

Research Report

Recognition of Family Caregivers in Managed Long-Term Services and Supports

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Family Caregiving™

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Additional Information

This report summarizes the findings of a review of contract language related to family caregivers from 31 managed long-term services and supports programs in 23 states. Detailed summary tables for each of the 23 states are available at www.aarp.org/family-caregivers-in-mltss.

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The views expressed herein are for information, debate, and discussion, and do not necessarily represent official policies of AARP.

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Executive Summary

Nearly half of states have transitioned their Medicaid long-term services and supports (LTSS) delivery systems to managed care, referred to as *managed LTSS* (MLTSS). State Medicaid programs are leveraging their contracts with health plans to improve the coordination of acute care and LTSS and to provide more person-centered assessment and service delivery. These practices aim to improve Medicaid beneficiaries' health outcomes, quality of care, and quality of life. Many states also believe that MLTSS allows them to better control and predict Medicaid spending on LTSS, which was an estimated \$154 billion in 2016.¹

Family caregivers are often the critical factor that allows people who need LTSS to live at home and in the community. The value of the care they provide far exceeds expenditures by Medicaid, the largest government payer for LTSS.

In 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contribution was approximately \$470 billion.²

In addition to providing emotional support and help with daily living activities (such as bathing and dressing), many family caregivers today take care of relatives, partners or close friends with multiple and complex medical conditions, performing tasks that previously were the domain of health care professionals. As with most family caregivers, this role usually comes on top of their having a paying job and other family responsibilities. Consequently, the family's capacity as the primary care provider is becoming increasingly strained—especially in light of their typically lacking adequate supportive services for

themselves, or not even being formally identified as the family caregiver.

Because family members and other unpaid caregivers play such a key role for those with health and LTSS needs, understanding and addressing family caregiver needs is now regarded as a fundamental component of a high-performing LTSS system.³

“America’s caregivers deserve to be seen as valuable members of the health care team. They should be included in decision making, given opportunities to voice their concerns, and provided appropriate instruction. They should not be taken for granted—or worse, criticized for their perceived failures and inadequacies.”

– Home Alone Revisited: At a Glance,
AARP Public Policy Institute,
November 2019

A promising evolution in MLTSS is the advancement of person- and family-centered care. This approach recognizes and supports family caregivers beyond how a family caregiver can help the managed care member. States can include provisions in their managed care contracts that require MLTSS programs to systematically identify, engage, and meaningfully support their members' family caregivers. Such requirements make financial sense because involving and supporting family caregivers make it more likely

1 Susan C. Reinhard, Lynn Friss Feinberg, Ari Houser, Rita Choula, and Molly Evans, *Valuing the Invaluable: 2019 Update. Charting a Path Forward* (Washington, DC: AARP Public Policy Institute, 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>.

2 Ibid.

3 Susan C. Reinhard et al., 2017, <http://www.longtermcorecard.org>.

that they can sustain their roles and keep their relatives and friends out of expensive nursing homes.

ABOUT THIS REPORT

This report, based on a study of MLTSS programs, examined provisions in MLTSS contracts that are important for the support of family caregivers. The study comprised the review of 31 MLTSS programs for older adults and adults with physical disabilities in 23 states in 2019. Using key search terms, we identified a considerable amount of contract language that sheds light on elements of state contracts that help ensure family caregivers' inclusion and support in MLTSS programs.

It is important to keep in mind that this review of managed care contracts has limitations in providing a complete picture of caregiver support in MLTSS programs. Nevertheless, as the legal agreement between the state Medicaid program and its health plan partners, the managed care contract carries a great deal of weight in signaling the state's principles and priorities with respect to its MLTSS program.

FINDINGS

Key findings include:

- Nearly all state MLTSS programs include family caregivers in service planning and care coordination (upon the member's consent) and provide some services and supports (such as respite care or caregiver education and training) targeted to members' family caregivers.
- Most state MLTSS programs include family caregivers in their quality assessment and performance improvement (QAPI) programs⁴ and on member advisory committees.
- A minority of MLTSS programs assess (or reassess) the well-being and support needs

of their members' family caregivers, or allow for family caregivers to be paid as a provider in consumer-directed models of care.

RECOMMENDATIONS

Based on the findings above, this report makes the following recommendations:

1. **State contract language for MLTSS programs should clarify that a comprehensive assessment of the member includes questions directly asked of family caregivers about their own health and well-being, potential strain from juggling a paying job and caregiving, and any services and supports that they may need to be better prepared for their caregiving role.**
2. **The Centers for Medicare & Medicaid Services should provide guidance to states on promising practices in developing and administering family caregiver assessment tools in MLTSS programs.**
3. **All state MLTSS programs should provide ample and meaningful opportunity, including *but not limited to* member advisory committees, for family caregivers to have a voice in the program to improve care delivery, especially if family caregivers are to be part of the care team.**

CONCLUSION

While significant inroads have been made in recognizing the value of family caregivers in MLTSS, states can take additional steps to design services and supports around the needs and goals of members and their family caregivers in MLTSS programs. States that have clearly defined requirements in their contracts with respect to inclusion and explicit support of family caregivers send a strong message to all MLTSS stakeholders to improve the culture of care and promote person- and family-centered care as a standard form of practice.

⁴ See: QAPI Description and Background. <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/QAPI/qapidefinition>.

Introduction

Family caregivers are a lifeline for millions of individuals with chronic illnesses and disabling conditions, enabling them to live at home and in the community. In 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contribution was approximately \$470 billion.⁵

Today's family caregivers are increasingly providing complex care and carrying out tasks that nurses typically perform (such as performing wound care, giving daily injections, or operating complex medical equipment).⁶ Most (60 percent) of them are also employed either full-time or part-time, placing competing demands on the caregivers' time.⁷ The physical, emotional and financial strain on family caregivers—particularly on those caring for family members or close friends with the most intense and complex care needs—can be considerable for the care recipient and family, as well as the health care system as a whole.

