of services and supports.



Establishing a taskforce to assess the number of caregivers without resources to ensure continuity of care for their dependent care recipients (e.g., upon death of the caregiver or the care recipient “aging out” of services).

The task force also recommended specific legislative calls to action, including:

- Enacting the Caregiver Advise Record Enable (CARE) Act;
- Enacting legislation providing workplace flexibility and leave to family caregivers;
- Enacting a “Good Samaritan Law” that includes volunteer caregivers among the list of entities granted immunity for acts and omissions while rendering first aid or emergency care (*introduced as HB 174 in the 2017 Legislative Session*);
- Increasing Caregiver Service Funding (budget allocations for respite, training, and other services to support caregivers of individuals with disabilities and other chronic health conditions)

Step 4: Engage stakeholders in the design, implementation, and ongoing evaluation of the plan.

Alabama’s final report reflected input from ADSS, AARP Alabama and Alabama Lifespan Respite Network (Alabama Respite), a family caregiver, providers of long-term services, and other community-based organizations within the disability and aging networks. The task force concluded its work upon submission of its report to the Governor, Alabama State Legislature, and other public policy professionals.

⁸²<http://ucphuntsville.org/wp-content/uploads/2014/06/A-Voice-for-Family-Caregivers-Whitepaper-1.pdf>

⁸³In particular, the task force considered NAC and AARP’s 2015 *Caregiving in the U.S. report* and AARP’s *Long-Term Services and Supports Scorecard*. Based on findings in those reports, the task force concluded that an organized effort to educate policy makers and the larger community on the caregiving role and caregivers’ needs was necessary to improve quality of care and long-term services and supports.

CASE STUDY: DEVELOPING A PLAN FOR CALIFORNIA CAREGIVERS⁸⁴



Step 1: Establish and maintain a task force.

The California Task Force on Family Caregiving convened in 2016 under authority granted by Assembly Concurrent Resolution (ACR) 38. The legislature charged the task force with examining challenges faced by family caregivers and opportunities to improve caregiver support, reviewing the current network of caregiver services and supports available to caregivers, and making policy recommendations.

Step 2: Assess the needs of caregivers and the capacity of services and supports.

At the time the task force convened, California had an established network of Caregiver Resource Centers throughout the state that was able to assess caregiver needs in order to provide support tools.

Step 3: Develop a state plan for family caregivers across the lifespan.

California's task force engaged in a priority setting process and set a goal at its initial meeting to take a comprehensive, but flexible, approach to its mandate. From the outset, the task force identified six priority areas for its effort:

1. Integrated approach to care management
2. Comprehensive array and continuum of services
3. Caregiver compensation
4. Data on caregivers and services
5. Access to affordable and accessible services
6. Education and training

It met for two years, publishing an interim report⁸⁵ in 2017 ahead of submitting its final report to the state legislature in 2018. Administrative support for the task force was funded by grants from AARP California and Archstone Foundation to the University of Southern California's Leonard Davis School of Gerontology.

⁸⁴ California Task Force on Family Caregiving. (2018). *Picking up the pace of change in California: A report from the California Task Force on Family Caregiving*. https://secureservercdn.net/198.71.233.135/159.a31.myftpupload.com/wp-content/uploads/2018/07/USC_CA_TFFC_Report_Digital-FINAL.pdf.

⁸⁵ California Task Force on Family Caregiving. (2017). *Interim report from the California Task Force on Family Caregiving*. http://tffc.usc.edu/wp-content/uploads/2017/09/interim_report_final.pdf.

Examples of California's policy recommendations include:



Assess caregivers on their capacity and willingness to provide care.



Extend the Family Medical Leave Act job protections to those participating in the state's Paid Family Leave program.



Integrate family caregivers into hospital processes, support navigating care transitions, and increase caregiver choice regarding complex tasks.

Step 4: Engage stakeholders in the design, implementation, and ongoing evaluation.

Following the sunset of the task force, several members continued to serve on related commissions that provide platforms to amplify its recommendations and legislative calls to action (e.g., the advisory committee for California's Master Plan on Aging).

Step 5: Establish measurable goals for implementing the plan that guide periodic evaluation.

Early in its convening, the task force set a goal of recommending at least four legislative calls to action. It ultimately recommended the following legislative proposals:

- Enhance the state's paid family leave law (i.e., 100% wage replacement for those making less than \$100,000 per year and ease of use for associated forms);
- Pass a statewide tax credit for out-of-pocket family caregiving costs (50% of expenses up to \$5,000);
- Increase the respite care workforce, including tuition credit for care corps respite volunteers;
- Establish the Cognitive Impairment Task Force;
- Establish a single entry point for Aging and Disability Resource Center services;
- Increase the budget for the Caregiver Resource Center;
- Adopt the statewide Master Plan on Aging (including caregiver support and respite).

