



# RAISE Act State Policy Roadmap for Family Caregivers: Engagement of Family Caregivers in Health Care Systems

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## Section 2: Engagement of Family Caregivers in Health Care Systems

### Why Engage Family Caregivers in Health Care Services and Systems

States play a critical role in fostering the development of well-coordinated, comprehensive, and high-value health care systems that help individuals achieve good health outcomes and high quality of life, including remaining in their own communities as long as safely possible. For many people with complex conditions, achieving those goals requires coordination across both the health care and long-term services and supports (LTSS) systems, as well as the support of family or unpaid caregivers.

Family caregivers have a valuable role in both health care and LTSS systems. They provide services to their family members that might otherwise need to be provided by paid caregivers. They can be the first to recognize new symptoms, as well as changes in health conditions and individuals' ability to care for themselves. They often make it possible for their family members with self-care needs to live at home. However, current health care and LTSS systems are fragmented and not well-designed to support family caregivers, often causing them to become care coordinators across multiple systems. In addition, family caregivers may need training to recognize signs and symptoms that signal a change in care needs and a defined path for bringing that information to the attention of the care team.

In recent years, states have taken steps to improve family caregiver engagement in care delivery and planning. As of 2022, [45 states and territories](#) have enacted the Caregiver Advise, Record, and Enable (CARE) Act, legislation that requires hospitals to inquire if a patient has a family caregiver and, if so, include the caregiver in the discharge process and instruct them about the medical and nursing tasks they will do at home. Although the CARE Act is enacted in 45 states and territories, it lacks enforcement, which presents an opportunity for states to better support the act. State agencies can establish policies which align with the act, that are designed to ensure that family caregivers are included in care planning both initially and throughout the care process.

State Medicaid agencies have put in place services, such as structured family caregiving programs, that help family caregivers deliver and coordinate care by providing the caregiver with payment, individualized training, and a means for providing ongoing input into care planning. Area agencies on aging (AAAs) can also develop connections with home- and community-based services and health systems to assist in expanding referral systems to support caregivers. State policymakers hope that by adopting these policies they will not only help individuals achieve better health outcomes and quality of life but also help health systems reduce avoidable hospitalizations and readmissions — and ultimately contain cost by improving the delivery of care.

## RAISE Recommendations and State Challenges



### **RAISE Family Caregiving Advisory Council Recommendations: Engagement of Family Caregivers in Health Care and Long-Term Services and Supports**

Goal 3: Family caregivers are recognized, engaged, and supported as key partners with providers of health care and long-term services and supports.

- **Recommendation 2.1:** Identify and include family caregivers as essential members and partners in the care team of the person receiving support.
- **Recommendation 2.2:** Engage family caregivers through the use of evidence-supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support.
- **Recommendation 2.3:** Increase the integration of care through the inclusion of family caregivers in all relevant care coordination and transitions across providers and settings and when desired by both caregiver and the person receiving support.
- **Recommendation 2.4:** Ensure the impact of policy and practices on family caregivers are studied and understood before changes are made in health care systems.
- **Recommendation 3.5:** Strengthen the training of health care, social service, and allied health professionals to maximize family caregiver engagement and referrals to services in the community.

The above recommendations offer a starting point for states to more effectively engage family caregivers as key partners in the planning and provision of care. Some states have already implemented strategies that advance this goal, such as establishing Medicaid policies that require providers and contracted managed care plans to include an individual's family caregiver as a member of their care team. However, fully implementing these recommendations would likely require state legislation and changes to regulations, contracts, and procedures. It is also likely to require action by multiple state agencies, including Medicaid, aging, disability, licensing, and other agencies. Some of the challenges these efforts will likely encounter include the following:

- Protocols for recording family member information are not systematically or consistently implemented in health systems' electronic health or medical records.
- Family caregiver assessments are not consistently integrated into the intake process or the discharge process.
- Data and health information exchange systems may not currently be set up to include contact with family caregivers.
- Health professionals' continuing education requirements may not include content regarding family caregivers.
- Quality initiatives may not include family caregiver assessment or feedback.

## State Strategies

Some of the strategies that states are already using to implement the RAISE Family Caregiving Advisory Council recommendations include the following. Each of these is explored in more detail below, with specific examples for family caregivers who are caring for older adults and adults with physical disabilities.