By contrast, evidence suggests that when family caregivers are adequately assessed for unmet needs and provided targeted supportive services (such as education and training, respite care, and counseling), it helps maintain their own

health and well-being, sustains their ability to provide care, provides better outcomes for the care recipient, and prevents or delays nursing home placement.⁸ Yet, greater recognition of and support for family caregivers is needed to adopt meaningful person- and family-centered care as routine practice in managed LTSS.^{9,10,11,12}

Understanding and addressing family caregiver needs is now regarded as a fundamental component of a high-performing long-term services and supports (LTSS) system.¹³

Medicaid—the nation's largest public health insurance program for people with low-incomes—also serves as the primary source of public funding for LTSS. Thus, state Medicaid agencies with managed LTSS programs have an interest in understanding and addressing family caregiving issues because family members and other unpaid caregivers play a key role for those with health and LTSS needs. State Medicaid programs that deliver LTSS through managed care can use their contracts with health plans to advance person- and family-centered delivery systems that identify and support their members' family caregivers.

Medicaid programs that use managed care to deliver LTSS to members are referred to as *managed LTSS* (MLTSS). Since 2000, states have rapidly increased the use of managed care

5 Reinhard et al., *Valuing the Invaluable: 2019 Update, Charting a Path Forward*.

6 Susan C. Reinhard, et al., *Home Alone Revisited: Family Caregivers Doing Complex Care* (Washington, DC: AARP Public Policy Institute, 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf>.

7 Lynn Friss Feinberg, *The Dual Pressures of Family Caregiving and Employment* (Washington, DC: AARP Public Policy Institute, 2016), <https://www.aarp.org/ppi/info-2016/the-dual-pressures-of-family-caregiving-and-employment.html>.

8 National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America* (Washington, DC: The National Academies Press, 2016), <https://nam.edu/families-caring-for-an-aging-america/>.

9 Ibid.

10 Susan C. Reinhard, Wendy Fox-Grage and Lynn Friss Feinberg, *Family Caregivers and Managed Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, 2016), https://www.aarp.org/content/dam/aarp/ppi/2016-08/AARP1080_FSandMLTSS_REPORT_WEB.pdf.

11 Susan C. Reinhard, et al., *Emerging Innovations in Managed Long-Term Services and Supports for Family Caregivers*. (Washington, DC: AARP Public Policy Institute, 2017), http://www.longtermscorecard.org/~/_media/Microsite/Files/2017/2017%20Scorecard/AARP1202_EI_EmerInnovationLTSS_Oct31v2.pdf.

12 Lynn Feinberg, *Moving Toward Person- and Family-Centered Care* (Washington, DC: AARP Public Policy Institute, 2012), <https://moving-toward-person-and-family-centered-care-aarp.pdf>.

13 Susan C. Reinhard et al., 2017, <http://www.longtermscorecard.org/>.

programs to deliver LTSS to Medicaid members with complex care needs.¹⁴ Nearly half of states (24 states) now have implemented these programs, and the total number of programs in these states have more than quadrupled, from nine in 2004 to 41 in 2017.¹⁵ With rising demand for MLTSS, states and the federal government have been exploring a variety of innovative approaches and policies to support better outcomes for enrollees while still stabilizing costs.

In recent years, there have been a number of milestones in the evolving field of family caregiver assessments and supports in MLTSS. At the federal level, increased awareness among key stakeholders of the benefits of supporting family caregivers has resulted in several policy developments. The Medicaid Managed Care Final Rule of 2016 acknowledges the critical role of family caregivers.¹⁶ However, the rule falls short in setting forth requirements for how MLTSS programs should include and support them.¹⁷

In 2018, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act was enacted, directing the Secretary of the Department of Health and Human Services (HHS) to develop, maintain, and update a strategy to recognize and support family caregivers of an individual (of any age) with a chronic or other health condition, disability, or functional limitation. The law calls for an evaluation of the impact of family caregiving on Medicare,

Medicaid, and other federal programs. The strategy will recommend actions that promote greater person- and family-centered care in all health care and LTSS settings, and address assessment and service planning involving care recipients and family caregivers, among other actions.¹⁸

In addition, a number of states have adopted promising innovations in their Medicaid managed care plans to recognize and support family caregivers, when the plan's member depends on them for care.¹⁹ While significant inroads have been made in recognizing the value of family caregivers in MLTSS, states can take additional steps to design services and supports around the needs and goals of members and their family caregivers in managed care programs.

The AARP Public Policy Institute (PPI) contracted with IBM® Watson Health™ to review current MLTSS contracts to determine if there has been progress made on provisions related to family caregivers, since an earlier contract review in 2014.²⁰ This report adds to the knowledge base that PPI has developed over a decade of extensive research and dialogue on family caregiver services and supports in MLTSS including surveys, research reports, roundtables, and learning collaborative discussions with key stakeholders on promising practices in MLTSS. Common terms used throughout this report are defined in Exhibit 1.

14 Elizabeth Lewis, Steve Eiken, Angela Amos, and Paul Saucier, *The Growth of Managed Long-Term Services and Supports Program: 2017 Update* (Greenwood Village, CO: Truven Health Analytics, 2018), <https://www.medicaid.gov/medicaid/managed-care/downloads/ltss/mltssp-inventory-update-2017.pdf>.

15 Lewis et al., 2018 and Saucier et al., 2005. The growth in the number of MLTSS programs exceeds the growth in the number of states with MLTSS programs because a number of states have built on their initial MLTSS experience by taking advantage of the Financial Alignment Initiative to develop programs to better serve those dually eligible for Medicare and Medicaid and by adding programs for populations which they had previously excluded from MLTSS such as individuals with developmental disabilities.

16 Susan C. Reinhard, Wendy Fox-Grage, and Lynn Friss Feinberg, *Family Caregivers and Managed Long-Term Services and Supports*.

17 Ibid.

18 See: <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>.

19 Reinhard et al., *Emerging Innovations in Managed Long-Term Services and Supports for Family Caregivers*.

20 Paul Saucier, and Brian Burwell, *Care Coordination in Managed Long-Term Services and Supports*, (Washington, DC: AARP Public Policy Institute, 2015), <https://www.aarp.org/content/dam/aarp/ppi/2015/care-coordination-in-managed-long-term-services-and-supports-report.pdf>. This report focused primarily on care coordination in managed LTSS, including how family caregivers are incorporated into the process. There is some overlap between the current study and this earlier study on the contract elements examined, but an exact comparison cannot be made. See Appendix B. Detailed Description of Approach for more information.