CASE STUDY: DEVELOPING A PLAN FOR IDAHO CAREGIVERS⁸⁶



Step 1: Establish and maintain a task force.

Unlike other case studies highlighted in this report which were created by a legislative act or a governor's executive order, the Idaho Family Caregiver Task Force was formed in 2015 by the Idaho Caregiver Alliance.⁸⁷ That year, Idaho's legislature also passed the House Concurrent Resolution endorsing the Idaho Caregiver Alliance and the creation of the task force to supporting unpaid family caregivers.

Step 2: Assess the needs of caregivers and the capacity of services and supports.

In addition to nationally-available data about caregiving, the task force was informed by the Idaho Caregiver Alliance's statewide respite capacity and needs assessment data, studies and caregiver programs.

Step 3: Develop a state plan for family caregivers across the lifespan.

The task force met for six months and published "Caregivers in Idaho: A Report from the Idaho Family Caregiver Task Force and the Idaho Caregiver Alliance" in December 2015. Its report identified three priority areas: family caregiver supports, community awareness and engagement, and system change.

Examples of policy recommendations include:



Build community resources and integrate caregivers in the development of medical-health neighborhoods⁸⁸ through the state's State Health Innovation Plan (SHIP) Regional Health Collaboratives (including identifying family caregivers to serve as liaisons to each collaborative).



Include caregivers and strengthen their roles in the development of person-centered planning training through collaboration with the statewide No Wrong Door (NWD) Initiative.

Step 4: Engage stakeholders in the design, implementation, and ongoing evaluation.

The Idaho Caregiver Alliance convened participants from varied backgrounds (e.g., community-based organizations, providers, health plans, government agencies) to participate in the task force. Since the effort was not tied to a specific legislative mandate or executive order with an expiration date, the Alliance is positioned to continue developing programs and partnerships to advance priorities set by the task force. Alliance members are currently taking action on several recommendations, including creating a caregiver assessment and piloting a Family Caregiver Navigator, which focuses services on the caregiver rather than the person receiving care.⁸⁹

Step 5: Establish measurable goals for implementing the plan that guide periodic evaluation.

The Idaho Caregiver Alliance has included the priorities identified by the 2015 task force in its 2020-2024 strategic plan, along with new goals to build a sustainable infrastructure that ensure a coordinated voice for family caregivers across the lifespan.⁹⁰

⁸⁶ Idaho Family Caregiver Task Force and the Idaho Caregiver Alliance. (2015). *Caregivers in Idaho: A report from the Idaho Family Caregiver Task Force and the Idaho Caregiver Alliance*. <https://lifespanrespite.wildapricot.org/resources/Documents/Respite%20and%20Caregiver%20Task%20Force%20Reports/Final%20Report%20Caregivers%20in%20Idaho.pdf>.

⁸⁷ The Idaho Family Caregiver Task Force's work was supported through funding from AARP – Idaho and the Idaho Caregiver Alliance. The Idaho Caregiver Alliance coalition of individuals and organizations working to expand respite across the lifespan. It was established through National Lifespan Respite grant funding to the Idaho Commission on Aging. <https://idahocaregiveralliance.com/about-the-ica/>.

⁸⁸ A "medical neighborhood" is a clinical-community partnership that provides medical and social supports. <https://www.astho.org/StatePublicHealth/Integration-in-Action-Idaho-Department-of-Health-and-Welfare-Advances-Healthy-Connections/3-8-17/>.

⁸⁹ Idaho Caregiver Alliance. *The family caregiver navigator project*. <https://idahocaregiveralliance.com/navigator/>.

⁹⁰ Idaho Caregiver Alliance. (2020). *Strategic plan 2020-2024*. https://drive.google.com/file/d/1Uv4DEL_ag5Yulzax4A8XdYfG7RhTFKZt/view.

CASE STUDY: DEVELOPING A PLAN FOR MARYLAND CAREGIVERS⁹¹



Step 1: Establish and maintain a task force.

The Maryland General Assembly authorized creation of the Task Force on Family Caregiving and Long-term Supports in 2015. The 27-member task force, which was co-chaired by members of the State Senate and House of Delegates, was charged with identifying and reporting on policies, resources, and programs available to the states' family caregivers.⁹²

The Maryland Caregivers Support Coordinating Council (MCSCC) was previously established in 2001 with 17 members, representing state agencies, family caregivers, service providers, and advocacy groups, appointed by the Governor. However, it lacked staffing and resources to conduct the comprehensive study charged to the task force.

