

RAISE Act State Policy Roadmap for Family Caregivers: Using Research, Data, and Evidence-**Informed Practices to Support Family Caregivers**

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Section 5: Using Research, Data, and Evidence-Informed Practices to Support Family Caregivers

Introduction and Rationale

States value family caregiving as a key element of supporting care recipients living in the community. Data is central to states' abilities to support caregivers in providing care. Data enables the state to understand the demographics and needs of its caregivers and how they utilize supports. It also helps states determine their impact on the needs of Medicaid members and the costs associated with their care, which can be crucial to demonstrating cost effectiveness and securing funding for caregiver support programs. However, because many family caregiver support programs have limited funding, states often do not have the resources to pay for extensive family caregiver data collection and program evaluation. Currently, the main standardized national-level data source for state-level family caregiver information is the Centers for Disease Control and Prevention (CDC)'s **Behavioral Risk Factor Surveillance System (BRFSS) Caregiver module**. However, this module is optional for states, so information is not available for all states. Because states do not necessarily have significant data collection structures available for family caregiver programs in particular, developing information about the return on investment for family caregiver supports is challenging.

How States Assist Family Caregivers

"Washington [administered] the BRFSS Caregiver module over 10 years ago. We found [the BRFSS Caregiver module] helpful and leveraged the information from it to better understand the prevalence of caregiving in the state and how many hours of support are actually provided. We used the data to advocate for more funding for our family caregiver program and the need to implement a caregiver assessment tool."

- Washington State Official, July 2020

Identification of unpaid and family caregivers by state systems as part of a data collection process is key to understanding the full spectrum of caregiving. However, identifying unpaid caregivers is challenging if they do not self-identify as such. States have opportunities to collect family caregiver data through passage of the CARE (Caregiver Advise, Record, Enable) Act, which requires hospitals to identify a caregiver and collect their contact information, notify the caregiver of discharge planning, and train them in nursing or medical tasks they are asked to perform. The act has been passed in over 40 states, which presents a mechanism for data analysis to determine how the CARE Act requirements are implemented, as well as best practices. Furthermore, while the past decades have seen an increase in research about family caregivers, more research is needed to better understand caregivers' needs and outcomes, particularly at the state level. The Families Caring for an Aging America (2016) report and the RAISE Family Caregivers Act Report to Congress (2021) note growing research on family caregiving but also note gaps in the research literature. Much work and evidence on family caregiver interventions and support programs focuses on caregivers of those with Alzheimer's disease and related dementias; fewer evidence-based caregiver interventions for other populations exist. There is still much to be learned about translating evidence-based caregiver interventions into multiple settings and the impact of caregiving on outcomes in communities of color and on LGBTQ caregivers.

To better understand the needs of family caregivers, it is important for state policymakers to have a data collection and evidence base that illustrates caregivers' support needs, available services, and potential service gaps. This data can be used to target resources toward evidence-informed caregiver services that can help family caregivers continue to provide care at home. These services could in turn help lower care costs at the state level and support states' work in Medicaid rebalancing toward providing more home- and community-based services.

State Challenges

While federal agencies collect information about family caregivers, less data collection and research around family caregivers is conducted at the state level, particularly as Medicaid does not collect family caregiver data. Federal agencies that collect data include the Administration for Community Living (ACL) — through data collection from the National Family Caregiver Support Program; the AGing, Independence, and Disability (AGID) online portal; and the National Survey of Older Americans Act Participants — and the Centers for Disease Control and Prevention — through the Behavioral Risk Factor Surveillance System (BRFSS)'s optional Caregiver Module.

States may not have a standardized mechanism for collecting various levels of data, such as:

- Population data: the BRFSS Caregiver module is optional and funded by the states.
- Administrative data: family caregivers are not identified in Medicaid claims or encounter data.
- Clinical data: family caregivers are not consistently captured in electronic health records.

Data on family caregivers is included in certain programs such as the National Family Caregiver Support Program and the VA Caregiver Support program, but data collection is limited and faces many challenges, including:

- A lack of longitudinal state data on family caregivers that has been exacerbated during the COVID-19 pandemic, which saw a greater reliance on family caregivers.
- Narrow state definitions of family caregivers, which constrains the types of caregivers that can receive support, such as those caregivers who are not related by blood or marriage
- Family/unpaid caregivers often not self-identifying as caregivers.
- States lacking dedicated funding streams to regularly collect and analyze data and research on family caregivers.