Exhibit 1. Key Terms

Caregiver Support Services: Family caregiver supportive services include information about managing chronic conditions and available services, assistance in gaining access to services and supports, education and training on direct care skills, and respite care (to provide temporary relief from caregiving tasks). Support services may also include counseling, short-term therapy groups to increase coping skills, family meetings, in-persona and online support groups, and assistive technologies.^a

Consumer-Direction (also referred to as *Participant-Direction* or *Self-Direction*): Consumer-direction allows for members, or their representatives, to decide how, when and by whom care is provided, such as paying family caregivers to provide certain services. States have the option to offer this type of service delivery; most often, states elect consumer direction for services that provide daily direct care for a member, such as personal care, homemaker, or attendant care services.

Family Caregiver: Broadly defined, refers to any relative, partner, friend, or neighbor who has a significant personal relationship with, and who provides a broad range of assistance for, an older person or an adult with a chronic, disabling, or serious health condition.

Family Caregiver Assessment: A systematic process of gathering information about a family caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the caregiver's ability to contribute to the needs of the care recipient.^{b,c} A family caregiver assessment asks questions of the family caregiver. It does not ask questions of the care recipient about the family caregiver.^d

Family Caregiving: Providing a wide array of help for an older person or other adult with a chronic, disabling, or serious health condition. Such assistance can include help with personal care and daily living activities (such as bathing, dressing, paying bills, handling insurance claims, preparing meals, or providing transportation); carrying out medical or nursing tasks (such as administering multiple medications, performing wound care, or handling medical equipment); locating, arranging, and coordinating services and supports; hiring and supervising direct care workers (such as home care aides); serving as an "advocate" for the family member or friend during medical appointments or hospitalizations; communicating with health and social service providers; and implementing care plans.

Long-Term Services and Supports (LTSS; also referred to as *Long-Term Care*): The broad range of day-to-day help needed by people with long-term conditions, disabilities, or frailty. This can include personal care (such as bathing, dressing, and toileting); complex care (such as medications or wound care); help with housekeeping, transportation, paying bills, and meals; and other ongoing social services. LTSS may be provided in the home, in assisted living and other supportive housing settings, in nursing facilities, and in integrated settings such as those that provide both health care and supportive services. LTSS also includes supportive services provided to family members and other unpaid caregivers.^e

Managed Care: A health care delivery system organized to manage cost, utilization, and quality. Medicaid managed care provides for the delivery of Medicaid health benefits and additional services through contracted arrangements between state Medicaid agencies and managed care organizations (MCOs) that accept a set per member per month (capitation) payment for these services.^f

Managed Long-Term Services and Supports (Managed LTSS): A Medicaid managed care program that includes most or all LTSS in the managed care organization (MCO) benefit package and payment rate.

Member: The Medicaid beneficiary who is receiving the services through the managed care delivery system, also referred to as the *enrollee, member, managed LTSS program participant, or care recipient*.

Person- and Family-Centered Care (PFCC): An orientation to the delivery of health care and social services that addresses an individual’s needs, goals, preferences, cultural traditions, family situation, and values. PFCC improves care and quality of life through its focus on how care is delivered from the perspective of the older adult or the person with disabilities and, when appropriate, his or her family. PFCC both recognizes and supports family caregivers.^g

Representative: An individual who is authorized by the member to intervene as necessary on his or her behalf when interacting with the health plan, providers, or the Medicaid program. Representatives can be a member’s guardian or other legally responsible individual, but they are not required to be. Representatives can complete tasks such as filing appeals or grievances on behalf of the member or hire and training or firing consumer-directed service employees at the request of the member.

Respite: Respite is planned or emergency care provided to an individual with special needs in order to provide temporary relief to family caregivers who are caring for that individual.^h

^a Susan C. Reinhard, et al., *Emerging Innovations in Managed Long-Term Services and Supports for Family Caregivers* (Washington, DC: AARP Public Policy Institute, 2017).

^b Family Caregiver Alliance, *Caregiver Assessment: Principles, Guidelines, and Strategies for Change, Report from a National Consensus Development Conference*, vol. 1. (San Francisco, CA: Family Caregiver Alliance, 2006).

^c Lynn Feinberg and Ari Houser, *Assessing Family Caregiver Needs: Policy and Practice Considerations* (Washington, DC: AARP Public Policy Institute, 2012).

^d Kathleen Kelly et al., *Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home- and Community-Based Service Waiver Programs* (Washington, DC: AARP Public Policy Institute, 2013).

^e Susan C. Reinhard, et al., *Picking Up the Pace of Change: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (Washington, DC: AARP Public Policy Institute, 2017).

^f Medicaid.Gov, *Managed Care*, Accessed December 5, 2019, at <https://www.medicaid.gov/medicaid/managed-care/index.html>.

^g Lynn Feinberg, *Moving Toward Person- and Family-Centered Care* (Washington, DC: AARP Public Policy Institute, 2012).

^h Arch National Respite Network, *What is Respite?*, Accessed December 27, 2019, at <https://archrespite.org>.

Exhibit 2. Managed LTSS Contract Elements Related to Family Caregivers

1. **Assessment of family caregiver** – an assessment of the family caregiver’s health and needs that is separate from the assessment of the member’s health and needs.
2. **Inclusion of family caregivers in development of service plan and coordination of care** – a service planning and/or care coordination process that includes family caregivers.
3. **Services and supports for family caregivers** – services or supports that directly help the family caregiver.
4. **Consumer direction that includes family caregivers** – a consumer direction program that allows payment to the family caregiver.
5. **Reassessment triggered by loss of family caregiver** – the loss of the family caregiver triggers the health plan to conduct a reassessment of the member’s health and needs, with loss defined broadly as a change in status that affects the caregiver’s ability to provide care to the member (e.g., death, hospitalization, illness, employment, or financial strain).
6. **Inclusion of family caregivers in managed LTSS health plan member advisory committee** – inclusion of family caregivers in the member advisory committee that is required in managed LTSS contracts that started on or after July 1, 2017 (42 Code of Federal Regulations [CFR] §438.110).
7. **Quality of care measures or processes that involve family caregivers** – quality or performance measures related to family caregivers and/or quality assessment or performance improvement processes that include or relate to family caregivers.

direct but important impact on the member and family caregiver’s overall experience of care. A member advisory committee is required in MLTSS programs and must include “at least a reasonably representative sample of the LTSS populations, or other individuals representing those enrollees, covered under the contract with the [managed care entity].”²² Quality assessment and performance improvement (QAPI) are clearly defined processes with extensive requirements in Medicaid managed care that are based on the Centers for Medicare & Medicaid Services (CMS) Quality Strategy. Family caregivers’ involvement in a health plan’s member advisory committee and quality of care processes gives them a voice in how the program is working for the member and for them. The relationships among these elements are shown in Figure 2.