1. Foster caregivers' inclusion on the care team.
2. Help family caregivers function effectively as a member of the care team.
3. Build identification and uniform assessment of family caregivers into state-funded programs and services.
4. Ensure that family members receive the information they need to care for the individual in the new setting prior to transitions in care setting, especially hospital discharge.
5. Ensure providers and other members of the care team know how to effectively engage family caregivers.
6. Measure family caregiver engagement and incorporate that information into quality improvement and value-based payment efforts.

## 1. Foster caregivers' inclusion on the care team

### Medicaid

The first step to engaging family caregivers as key partners is to formally recognize that role. Medicaid agencies can accomplish this by leveraging their role as a payer. States that deliver services through managed care, especially those that deliver both health and LTSS through managed care systems, [can leverage their Medicaid managed care contracts](#). A [2019 AARP study](#) found that 23 states with managed LTSS for older adults and people with physical disabilities include some contractual obligation for care coordinators to engage with family caregivers. States with fee-for-service delivery systems can leverage the Medicaid policies governing the payment for those services. There are also opportunities outside the Medicaid program. For example, states can leverage the state plans on aging that they are required to submit to the Administration for Community Living to receive Older Americans Act funding.

*New Jersey: including family caregivers in managed care delivery systems.* States can leverage managed care contracts to incorporate caregivers into plans of care and care coordination contact requirements. For example, New Jersey's [FamilyCare managed care organization](#) (MCO) contract requires care managers to make their contact information available to the caregiver and engage the caregiver in the plan of care development process. For managed LTSS plans of care, caregiver support is identified as an essential element in a member's plan of care. Finally, MCOs are required to maintain electronic care management records that identify the member's family support system and note their availability and any barriers to providing assistance.

*New York: including family caregivers in multiple delivery systems.* In a fee-for-service delivery system, state Medicaid agencies pay providers directly and establish expectations of how services are delivered. These policies are expressed in regulation, provider handbooks, and other documents. State Medicaid agencies not only deliver health services (e.g., inpatient hospitalizations and home health) but also case management and care coordination. Case management and care coordination may be delivered as a stand-alone service (e.g., [targeted case management](#) or under a [1915\[c\] waiver](#)) or as part of another service (e.g., [health homes](#)). The policies governing how these services are delivered can be leveraged to foster family caregiver engagement on the care team. For example, [New York Standards and Requirements for Health Homes and Care Managers and Managed Care Plans](#) requires health home providers to identify the supports that family members provide in the patient's plan of care. Further, if appropriate and desired by the individual, the plan of care must reflect the preferences of the family (in addition to those of the individual) and be accessible to the family.

### Older Americans Act

Within the Older Americans Act, states are required to create and submit a state plan on aging to the Administration for Community Living to receive funding. State plans on aging describe a state's goals and strategies for implementing programs and services for older adults. Many state plans on aging include information about states' supports and plans for supporting family caregivers of older adults. State plans on dementia also may contain information on objectives

and strategies to support caregivers of people with Alzheimer's disease and related dementias. These state plans offer opportunities for states to include objectives around incorporating caregivers specifically into the care planning processes in health care and LTSS.

*Delaware: incorporating case management services for older adults.* [Delaware's State Plan on Aging](#) lays out the state's seven strategies to "promote the development, expansion, and capacity of comprehensive and coordinated programs that serve and support caregivers" through supports such as the [Caregiver Resource Centers Network](#), services such as [Respite Care](#), and other activities supported by the Delaware Division of Services for Aging and Adults with Physical Disabilities. Delaware's Aging and Disability Resource Center provides family caregivers with information and referral to services such as [case management](#), [options counseling](#), and more for older adults and adults with physical disabilities.