To address these challenges, the RAISE Family Caregiving Advisory Council has developed a series of recommendations for a national family caregiving strategy that incorporates the development of and access to data and evidence-informed family caregiving supports.

State Strategies and Promising Practices

To implement the above recommendations, state policymakers can use the following strategies:

- 1. Use broader definitions of family caregiver.
- 2. Administer the BRFSS Caregiver module.
- 3. Use family caregiver assessments and plans of care as aggregate data collection.
- 4. Prioritize collecting family caregiver data and outcomes.
- 5. Compile state inventories of family caregiver services.
- 6. Develop state evaluations of family caregiving programs.
- 7. Implement evidence-supported programs for family caregivers.

#1. Use Broader Definitions of Family Caregiver

How family caregivers are defined within state programs affects the types of caregivers who can access services. Narrow state definitions of family caregivers, which exclude, for example, non-biologically or legally related caregivers, lead to an incomplete understanding of family caregiving, as well as inequity. Developing broader definitions that include a range of caregivers from families of choice, such as non-legally or non-biologically related caregivers, can ensure that more types of unpaid caregivers receive support. Additionally, using broader definitions can capture the experiences of individuals who may not identify as caregivers, such as grandparents raising children, LGBTQ caregivers, neighbors, and friends. Broader definitions would allow flexibility to conduct outreach to underserved populations, such as rural caregivers or caregivers that are not biologically or legally related to care recipients. Flexible definitions can also allow for outreach to a variety of cultural communities (see Section 1 of this roadmap).

RAISE Family Caregiving Advisory Council Recommendations: Research, Data, and Evidence-Informed Practices

Goal 5: Family Caregivers are engaged stakeholders in a national research and data gathering infrastructure that documents their experiences, translates evidence into best practices, develops person- and family-centered interventions, and measures progress toward the National Family Caregiver Strategy.

- <u>Recommendation 5.1</u>: Establish a national infrastructure using standardized data, questions, and a definition of "family caregiver" for obtaining, analyzing, and disseminating information about caregivers and their experiences.
- <u>Recommendation 5.2</u>: Increase family caregiver research that facilitates the development and delivery of programs and services that support and enhance the health and well-being of the caregiver and care recipient.
- <u>Recommendation 5.3:</u> Increase the promotion, translation, and dissemination of promising and evidence-supported practices to support family caregivers in the delivery of healthcare and long-term services and supports.

Examples of defining unpaid caregivers broadly are as follows:

• The RAISE Family Caregivers Act defines a family caregiver as "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."

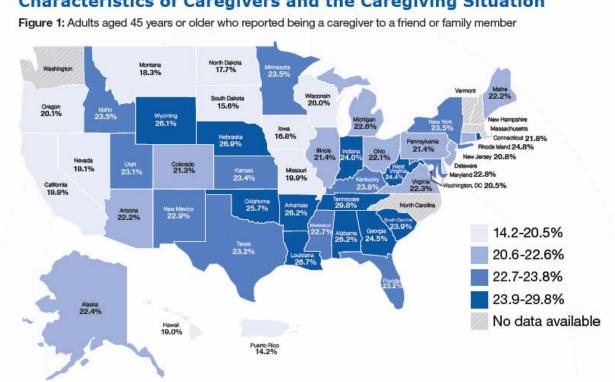
• The Lifespan Respite Care Act of 2006 defines a family caregiver as "an unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special need."

• Utah's New Choices Medicaid 1915 (c) waiver's Caregiver Training service defines unpaid caregivers eligible for the service as "any person, family member, neighbor, friend, companion, or co-worker who provides uncompensated care, training, guidance, companionship, or support to a person served on the waiver."

The U.S. Department of Veteran Affairs' Program of Comprehensive Assistance for Family
Caregivers notes an eligible family caregiver is either "the eligible veteran's spouse, son, daughter,
parent, stepfamily member, or extended family member; or someone who lives with the eligible
veteran full-time or will do so if designated as a family caregiver." The Program of General Caregiver
Support Services notes that within the program, a general caregiver is "a person who provides
personal care services to a veteran enrolled in VA healthcare who: needs assistance with one or
more activities of daily living or needs supervision or protection based on symptoms or residuals of
neurological care or other impairment or injury. General caregivers do not need to be a relative or
live with the veteran."