SEARCH TERMS

We used the following search terms to identify contract language related to the seven elements included in the study, in addition to any unique terms found in individual contracts (e.g., *ally* in the Michigan MI Choice Waiver Program):

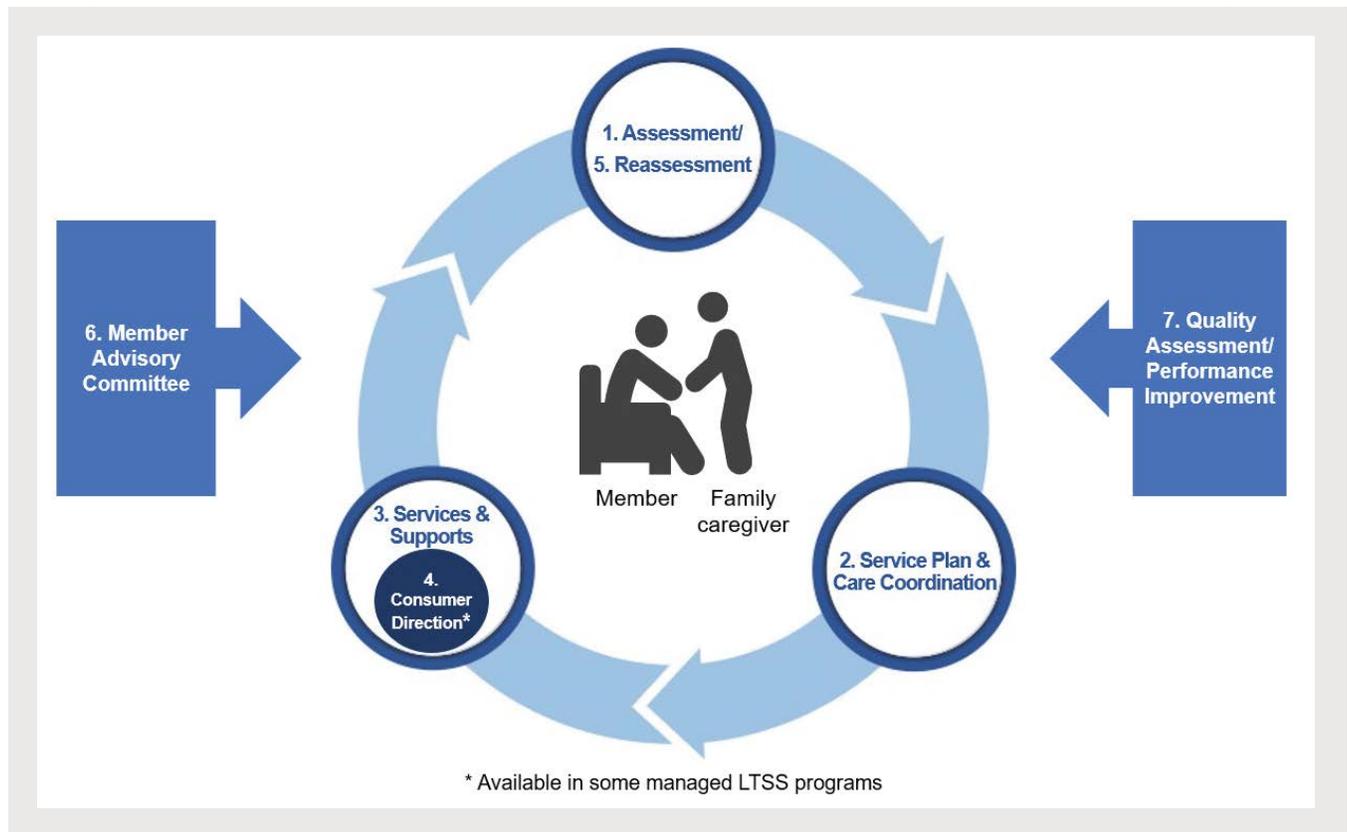
- Family caregiver/caregiving²³
- Informal caregiver/caregiving
- Informal support
- Caregiver/caregiving
- Representative (i.e., family member or friend who is a representative of the managed LTSS member)
- Family/families
- Spouse

In general, we assumed that any of these terms could apply to a family caregiver.

22 Centers for Medicare & Medicaid Services. May 2016. *Medicaid and Children’s Health Insurance Program (CHIP) Programs; Medicaid Managed Care, CHIP Delivered in Managed Care, and Revisions Related to Third Party Liability*. Final Rule. 81 Fed. Reg. 27497 § 438.110. Accessed December 5, 2019, at <https://www.govinfo.gov/content/pkg/FR-2016-05-06/pdf/2016-09581.pdf>.

23 We included alternative spellings: care giver, care giving.

Figure 2
Managed LTSS Contract Elements that Directly Affect the Member and the Family Caregiver



STATE REVIEW AND FEEDBACK

After compiling the findings based on the contract review, we sent them to the respective study states for validation. Twelve of the 23 states responded, and seven provided supplemental information (not found in their MLTSS contracts) on how their programs address elements examined in the study. This information is included with qualifying contract language in state summary tables available on the AARP website at www.aarp.org/family-caregivers-in-mltss.

STUDY LIMITATIONS

There were several limitations to the study. The most important was that in order to produce timely findings, the scope was limited to a review of MLTSS contracts and did not include other potentially relevant program materials, such as operational protocols, handbooks, or HCBS waiver program applications.²⁴ Another limitation is that managed care contracts do not convey all the ways in which MLTSS programs or individual health plans address the needs of family caregivers in practice. Finally, as described above, some states provided supplemental information, either anecdotally or based on other documents, while others did not.

24 HCBS waiver program applications contain detailed information on services covered through the waiver and on the assessment and service plan development processes.