Step 2: Assess the needs of caregivers and the capacity of services and supports.

MCSCC surveyed 1,800 Maryland caregivers across a three-month period in 2014-15. Outreach was performed to caregivers across the lifespan and every jurisdiction, with caregivers assisting the design. The survey was translated to Spanish and delivered via hard copies and online. Based on that survey, State Senator and MCSCC Co-Chair Deborah Kelly advocated for establishment of the new task force in 2015 to strengthen the work of the Commission.

Step 3: Develop a state plan for family caregivers across the lifespan.

The task force submitted its final report to the Governor and General Assembly in 2016.

Examples of recommendations included:



Implement and fund training programs to support caregivers of individuals living with mental illness, including education, support, and skill-building for peer mentorship.



Develop a state plan to build respite capacity.

Step 4: Engage stakeholders in the design, implementation, and ongoing evaluation.

Including lawmakers in the task force's membership helped ensure an ongoing effort to advance caregiver supports and services in the state. With backing by its legislative members, the task force successfully recommended and relaunched the MCSCC as the Maryland Commission on Caregiving (MCC).

Step 5: Establish measurable goals for implementing the plan that guide periodic evaluation.

MCC is a staffed unit within Maryland's Department of Human Services. Among its legislative mandates is monitoring and implementing policy recommendations.

Step 6: Learn from other states.

To strengthen its respite capacity, Maryland looked to and applied for funding under the National Lifespan Respite program. It has successfully established and leveraged strategic community partnerships to deliver respite throughout the state without using grant funding for administrative costs.

⁹¹Task Force on Family Caregiving and Long-Term Supports. (2016). 2016 final report: Task Force on Family Caregiving and Long-Term Supports. <https://lifespanrespite.wildapricot.org/resources/Documents/Respite%20and%20Caregiver%20Task%20Force%20Reports/MD%20Final%20Report%20of%20Task%20Force%20on%20Caregiving.pdf>.

⁹²AARP Maryland provided administrative support to the Task Force.

CASE STUDY: DEVELOPING A PLAN FOR WISCONSIN CAREGIVERS⁹³



Step 1: Establish and maintain a task force.

Wisconsin's Governor's Task Force on Caregiving was established in February 2019 by Executive Order #11.⁹⁴ Governor Tony Evers charged the task force with analyzing strategies to attract and to retain a strong direct care workforce and assist families providing caregiving supports and services.

Step 2: Assess the needs of caregivers and the capacity of services and supports.

The task force was developed in response to the state's growing caregiver shortage and rising level of need. Its work was informed by nationally-available data on the ability of the direct care workforce and family caregivers to keep up with care needs, a 2016 survey by the Survival Coalition related to Wisconsin's caregiving needs for people living with disabilities, and a 2019 survey of family caregivers by the University of Wisconsin Madison's Department of Human Development and Family Studies.

Step 3: Develop a state plan for family caregivers across the lifespan.

The task force convened in September 2019, forming working groups and holding periodic public meetings. The final report was issued in September 2020 and included recommendations aimed at strengthening the direct care workforce and addressing the needs of family caregivers directly.

Examples of recommendations included:



Assess compensation and fringe benefits for caregivers, including ways to make health care affordable for the caregiving workforce through employer-sponsored plans, Medicaid buy-in plans, or other health insurance coverage options.



Conduct a one-year, HIPAA-compliant Home Care Provider Registry Pilot to facilitate data sharing.

⁹³Governor's Task Force on Caregiving. (2020). *Wisconsin caregivers in crisis: Investing in our future*. <https://gtfc.wisconsin.gov/gtfcfiles/docs/gtfc-report.pdf>.

⁹⁴Exec. Order No. 11. (February 18, 2019). https://docs.legis.wisconsin.gov/code/executive_orders/2019_tony_evers/2019-11.pdf.



MOVING THE FIELD FORWARD

To realize its vision of a society that values, supports, and empowers family caregivers, NAC builds partnerships in research, advocacy, and innovation to make life better for family caregivers. Addressing the social, medical, physical, financial, spiritual, and emotional needs of family caregivers across the lifespan requires a robust, consensus-building movement rooted in a similarly wholistic approach. The movement to build a strong national caregiving infrastructure calls for research and evidence-informed practices to inform caregiving advocacy, as well as collaboration and innovation across public and private sectors. With this report, NAC calls upon policymakers, researchers, and advocates alike to move the field forward toward a society equipped to address the needs of caregivers across the lifespan.