#2. Administer the BRFSS Caregiver Module

One data collection option available to states is administering the Behavioral Risk Factor Surveillance System's (BRFSS) optional Caregiver module. This module can allow states to develop a baseline level of data from which to better understand the state's caregiving population and identify high needs of caregivers in order to target services. The most recently revised version from 2019 of the BRFSS Caregiver module contains nine questions, including the amount of caregiving, the types of tasks caregivers perform, the relationship between the caregiver and care recipient, and an individual's expectation of becoming a caregiver in the next two years. Most recently, a question measuring whether the care recipient also had Alzheimer's disease or another dementia was added. Eight states used the Caregiver module in 2020. However, between 2015 and 2018, 44 states, along with DC and Puerto Rico, administered the module at some point. States must pay the cost to administer the module along with funding analysis of the data. States must also consider the additional time required to administer optional modules, given the long mandatory sections of BFRSS. However, combining the optional Caregiver and Cognitive modules can produce helpful data that state administrators can use for evaluations, particularly if states have funded the administration of the modules through state or other programs targeted to caregivers of Alzheimer's disease or related dementias.



Characteristics of Caregivers and the Caregiving Situation

Source: CDC.gov (2015–2017 BRFSS data)

New York State: administering the BRFSS Caregiver module as part of larger grant funding. New York State funds BRFSS Caregiver module data collection by linking the optional Caregiver and Cognitive modules through its Alzheimer's Disease Assistance Fund. This fund also supports projects from New York State's five-year Alzheimer's Disease Caregiver Support Initiative, which is intended to use an evidence-based approach to support people with Alzheimer's disease and related dementias and their family caregivers. Partners such as the Alzheimer's Association also create outreach materials with information about caregivers in New York. The Caregiver module allows New York State's Department of Health to assess population-level data on prevalence and characteristics of caregiver populations served, along with caregiver outcomes. The estimated cost for the modules was \$5,000 per question for both modules (15 questions total) as of 2022. New York State has used Caregiver and Cognitive Module data in its Alzheimer's Disease Caregiver Support Initiative evaluation. This evaluation found caregivers served by the program were providing more intense care for longer time periods compared to the national population. In the first year of the program, collected data suggested that diverse ethnic minority populations were underrepresented in the initiative's served population compared to the general state population and a national sample of caregivers.

#3. Use family caregiver assessments and plans of care as aggregate data collection

The majority of states use some form of family caregiver assessment, often within smaller family caregiver support programs rather than in Medicaid programs. While these assessments are important for assessing family caregivers' own needs and creating comprehensive care plans, states can also use this information to collect and analyze data to understand outcomes and make

informed policy decisions. More specifically, states can use this information to better understand caregiver demographics, assess the need for currently available supports, and develop or expand access to services and supports that are most needed and most effective.

Texas: using caregiver assessments across different funding streams. Texas state

legislation required Texas' Health and Human Services Commission (HHSC) to analyze data about unpaid caregivers collected via caregiver assessments and then evaluate the data and strategies taken to support informal caregivers. The caregiver assessments include the Caregiver Status Questionnaire (CSQ) and the Caregiver Assessment Questionnaire (CAQ). The CSQ, administered through HHSC, is used to collect caregivers' demographics and referral needs at intake for specified Medicaid and other programs, including employment and caregiver stress level. The CAQ, administered by area agencies on aging (AAAs), is used to evaluate caregivers receiving care coordination or caregiver support coordination services through the federally funded National Family Caregiver Support Program and includes demographics and in-depth needs assessments. The CSQ & CAQ were developed through a state-led evidence review and stakeholder workshop. HHSC which collects CSQ data directly and receives CAQ data from AAAs - reviewed the data, created in-depth reports, and submitted them to the legislature. These reports contain the department's findings on how to support and strengthen access to family caregiver services. Data include information about caregiver demographics, challenges, skills and training, caregiver knowledge and acceptance of services, and the effect of caregiving on employed caregivers. The reports also note how the state has worked to address caregiver needs, through strategies such as addressing outreach through updating and promoting the state's caregiver website and promoting uptake of caregiver interventions. Texas plans to continue using data collected from the assessments to shape services. HHSC will continue coordinating data and information systems across its departments to ensure a broader understanding of caregiver and care recipient needs and efficiently coordinated services and supports.