Findings

OVERALL

As shown in Figure 3, two of the elements were by far the most commonly found in the MLTSS contracts: (1) inclusion of the family caregiver in service planning and care coordination and (2) services and supports for caregivers. Contracts for all but one MLTSS program include a reference to family caregivers as part of the care team, upon the member’s consent. And contracts for all but two MLTSS programs reference coverage of services such as respite care and caregiver training. The least common contract element was family caregiver assessments (seven programs in six states). We describe findings below by contract element. Appendix C includes a compilation of findings across elements and states.

FINDINGS BY MANAGED LTSS CONTRACT ELEMENT

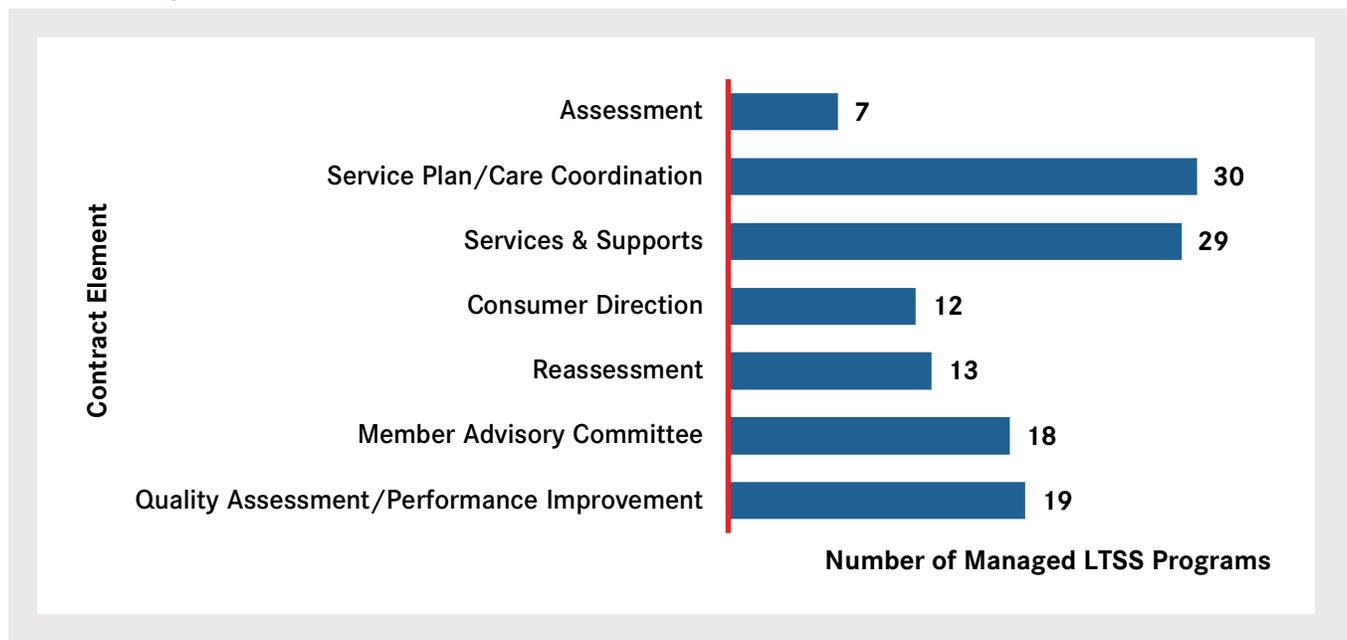
Family Caregiver Assessment

As part of the process for a member receiving LTSS, the health plan or other authorized entity

must complete an assessment to determine (1) the member’s needs and goals and (2) how those will be supported in the service plan. States vary in the types of LTSS assessment tools they use; assessment tools can be unique to the state or nationally recognized and validated (or a hybrid of the two). Assessments occur at regular intervals, generally at initiation of services and annually thereafter or when needs of the member change. However, these assessment processes generally are focused only on the member, without attention to family caregivers beyond their capacity to provide unpaid care. Yet providing high quality care for the member often requires an understanding of the family caregiver’s situation too.

Our review, identified language in contracts for seven MLTSS programs in six states that described assessment of the needs of family caregivers (beyond their capacity to provide support to the member). The contract language ranged from a focus on the risk of caregiver burnout (e.g., Hawaii QUEST Integration) to a

Figure 3
Number of Managed LTSS Programs with Family Caregiver References in Managed LTSS Contracts by Contract Element



more comprehensive inventory of the caregiver's health and well-being, level of stress, and training and other support needs (e.g., Tennessee's TennCare CHOICES in Long-Term Care). As noted in previous AARP PPI reports^{25,26} the TennCare CHOICES contract remains a standout both because it is the only one that contains a detailed section devoted to caregiver assessment and because of the level of specificity it provides on what the assessment should cover.

This focus on assessing the family caregiver for strain and other potential negative impacts of caregiving (such as increased depression or worsened physical health) is important because family caregiver burnout can be a factor in a member going from living at home to living in a nursing home, which can affect quality of life for the member (and Medicaid costs).²⁷

Inclusion of Family Caregivers in Service Planning and Care Coordination

Following an assessment of the member's needs and goals, a care coordinator develops a service plan; such plans generally must have a strict connection between all of the member's assessed needs and how they will be met, both through paid and unpaid supports. As part of person- and family-centered planning, it is important that discussions during service-plan development and review include the member, the care team, and others at the invitation of the member.

Such planning addresses the members' needs, goals, preferences, cultural traditions and values. It also considers not only how the family caregiver can help the member, but also what support the family caregiver needs to function in his or her caregiving role.

Nearly all programs reviewed (30 programs in 22 states) had managed care contracts that contained specific language requiring that family caregivers be included in service planning and care coordination at the preference of the member. This finding indicates that including family members in service planning and care

“The contractor shall ensure the person-centered planning process includes... at minimum, the member and if appropriate the member's legal representative, family, service providers and others directly involved in the member's care...”

- Iowa HealthLink

coordination has become common practice in MLTSS program contracts.

Including family caregivers in the service planning process is a cornerstone of person- and family-centered planning, an approach that features a team of people chosen by the member who work together to develop a service plan that meets the member's identified needs—as well as those of the member's family caregiver—especially when the execution of the service plan depends upon the family caregiver. Through the contract language, states recognize family caregivers as an essential part of the member's care team and the role they play in supporting the member to remain at home and in the community. One basic, yet critical, way to acknowledge this role is to ensure that family caregivers have the name and contact information for the member's care coordinator. Several states require health plans to provide this information to family caregivers.