Developing a nationwide strategy to support family caregivers across the lifespan is an evolving process. This process is strengthened by a commitment among caregiving advocates, policymakers, and public and private stakeholders to build upon each other's work and ensure that the policy landscape equally addresses the health and human services, as well as financial challenges, facing family caregivers. For states that have yet to establish formal caregiving strategies, this commitment means using the strategic process and core caregiving strategy elements recommended in this paper to build upon existing multi-jurisdictional policy recommendations, while tailoring efforts to meet community-level needs. For those jurisdictions that have already engaged in a strategic planning process, this commitment means recognizing that there is more to be done. Existing and emerging plans should be considered living documents that are regularly adapted to address community-level needs and ensure caregivers receive necessary physical, mental, social and financial supports, as well as recognition, to engage as vital participants in health and social systems of care.

The movement to establish a national public health infrastructure that promotes and protects family caregivers is underway, as demonstrated by multi-jurisdictional alignment across existing policy priorities. Ensuring that this infrastructure results in improved outcomes for caregivers' health and financial wellbeing will require strategic coordination of research, innovation and advocacy efforts across the lifespan. NAC will continue to help evolve this work and define the strategy, including convening advocates and stakeholders to refine and build upon each other's efforts and housing this guidance as a living document at www.caregiving.org.

With this report, NAC calls upon policymakers, researchers, and advocates alike to move the field forward toward a society equipped to address the needs of caregivers across the lifespan.

THE NATIONAL CAREGIVER ADVOCACY COLLABORATIVE

This work is driven by the lived experiences of family caregivers and their advocates, as represented by members of NAC's National Caregiver Advocacy Collaborative. The core group of advocates actively engaged in the project includes:

Sheila Palmer Harrod
University of Arkansas for Medical Sciences
Schmieding Home Caregiver Training
Program (AR)

Veva Arroyo
San Diego Caregiver Coalition (CA)

Ashley Costa
Lompoc Valley Community Healthcare
Organization (CA)

Sherry Pauline
University of Southern California, USC's
Rossier Organizational Change &
Leadership (CA)

Toula Wootan
Caregiver Coalition of Northeast Florida (FL)

Chris Damon
CareSmart Illinois (IL)

Joanna Fawzy Morales
Triage Cancer (IL)

Emily Kearns
Massachusetts Lifespan Respite Coalition
(MA)

Chris Kealey
Massachusetts Caregiver Coalition (MA)

Laurance Stuntz
Massachusetts Caregiver Coalition (MA)

Lylie Fisher
Montgomery County Caregiver Support
Program (MD)

Michelle Mills
Baltimore County Department of Aging (MD)

Beth Wiggins
Metropolitan Caregiver Service Collaborative
(MN)

Shawn Moore
Caregivers on the Homefront (MO)

Carol Degraw
United Way of New Jersey Caregivers
Coalition (NJ)

Debbie Carroll
The Senior Sage (NV)

Doris Green
New York State Caregiving and Respite
Coalition (NY)

Sheila Williams
Sunnyside Community Services (NY)

Janice Williams
Caregivers Respite (TN)

Gloria Miranda
WellMed Charitable Foundation/Alamo
Caregiver Support Coalition/Hispanic
Outreach Coalition (TX)

Faith Unger
Caregiver U - Central Texas (TX)

Debra Scammon
The David Eccles School of Business,
University of Utah (UT)

Linda Porter
Lifespan Respite Washington (WA)

Dana Allard-Webb
Washington State Department of Human
Services (WA)

Janet Zander
Greater Wisconsin Area Agency on Aging
Resources (WI)

In addition, national experts with subject-matter expertise in caregiving also supported the collaborative's effort, including:

Amy Gotwals
National Association of Area Agencies on
Aging

Connie Siskowski, R.N., Ph.D.
American Association of Caregiving Youth

Jennifer Rosen
Alzheimer's Association-Alzheimer's Impact
Movement

Jill Kagan
ARCH National Respite Network and
Resource Center

Joe Caldwell, Ph.D
Community Living Policy Center, Lurie
Institute for Disability Policy, Brandeis
University

Kelly O'Malley, Ph.D
Health & Agency Policy Fellow

Laura Blessing, Ph.D
The Government Affairs Institute,
Georgetown Univ., Senior Fellow

Lauren R. Bangerter, Ph.D
Health & Agency Policy Fellow

Molly Ramsey
Elizabeth Dole Foundation

Rhonda Richards
AARP

Sage Rosenthal
Coalition to Transform Advanced Care
(C-TAC)

Sherry Pauline
University of Southern California, USC's
Rossier Organizational Change &
Leadership



National Alliance for Caregiving

1730 Rhode Island Avenue NW
Suite 812
Washington, DC 20036

202.918.1013 phone
202.918.1014 fax
info@caregiving.org

caregiving.org



About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. NAC conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, NAC supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.