#4. Prioritize collecting family caregiver data and outcomes

States vary in their infrastructure for collecting data for mandatory reporting. All states are required to submit performance reports to ACL on Older Americans Act (OAA)-funded programs, including the National Family Caregiver Support Program (NFCSP). The required demographic data that states collect on caregivers include age, gender, rurality, ethnicity, race, and relationship to the care recipient. States are required to report numbers of caregivers served, along with expenditures and program income used for counseling and training, respite, supplemental services, self-direction, access assistance, and information services administered through the NFCSP. The data are now reported to ACL through the Older Americans Act Performance System (OAAPS), a data system for states to submit information on OAA-funded programs. However, an ACL report notes that states report challenges in budget and staffing regarding data collection and that the age and power of a state's data collection system affects the amount of additional program information they are able to collect.

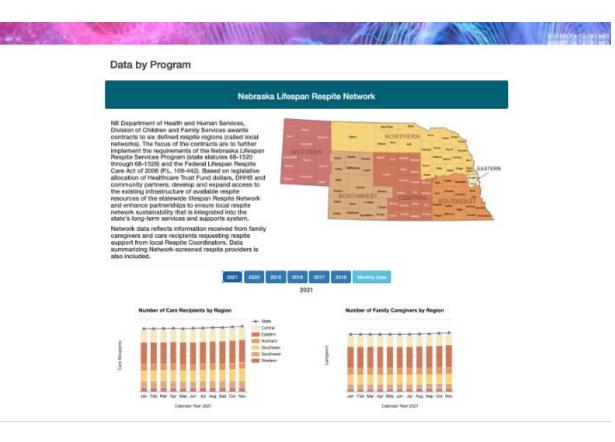
Despite these challenges, states including Alabama, Arizona, Colorado, Delaware, Indiana, Minnesota, and Montana include caregiver data collection goals or information in their state plans on aging, such as the administration of caregiver surveys, data collection structure development, and gap analysis for respite services that support caregivers.

Minnesota: analyzing NFCSP service gaps and opportunities. The Minnesota Board on Aging (MBA) contracted with the Wilder Foundation in 2016 to better understand how the state delivered NFCSP services to family caregivers and investigate opportunities for innovation and improvement. The research describes what services were available to caregivers, what services were being used, patterns in how services were being used, and opportunities to adapt services to better serve caregivers that could be reflected in Minnesota's state plan. Area Agencies on Aging (AAA), key experts, and stakeholders were interviewed to collect information about caregiver services, caregivers, and care recipients. Minnesota Department of Human Services and MBA caregiver information and data were also collated. The inventory found that a range of caregiver supports were available, including caregiver training and education, pilots of caregiver support interventions, and partnerships with health providers to support referrals. The researchers found that the NFCSP served a majority female and white population at or below 200% of the poverty level. Minnesota also found that caregivers reported the services were helpful and received a recommendation from AAAs that information on all caregiver supports, not only information from the NFCSP, should be collected. This report informed part of the background of Minnesota's 2019-2022 state plan on aging, which includes recommendations for strategic priorities to address caregiver needs.

#5. Compile state inventories of family caregiver services

States can collate information about currently available family caregiver services, gauge program gaps, and reach more caregivers by addressing program gaps.

Nebraska: coordinating a publicly available data dashboard. Nebraska's respite data dashboard contains lifespan respite data across multiple populations, including older adults, people with disabilities, and children. The dashboard, partially funded through an ACL Lifespan Respite Integration grant administered in 2014 and coordinated by the Department for Health and Human Services (DHHS), contains data across multiple programs that include number of care recipients and caregivers served. The aim of the dashboard is to provide a centralized source of lifespan respite data across programs. Participating organizations include state agencies supporting individuals with disabilities, children, adults, and families; state units on aging; area agencies on aging; and privately funded and volunteer programs.



Source: Nebraska DHHS

North Dakota: developing a state family caregiver support inventory across multiple funding

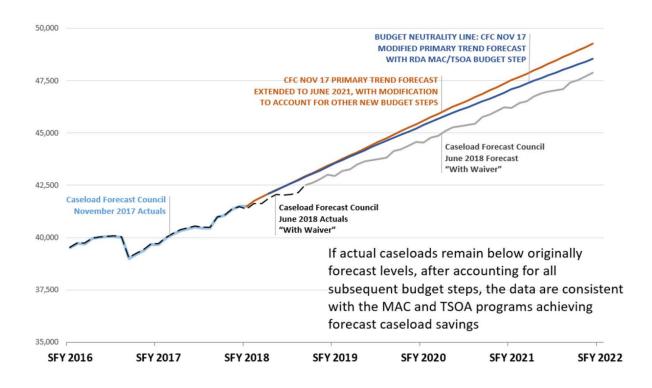
sources. North Dakota passed HB 1279, requiring the legislature to commission a project to identify policies and resources available to family caregivers. The North Dakota State Legislative Human Services Committee contracted with North Dakota State University to study supports to family caregivers in the state. The project aimed to identify resources, barriers, best practices, and emerging practices and provide recommendations to the committee. The university submitted an evaluation of family caregiver supports to the legislature. Findings included the need for more respite access, rural caregiver support, caregiver training opportunities, and outreach and sustainable funding for caregiver programs. North Dakota's Aging Services Division used the data and insights from this study to obtain an ACL Lifespan Respite Grant, develop presentations with community groups, and testify before the legislature about outcomes and lessons learned.