*Minnesota: developing consultation initiatives that incorporate both caregivers and health providers.* Minnesota's [Caregiver Consultants](#) program, a regional network funded partly through the National Family Caregiver Support Program, trains professional service providers to support caregiver needs through a person-centered approach. These professionals are trained through a joint effort of the Minnesota Board on Aging, the Minnesota Department of Human Services, and AAAs. The Caregiver Consultants program includes assessment of a caregiver's needs, development of an action plan, and ongoing coaching to meet goals. Caregiver consultants have knowledge and training in the unique needs of caregivers, family systems, and Alzheimer's disease and related dementias. [Almost 80 professionals are trained as caregiver consultants statewide and are providing services.](#) Minnesota's state plan on aging also notes the [Cultural Awareness in Dementia Care](#) initiative, the goal of which is to help health care providers and aging services providers deliver culturally appropriate services for people with dementia and their caregivers through connections with AAA staff trained to provide cultural consultant services. Additionally, the [Return to Community initiative](#) uses trained staff from the Senior LinkAge Line (a service of the Minnesota Board on Aging in partnership with Minnesota's AAAs) to help people who are living in a nursing home and want to move home or to a new setting in their community. Working with nursing facility staff, Senior LinkAge Line staff develop a list of services that people can consider having at home to help them after they leave the nursing home, including caregiver supports.

## 2. Help family caregivers function effectively as a member of the care team

Similar to establishing policies that foster inclusion of the family caregiver on the care team, states can leverage both their managed care and fee-for service delivery systems to enhance the abilities of family caregivers to function as a team member. These center on improving caregivers' abilities to provide care and recognize critical changes in care needs, as well as offering a pathway for incorporating information provided by the caregiver into care planning and service delivery. Ideally, this support is targeted to the specific needs of the individual and the family caregiver. States can also incorporate training for family caregivers as a provided service in their state plans on aging. The New York State Department of Health developed a resource to caregivers describing the health care system, what to expect when caregiving, information on programs, and tips and resources to facilitate their caregiving experience. The resource is available through an [online](#) version as well as a hard copy that can be ordered directly from the Department of Health. This resource includes information on communicating with health care professionals.

*Georgia: including caregivers in electronic case management.* Georgia's [Structured Family Caregiving service](#) offers a Medicaid fee-for-service example of a policy that incorporates the family caregiver. This service features individualized assistance (and a daily stipend) to unpaid family caregivers who live with a qualified Medicaid 1915(c) [elderly and disabled waiver](#) participant. The individualized assistance features telephone and electronic support, including access to a secure electronic system for case management documentation (e.g., care plan notes) that is shared among the care team, including the family caregiver. The family caregiver enters daily notes into the electronic system, and the agencies administering the service are required to use the notes in care planning and service delivery. The family caregiver also has the support of other care team members, a health coach, and a registered nurse. Managed care contracts could require similar support, such as the usage of an electronic system that the caregiver has access to and can enter information and integration of the caregivers' notes into the care process.

## 3. Build identification and uniform assessment of family caregivers into state-funded programs and services.

A family caregiver assessment determines the availability, ability, and support needs of family caregivers in providing care and support. State agencies use these [assessments](#) to ask family caregivers about their own needs and connect them with services such as respite care, training, and other resources.



## Key Elements of Family Caregiver Assessments

- Caregiver demographics
- Caregiver supports currently available to the caregiver
- Caregiver tasks — intensity, duration, and type
- Caregiver stress or perceived burden
- Caregiver willingness to provide support
- Caregiver supports that are needed

More than half of state units on aging surveyed in a 2017 National Family Caregiver Support Program evaluation reported including Older Americans Act-funded caregiver assessments as part of family caregiver support programs. Many state Medicaid programs do not assess family caregivers specifically, but Tennessee and South Dakota are among the exceptions. Illinois is an example of expanding family caregiver assessment statewide through its AAAs.

*Tennessee: including caregiver assessment requirements in managed care contracts.* Tennessee contractually requires its MCOs to prepare and maintain a person-centered support plan for their members who participate in Tennessee’s CHOICES program. (CHOICES serves adults with disabilities and those over age 65 who require LTSS.) MCOs must conduct a caregiver assessment as part of the care plan process. Caregivers are defined as “a person who is (a) a family member or is unrelated to the member but has a close, personal relationship with the member and (b) routinely involved in providing unpaid support and assistance to the member.” The contract includes minimum required elements for a caregiver assessment. These requirements include a description of who is currently providing support to the care recipient, the caregiver’s needs and well-being, the caregiver’s stress level, caregiver training needs, and other caregiving support needs.

*South Dakota: incorporating caregiver assessment into Medicaid waiver services.* South Dakota’s Medicaid program has established structured family caregiving as a service in its Home and Community-Based Options and Person-Centered Excellence (HOPE) 1915(c) waiver, targeted to older adults and people with disabilities. This state delegates service delivery to qualified agencies who, among other tasks, are required to conduct a comprehensive caregiver assessment and establish a plan for educating, coaching, and supporting the caregiver. The state projects 126 users of the structured family caregiving service across all tiers of service, according to the HOPE Waiver’s Appendix J, in year one, increasing to 227 users in year five.