Some states also specified that any services provided by a family member or other unpaid supports must be noted as part of the care plan. However, such contract language did not address a family caregiver's capacity to carry out caregiving tasks or their own support needs (such as if the caregiver works at a job on top of caregiving responsibilities). Services provided by family caregivers should only be included in the care plan if the caregiver has agreed to provide these

25 Paul Saucier and Brian Burwell, *Care Coordination in Managed Long-Term Services and Supports*.

26 Susan C. Reinhard, Wendy Fox-Grage, and Lynn Friss Feinberg. *Family Caregivers and Managed Long-Term Services and Supports*.

27 Ibid.

services and has indicated their ability to carry out the actual tasks.²⁸

Services and Supports for Family Caregivers

If family caregivers' needs are accounted for in the assessment process and the development of the service plan, then it follows that the service plan will include services and supports for the family caregiver as a covered benefit, particularly if the member relies on the family caregiver to provide any level of sustained care and support to continue living at home and in the community.

“The case management system must provide caregiver supports and facilitation of caregiver respite to assist enrollees to remain at home.”

– Minnesota Senior Care Plus and Senior Health Options

“The Managed Care Plan shall implement and maintain a formal Caregiver Training Program. The Caregiver Training Program shall address the financial, emotional, and physical elements of caregiving, as well as outline the resources available to caregivers in crisis.”

– Florida Statewide Medicaid Managed Long-Term Care Program (Quality Enhancement)

A total of 29 programs in 21 states reference services and supports for family caregivers in contract language. This contract element is not quite as common as the inclusion of family caregivers in the service plan development

process; however, it is important to note that depending on the design of the program, detailed information about covered services may more likely be in other MLTSS program documents than in the contract.²⁹

Most often, the services offered as a covered benefit to support family caregivers include respite care and training and consultation. Respite care offers family caregivers a short-term break from the day-to-day care of the covered member. Respite care can be provided in the home or in a facility on an hourly or daily basis as defined by the program. States that offer respite care vary on whether they place limits on the service; those that do typically have limits that range from 14 to 30 days per calendar year.

Training and consultation services also are regularly offered to support caregivers. These services are targeted toward training caregivers in necessary skills for continued care of the covered member and for the member to remain at home. They can include workshops that teach caregivers about expectations for a member returning home from a stay in a nursing home (Delaware Diamond State Health Plan Plus) or one-to-one or group training to improve coping skills for caregivers caring for a member with a disability (New Jersey FamilyCare). Less common examples of family caregiver support services are presented in Exhibit 3.

Consumer Direction that Includes Family Caregivers

As part of person-centered care for members receiving LTSS, states and their health plan partners have long offered some level of consumer or participant direction for some types of benefits. Consumer direction allows for the member, or representative, to act as the employer of the service provider, with the ability to hire, train, and fire the provider. In general, consumer direction is offered for services that provide day-to-day assistance with activities of daily living, such as

28 Eric Carlson, “Voluntary Means Voluntary: Coordinating Medicaid HCBS with Family Assistance,” Justice in Aging Issue Brief, Justice in Aging, Oakland, CA., May 2016.

29 For example, for managed LTSS programs that include section 1915(c) waiver programs, detailed information on covered waiver services is included in the section 1915(c) waiver application. The Section 1915 (c) waiver allows states to use Medicaid funding to provide home and community-based services (HCBS) to enrollees who otherwise would have been provided institutional care, <https://www.medicare.gov/medicaid/hcbs/authorities/1915-c/index.html>.

Exhibit 3. Examples of Less Common Services and Supports Targeted toward Family Caregivers in Managed LTSS Contracts

- Health promotion and wellness activities (**multiple states, for those with Financial Alignment Initiative Demonstrations**)
- Gas reimbursement for transportation to Medicaid-covered services (**Virginia Commonwealth Coordinated Care Plus**)
- Training in how to use specialized equipment and supplies (**Michigan MI CHOICE**)
- Hospice (**Arizona Long-Term Care Services**)
- Management of dementia (**Massachusetts Senior Care Options**)
- Consultative clinical and therapeutic services (**Wisconsin Family Care and Family Care Partnership**)
- Social day care (**New York Managed Long-Term Care Partial Capitation**)

“Members shall have the flexibility to hire persons with whom they have a close personal relationship to serve as an Attendant Care Employee, such as neighbor, friend, or family member.”

– Delaware Diamond State Health Plan Plus

dressings, bathing, or eating. In most states, the health plan or other fiscal management entity then provides administrative support, such as fulfilling payroll functions for providers employed by the member.

For the purposes of the study, we looked for contract language that supports the member’s choice to “employ” the family caregiver, who is allowed to receive payment for those services. Twelve MLTSS programs in 11 states now support consumer direction in which a spouse or other family member may be paid to provide care to the member, at the member’s choice—highlighting the importance of a member being cared for by a provider that he or she chooses.

Some states define conditions within their contracts in order for a family caregiver to be paid for services. For example, some state contracts specify minimum age (e.g., 18 years

old). Others clarify that the activities for which family caregivers would be paid are outside of the expected realm of care that a family member would typically provide or exclude legally responsible individuals from providing care.

Many more MLTSS programs promote consumer direction in general, without specifically noting that a family member may provide the care. With this foundation for consumer-directed care already developed, it is likely that additional states and programs may allow family caregivers to be paid caregivers in the future.

Reassessment Triggered by Loss of Family Caregiver

As noted previously, a member’s functional status and unmet care needs are assessed at initiation of service and reassessed at regular intervals, usually annually, or when there is a change in condition. We looked for references in the contracts to a loss of a family caregiver as a change in condition that would prompt or trigger a member’s reassessment of needs and goals. We defined *loss* broadly to include death, hospitalization, illness, employment, or other circumstances such as financial strain, that affect the family caregiver’s ability to provide care. Given the relationship between the assessment and the care plan, such loss also might necessitate a revision or modification to the plan to add a new service that previously may have been provided by the family

“Changes in the enrollee’s condition or needs that may warrant a comprehensive re-assessment include, but may not be limited to: hospitalization, significant changes in medication, change in, or loss of, a caregiver, medical psychosocial or behavioral health crisis, excessive emergency department utilization, other major changes in the enrollee’s psychosocial, medical, behavioral condition, or major changes in caregivers or housing.”