#6. Develop state evaluations of family caregiver programs

Very few states have consistently measured family caregiver outcomes. States may lack the capacity to evaluate family caregivers and care recipients' outcomes, especially quality of life in home and community-based settings, compared to a national sample. States may also lack the capacity to examine family caregiver programs' effects on reduced transitions to Medicaid, nursing homes, and hospitals, which can decrease costs for states. Washington State and California are examples of states examining family caregiver outcomes.

Washington: using data to project cost estimates of family caregiving programs

Washington has made data collection and analysis a central part of its Medicaid Transformation Project (MTP) 1115 waiver, which builds on the state's family caregiver support program. Washington uses a commercially available family caregiver assessment tool, TCARE, for two programs within its Medicaid Transformation Project: Medicaid Alternative Care (MAC) for Medicaid-eligible individuals not currently using Medicaid LTSS, and Tailored Services for Older Adults (TSOA) for certain individuals likely to need Medicaid LTSS in the future. TCARE is used to screen and assess family caregivers of individuals participating in these programs. TCARE screenings are one of two primary ways that MAC and TSOA collect data, along with participant surveys. Under the waiver, an estimated "synthetic" model is developed using Medicaid baseline utilization data among demographic groups and service modes, and demographic projections, which show the expected Medicaid utilization in the absence of the program. The actual utilization rates are later analyzed and compared to the model in the final evaluation report, allowing Washington to assess the impact of MTP on overall Medicaid utilization and expenditures. TCARE assessments play a role in this analysis by helping Washington determine who is being served by the waiver and helping the state conduct subgroup analyses of results under the program. Because participating caregivers are screened using TCARE every six months, longitudinal analysis of participants is possible. As a result, assessments serve a dual role of helping the state determine the needs of the caregiver while also analyzing the impact of the program on LTSS expenditures.



Source: Washington State Department of Social and Health Services

While Washington's analysis is not yet completed, early survey results suggest that the waiver is achieving its goals of lowering Medicaid spending. Washington is funding a one-year extension (year six) of its 1115 waiver through local intergovernmental transfer funds. The Centers for Medicare and Medicaid Services (CMS) is phasing out these Delivery System Reform Incentive Payment (DSRIP) 1115 waivers, so the state plans to continue to use local intergovernmental transfer funds for its five-year renewal going forward.

California: using national caregiver data as a comparison for state-level outcomes

California's Caregiver Resource Centers (CRCs) collect information from family caregivers that they serve, and these data were used in a recent evaluation of California's caregiver services. Funded primarily by California's Department for Health Care Services, CRCs provide support for people with cognitive impairments and debilitating conditions and their caregivers. The Family Caregiving Institute at the University of California (UC) Davis's Betty Irene Moore School of Nursing, in collaboration with the Family Caregiver Alliance, conducted the evaluation. This evaluation is notable because it includes comparison data from a national level (Caregiving in the U.S. Survey) and a state level (California Health Interview Survey). The evaluation also included CRC-reported outreach and education data and qualitative data collected from individuals associated with CRCs. Caregivers served by CRCs came from all parts of the state and reflect the diversity of the state, with 48% reporting as non-white; 1,250 educational activities in multiple languages reached over 67,000 caregivers over the fiscal year. CRCs report outreach to non-English speakers through offering services in multiple languages, creating a shared calendar of online education activities available throughout the state, and advertisement campaigns that include non-English-speaking targeting populations. CRCs are required to report a summary and evaluation of their services, including client, caregiver, services, and cost data. The evaluation found that the caregiver population served was at comparatively higher risk than the general population in line with CRCs' targeting of caregivers of people with chronic conditions.