*Illinois: expanding caregiver assessment statewide.* Illinois recently expanded usage of the Tailored Caregiver Assessment and Referral (TCARE) family caregiver assessment tool. As of 2022, AAAs in 12 of the 13 regions of the state use or plan to utilize TCARE, an evidence-supported tool developed for assessing family caregivers’ needs. Illinois received \$5.2 million in Title III-E family caregiver funding from the American Rescue Plan Act (ARPA) funding, which included grant funding for AAAs to develop usage of TCARE. In particular, AAAs have submitted plans for ARPA funding that can include support for a TCARE specialist.



#### 4. Ensure that family members receive the information they need to care for the individual in the new setting prior to transitions in care setting, especially hospital discharge.

Family members play a [significant role](#) in providing ongoing care after hospital discharge, and this care is often complex. Family members, who are not professional caregivers, may be unprepared for this care role. Thus, transitions in care setting, such as hospital discharges or transitions from nursing facilities to the community, can be both a time of greater risk for individuals and a defined opportunity to support and engage family caregivers. One way to both mitigate the risk of the change and engage caregivers is to ensure that they are armed with the information they need to help make the transition successful before the transition occurs.

States can enact legislation establishing requirements for how providers deliver care to all patients — and these requirements can include requirements about care transitions. The [Caregiver Advise, Record, Enable \(CARE\) Act](#) is model legislation that has been adopted by [a number of states](#). This act requires hospitals to inform individuals of the opportunity to identify a family caregiver in their record, record caregiver contact information in a patient's health record with permission, train the family caregiver on needed medical or nursing tasks, and provide advance notice and consultation regarding discharge plans. The handful of states that have not yet enacted the legislation could do so. State legislators could also enact similar laws to support other critical transitions, such as transitions from a nursing facility or other setting to the community. Finally, states that have already enacted the legislation could support its implementation.

*[New York: developing educational resources for providers on discharge planning.](#)* In 2016, the New York Health Foundation issued the report “[Improving the Discharge Planning Process in New York State](#),” which outlines barriers, best practices, and recommendations for the hospital discharge process. One recommendation, which has been [enacted into law](#), requires hospitals to provide the opportunity to incorporate the patient's family/representative into the discharge planning process.

To better support the CARE Act, state agencies can embed assessment requirements into licensure requirements. To raise awareness of the CARE Act, state agencies and governors' offices can spreadhead outreach campaigns, develop public letters for health systems, and publicize the signing of the CARE Act through outreach to family caregivers, as [New York State](#) does.

*[Delaware: defining requirements that include family caregivers in Medicaid managed care contracts.](#)* States place a high priority on transitioning beneficiaries from nursing facilities to their communities. These transitions also offer an opportunity to engage family caregivers in care delivery and planning. Delaware's [MCO contract \(Section 3.8.6\)](#) defines MCO requirements for supporting nursing facility transitions, which include accepting referrals for transitions from family members and incorporating the family/caregiver in the transition planning process.



### Opportunities to involve caregivers in care transitions and discharge planning

- Electronic medical records, health information exchanges, and care plans in care settings can include family caregivers' contact information.
- Managed care plans can incorporate family caregiver supports within the care plan, including information on current supports and anticipating future needs. They can also require inclusion of family caregivers as care team members.
- Targeted case management services can be developed for older adults and people with physical disabilities to provide specialized care transition support that incorporates family caregivers.
- Incorporating communication skills within provider training, in particular around communication with family caregivers during the care process, can better help providers engage with family caregivers and increase caregiver referrals to support services.

## 5. Ensure providers and other members of the care team know how to effectively engage family caregivers.

Research published in 2020 found that approximately 1 out of 10 family caregivers reported communicating often with the health care team about their care recipient. This lack of communication may stem from providers not viewing family caregivers as part of the overall care team. Health care professionals, who are not trained in person- and family-centered care, may not be aware of the value of regularly engaging family caregivers in care discussions or may feel unsure of how to approach conversations about incorporating family caregivers, particularly if the care recipient does not want family caregivers to participate. One strategy that states could implement is to ensure that the providers and other members of the care team know how to effectively engage family caregivers. For example, Delaware's [Master Service Agreement](#) requires managed care organizations to ensure that their case managers have the ability to "collaborate with caregivers (3. 7.1.2.2.6)."