– Rhode Island Integrated Care Initiative

caregiver or increase hours of services received through other providers.

We found that 13 MLTSS programs in 10 states require a reassessment to be completed for a member affected by the loss of a family caregiver. As with other contract elements, the specificity of the contract language varies by state, with some states specifying that any change in caregiver status warrants a new assessment and others specifying that a change in caregiver status warrants a new assessment only when the member’s health or functional status has been affected. States also vary in whether they identify a timeframe for the reassessment. For example, Pennsylvania Community HealthChoices requires the reassessment to be completed as soon as possible but no longer than 14 days after the event has been reported to the health plan.

Inclusion of Family Caregivers in Health Plan’s Member Advisory Committee

The Medicaid Managed Care Final Rule of 2016 requires that MLTSS programs establish member advisory committees, to include “at least a reasonably representative sample of the LTSS populations, or other individuals representing

those enrollees.”³⁰ This provision was effective for contracts starting on or after July 1, 2017.

The feedback from members and other involved parties on member advisory committees, including family caregivers, provides valuable insights into members’ experiences and the quality of care they are receiving. Family caregivers are well positioned to help members provide such feedback, in addition to providing their own. Many of the MLTSS contracts we reviewed have language referring to a member advisory committee, but just over half of the programs (18 programs in 16 states) require health plans to include family members or caregivers. Given that MLTSS programs are now required to include member advisory committees, all MLTSS programs should see the value in directing health plans to ensure that family caregivers are on them.

“The Contractor shall establish an Enrollee advisory committee that will provide regular feedback to the Contractor’s governing board on issues of Demonstration management and Enrollee care. The Contractor shall ensure that the Enrollee advisory committee: Is comprised of Enrollees, family members and other caregivers that reflect the diversity of the Demonstration population, including individuals with disabilities. CMS and DHCS reserve the right to review and approve Enrollee membership.”

– California Cal MediConnect

Quality Systems that Involve Family Caregivers

The Medicaid Managed Care Final Rule of 2016 indicates that a state “must require, through its

30 Centers for Medicare & Medicaid Services. May 2016. *Medicaid and Children’s Health Insurance Program (CHIP) Programs; Medicaid Managed Care, CHIP Delivered in Managed Care, and Revisions Related to Third Party Liability*. Final Rule. 81 Fed. Reg. 27497 § 438.110. Accessed December 5, 2019, at <https://www.govinfo.gov/content/pkg/FR-2016-05-06/pdf/2016-09581.pdf>.

contracts” that each health plan “establish and implement an ongoing comprehensive quality assessment and performance improvement program for the services it furnishes,” including methods to “assess the quality and appropriateness of care” furnished to members receiving LTSS.³¹ Because family caregivers are often intimately involved in the member’s care, including them in the health plan’s quality systems could be one source of candid information to identify what has gone well and what can be improved in care delivery.

We found that most MLTSS programs studied, 19 programs in 16 states, have language in their contracts that require health plans to include family caregivers in QAPI processes. In general,

this language centers around the health plan creating and maintaining a mechanism for family members to provide feedback on quality-of-care issues; some states use family member involvement in a quality committee (or member advisory committee) as this mechanism. Other states’ program contracts have specific language requiring data about a member’s experience of care to be collected from them and their family members; *experience of care* generally relates to members self-reporting via an interview or survey about the quality of their care. The contract language identifies quality assurance feedback to be gathered about both quality of the member’s care and about system performance, such as the ease of referrals or the clarity of information provided by member services.

“The Contractor shall have an ongoing quality management program for the services it furnishes to members . . . The Quality Management program shall include, but is not limited to:

- Regular, and as requested, dissemination of subcontractor and provider quality improvement information including performance measures, dashboard indicators and member outcomes to [Arizona Health Care Cost Containment System] AHCCCS and key stakeholders, including members and family members.
- Developing and maintaining mechanisms to solicit feedback and recommendations from key stakeholders, subcontractors, members, and family members to monitor service quality and to develop strategies to improve member outcomes and quality improvement activities related to the quality of care and system performance.”

– Arizona Long-Term Care Services

31 81 Federal Register. 27497 §438.330, op. cit.

Themes

Overall, we found that nearly all MLTSS contracts reviewed include provisions that acknowledge the family caregiver's role in the development of the service plan and as part of the care team. We further found that nearly all contracts require health plans to provide some services and supports for family caregivers, such as respite care and caregiver education and training. However, considerably fewer contracts have requirements for health plans (or other entities conducting assessments) to assess the well-being and support needs of their members' family caregivers.

Three key themes emerged from the study:

States are commonly including elements in their MLTSS contracts with health plans that recognize and support their members' family caregivers.

The 2016 PPI report *Family Caregivers and Managed Long-Term Services and Supports Programs* concluded that "family caregiver support is not common practice in MLTSS."³² Based on the current review of MLTSS contracts, much progress has been made. We found that most states and programs studied addressed family caregivers in several contract elements, including service planning and care coordination, services and supports, quality assessment/performance improvement, and member advisory committees.

Recognition of and support for family caregivers are becoming standard practice in MLTSS for some contract elements.

Inclusion of family caregivers in service planning, care coordination, or both and the provision of some services or supports for (or that directly benefit) family caregivers are growing elements of practice in MLTSS. As described below, nearly all of the MLTSS programs studied have contractual requirements related to the inclusion of family caregivers in the health plan's care team, contingent on the member's approval. Similarly, nearly all of the MLTSS programs have contractual requirements related to coverage of some services and supports for family caregivers, such as respite care or training. Other contract elements identified in most contracts were the inclusion of family caregivers in quality assessment/performance improvement processes and in member advisory committees.

There were relatively few examples of contract language that describes assessing the well-being and support needs of family caregivers.

Many contracts that reference the family caregiver as part of the member assessment do so only in the context of the caregiver's capacity to support the member. Contracts for seven out of 31 programs describe assessment of the caregiver, and only a few of those specify what the assessment should address (e.g., health, welfare, stress, or burnout) or a caregiver assessment tool.

32 Susan C. Reinhard, Wendy Fox-Grage, and Lynn Friss Feinberg, *Family Caregivers and Managed Long-Term Services and Supports*.