Additionally, the evaluation found high satisfaction with the CRC services and proposed the possibility of using CareNav as a framework to support caregiver assessment in other systems outside of CRCs. CareNav, which is compliant with the Health Insurance Portability and Accountability Act (HIPAA), is a client-facing, proprietary interactive record system service, enabling client access at any time to start services via online application and to interact with a client dashboard. CareNav contains secure communication platforms for assessment, counseling, individual and group counseling, education and training (real time and on demand), and for ongoing family consultation encounters. Data from the record system are available to the sites in real time and were exported for formal evaluation by the UC Davis Betty Irene Moore School of Nursing. CareNav collects demographic information, caregiver health status, level of care intensity, the care recipient's health needs, types of caregiving tasks administered, and tasks for which the caregiver needed help.

#7. Implement evidence-supported programs for family caregivers

States serve a role in providing direct access to evidence-supported training, programs, and interventions for caregivers through NFCSP, Medicaid, or other sources of funding. However, the majority of evidence-supported interventions are for dementia caregivers.

Massachusetts: funding access to evidence-based programs. The Healthy Living Center of Excellence, with support from the state of Massachusetts, has provided access to evidence-based programs such as the Savvy Caregiver (both in English and Spanish) and Powerful Tools for Caregivers to caregivers in a variety of ways, which include the Home Care Program, the Family Caregiver Support Program, and when an older adult is being cared for by an individual eligible for the Medicaid 1915 (c) Frail Elder waiver. The Savvy Caregiver and Powerful Tools for Caregivers are on ACL's approved list of evidence-based programs that have been evaluated as effective. The Savvy Caregiver and Powerful Tools for Caregivers programs provide training, counseling, coaching, and other types of caregiver support to help caregivers feel more confident about providing care. Savvy Caregiver is a six-week program in which caregivers of people with Alzheimer's disease or other dementia learn about their caregiving role, dementia, and techniques to manage stress. Powerful Tools for Caregivers is a six-week course for caregivers on self-care and stress management.



Evidence-Informed Interventions for Dementia Family Caregivers

The following two resources provide state administrators with a list of dementia family caregiver evidence-based programs that can be implemented in Medicaid, family caregiver support programs, and Alzheimer's disease and other grant programs:

•ACL's evidence-based and evidence-informed interventions list for services and supports to people with Alzheimer's disease and related dementias and their caregivers.

•Best Practice Caregiving: an online database of vetted effective programs of dementia programs for family caregivers from a partnership of the Benjamin Rose Institute on Aging and the Family Caregiver Alliance.

Lessons Learned

While there is strong evidence of the importance and prevalence of family caregiving, state data collection on family caregivers — their needs, the effectiveness of interventions, the evidence-base for services and supports, and the cost-effectiveness of these services — is very limited, particularly for minority populations.

- States lack mechanisms for this type of data collection because family caregivers are not included in Medicaid claims data or electronic health records. States can collect population data through the BRFSS Caregiver module, but it is an optional module that survey recipients have little time for given the long length of the required BRFSS survey module questions.
- Despite these challenges, there are a number of promising practices in evaluations, inventories, and programmatic data collection that are highlighted in this roadmap that states can replicate.
- Improved state data collection could lead to a better understanding of the return-on-investment of caregiver services and supports and how to best close the service gaps among underserved caregivers.

About this Roadmap

The purpose of this roadmap is to assist states interested in expanding supports for family caregivers of older adults by offering practical resources on innovative and emerging policy strategies. Although families care for people across the life span, the focus of this roadmap is on policies, programs, and funding for family caregivers of older adults.

NASHP created this roadmap with guidance from policymakers and leaders from across state government, using the RAISE Act goals and recommendations as a framework. Congress enacted the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act in 2018, which created an advisory council to develop the country's first national Family Caregiver Strategy. With support from The John A. Hartford Foundation and in coordination with the U.S. Administration for Community Living, NASHP's RAISE Family Caregiver Resource and Dissemination Center aims to support states as they develop policies to address family caregivers.

The RAISE Family Caregiving Advisory Council recently published its **Report to Congress**, which highlights ways to better support family caregivers. In alignment with the Council's work, the roadmap is organized into the following sections as a series:

Section 1: Public Awareness and Outreach to Family Caregivers

Section 2: Engagement of Family Caregivers in Health Care Services and Systems Section 3: Services and Supports

- Services and Supports for Family Caregivers
- The Direct Care Workforce

Section 4: Financial and Workplace Security for Employed Family Caregivers Section 5: Research, Data, and Evidence-Informed Practices

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