State officials can provide information to help educate health care providers and health systems about coordinating with family caregivers. This information can be hosted on state websites and promoted through state channels.

- Created by the Minnesota Department of Health Stroke Program, the [Stroke Patient Transitions of Care Toolkit](#) was created for hospitals and health facilities to support patient transitions from hospitals to the community. The toolkit notes the care recipient and caregiver can be educated in self-management processes and that hospitals should develop processes to follow up with care recipients and/or caregivers post-discharge. The [Stroke Patient Post-Discharge Follow-up and Data Collection Guide](#) is an additional resource for hospitals that includes information on how to develop a follow-up process and collect data.
- New York State included a [checklist](#) for discharge planners on a state website for a Discharge Planning Workgroup. The workgroup was convened to support recommendations from a [council](#) charged with supporting integrated care settings for people with disabilities. This checklist included noting what informal supports are available

to the care recipient and their goals and knowing what types of communication modes are available for the individual caring for the care recipient at home.

## 6. Measure family caregiver engagement and incorporate that information into quality improvement and value-based payment efforts.

Ultimately, states interested in strengthening family caregiver engagement would need to measure it to know how well their efforts are going and identify needed improvements. Some states may choose to incorporate measurements of family engagement into the value-based payment efforts.

*Tennessee: incorporating family engagement into value-based payment models.* Tennessee has established a value-based payment model for nursing facilities that considers family engagement throughout, including considering family input in selection of quality outcome and staff training measures and family satisfaction in measurement of culture change and quality of life. The [most recent iteration of this model](#), which is for the 2021 performance year, considers survey results to the question, “Overall, do you and your family have enough input or say in your care?”

*Massachusetts: supporting coordination and partnerships between organizations that serve caregivers.* Massachusetts has taken a more indirect approach to measuring family caregiver engagement. The state has prioritized family caregiver supports through its [State Plan on Aging](#), created by the state’s Executive Office of Elder Affairs. One of Massachusetts’s six stated goals is to strengthen Massachusetts as an age- and dementia-friendly state. Massachusetts’s strategies for achieving this goal include strengthening partnerships among aging and disability resource center service providers, health care organizations, and individuals living with dementia and their caregivers, leading to an expansion of programs and services for family caregivers of people living with dementia.

*Washington and California: incorporating evidence-informed assessment of family caregivers into programs.* [Washington](#) and [California](#) show diverse examples of using assessment and data collection to better understand family caregiver needs and evaluate family caregiver programs’ outcomes. Washington and California enacted legislation supporting evidence-informed assessment for family caregivers. For more information about family caregiver services and supports, see the RAISE Act State Policy Roadmap [Section 3a](#).

## Lessons Learned

- States can foster engagement of family caregivers as key partners in the provision and planning of services by incorporating family caregivers into assessment, plans of care, and care coordination, as well as data and quality processes.
- Although most states have enacted the CARE Act, it lacks enforcement. States can work with hospital associations to develop timelines around implementation and guidance for hospitals.
- States, managed care plans, primary care providers, and others can all engage caregivers in care transitions and discharge planning to ensure that potential post-discharge needs are addressed in advance of discharge and that caregivers receive adequate preparation to provide care.
- States can incorporate family caregiver assessment or feedback into quality measurement and value-based initiatives.

## 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 lifespan, 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, establishing the [RAISE Family Caregiving 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](#) supports states as they develop policies to address the needs of family caregivers.

The RAISE Family Caregiving Advisory Council published its [RAISE Report to Congress](#), which highlights ways that states can 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 (this section)**

Section 3: Services and Supports

- [Services and Supports for Family Caregivers](#)
- [The Direct Care Workforce](#)

Section 4: [Financial and Workplace Security for Family Caregivers](#)

Section 5: [Research, Data, and Evidence-Informed Practices](#)

**This section — Engagement of Family Caregivers in Health Care Services — is the sixth and final publication in this series.** This roadmap was made possible by support from [The John A. Hartford Foundation](#) and the [RRF Foundation for Aging](#).