Recommendations

Each of the contract elements described in this study present an opportunity for MLTSS programs to have meaningful engagement with family caregivers. Through these interactions, family caregivers can provide valuable input to improve care for the member and to ensure that they are supported in keeping the member at home and in the community.

It is important to keep in mind that this review of managed care contracts has limitations in providing a complete picture of caregiver support in MLTSS programs. Nevertheless, as the legal agreement between the state Medicaid program and its health plan partners, the managed care contract carries a great deal of weight in signaling the state's principles and priorities with respect to its MLTSS program.

The cornerstone of MLTSS is a comprehensive assessment of the member's needs and goals; it creates the foundation on which care planning, delivery, and coordination are based. The assessment drives the services and supports selected as part of the care plan—the frequency and duration of each service, and how services are coordinated among the care team. It is crucial that MLTSS programs approach assessment in a more holistic manner that includes the family caregiver's well-being and support needs; without a family caregiver assessment process, there is the possibility of a gap in services that fully support the family caregiver. This, in turn, puts the caregiver at risk for burnout and jeopardizes the member's ability to live at home and in the community.

As the agency responsible for oversight of MLTSS and the largest government payer for LTSS, CMS should provide leadership to states and health plans with respect to support for family caregivers.³³ Following a family caregiver assessment process, the caregiver should be connected to appropriate supportive services that

address identified needs, including education and training, support groups, family meetings, respite care, home modifications, assistive technology and transportation.³⁴

The requirement for an independent assessment of caregiver needs as established for the HCBS State Plan Option (SPO) sets a precedent that could be expanded to apply more broadly to Medicaid HCBS (including those provided through MLTSS). States that currently conduct caregiver assessments, either voluntarily or as required in HCBS SPOs, can offer valuable lessons learned to other states in the development and implementation of caregiver assessment tools and processes. CMS can leverage these early lessons to provide guidance to states and health plans at a national level.

To that end, we recommend the following:

1. **State contract language for MLTSS programs should clarify that a comprehensive assessment of the member includes questions directly asked of family caregivers about their own health and well-being, potential work strain from juggling a paying job and caregiving, and any services and supports that they may need to be better prepared for their caregiving role.**
2. **CMS should provide guidance to states on promising practices in developing and administering family caregiver assessment tools in MLTSS programs.**
3. **All state MLTSS programs should provide ample and meaningful opportunity, *including but not limited to* member advisory committees, for family caregivers to have a voice in the program to improve care delivery, especially if the family caregiver is part of the care team.**

Family caregivers can be important participants on member advisory committees to address the

³³ 42 Code of Federal Regulations 441.720(a)(4).

³⁴ Susan C. Reinhard, Wendy Fox-Grage, and Lynn Friss Feinberg, *Family Caregivers and Managed Long-Term Services and Supports*.

care experience and improve quality of care, including better understanding of issues related to family caregiving. As family caregivers may not always be available to participate on member advisory committees, states should consider other opportunities to obtain their input and encourage their involvement with the MLTSS program. These methods could include phone surveys, designated phone lines or email mailboxes, care manager or program administration outreach, or caregiver town hall meetings, among others.

Conclusion

While significant inroads have been made in recognizing the value of family caregivers in MLTSS, states can take additional steps to design services and supports around the needs and goals of members and their family caregivers in MLTSS programs. States that have clearly defined requirements in their contracts with respect to inclusion and explicit support of family caregivers send a strong message to all MLTSS stakeholders to improve the culture of care and promote person- and family-centered care as a standard focus of practice.

Appendix A. Managed LTSS Programs Included in Study

State	Program Name	Program Start Date	Date of Contract Used in Study (or Term of Contract)
Arizona	Arizona Long Term Care System (ALTCS)	1/1/1989	October 2018
California*	Cal MediConnect	4/1/2014	January 2018
Delaware	Diamond State Health Plan-Plus (DSHP-Plus)	4/1/2012	December 2017
Florida	Statewide Medicaid Managed Care Long Term Care Program	8/1/2013	February 2019
Hawaii	QUEST Integration	1/1/2015	August 2019 (Request for Proposal)
Idaho	Medicare-Medicaid Coordinated Plan	7/1/2014	2019
Idaho	Idaho Medicaid Plus (IMPlus)	11/1/2018	No date
Illinois	HealthChoice	1/1/2018	January 2018
Illinois*	Medicare-Medicaid Alignment Initiative (MMAI)	3/1/2014	January 2018
Iowa	Iowa Health Link	4/1/2016	January 2016
Kansas	KanCare (Managed LTSS Component)	1/1/2013	November 2017 (Request for Proposal for KanCare 2.0)
Massachusetts	Senior Care Options	3/1/2004	January 2018-December 2020
Michigan*	MI Health Link	1/1/2015	January 2018
Michigan	MI Choice	10/1/2013	October 2018
Minnesota*	Minnesota Senior Health Options (MSHO)	2/1/1997	January 2018
Minnesota	Minnesota Senior Care Plus (MSC+)	6/1/2005	January 2018
New Jersey	NJ FamilyCare (Managed LTSS Component)	7/1/2014	January 2019
New Mexico	Centennial Care (Managed LTSS Component)	1/1/2014	October 2018-December 2022
New York	MLTC Partial Capitation	1/1/1998	January 2015-December 2016
New York	Medicaid Advantage Plus	10/1/2007	January 2017-December 2021
Ohio*	MyCare	5/1/2014	July 2019
Ohio	MyCare (Medicaid-only)	5/1/2014	February 2019
Pennsylvania	Community HealthChoices	1/1/2018	January 2019
Rhode Island*	Integrated Care Initiative, Phase 2	12/1/2015	January 2018
South Carolina*	Healthy Connections Prime	2/1/2015	November 2017 and July 2018 amendment
Tennessee	TennCare CHOICES	3/1/2010	July 2019
Texas	Texas STAR+PLUS	1/1/1998	March 2019
Texas*	Texas Dual Eligibles Integrated Care Demonstration Project	3/1/2015	August 2017
Virginia	Commonwealth Coordinated Care Plus	8/1/2017	January 2019
Wisconsin	Family Care	1/1/1999	January 2018
Wisconsin	Family Care Partnership	1/1/1996	January 2018

* Financial Alignment Initiative (FAI): Demonstrations that align Medicare and Medicaid financing and integrate primary, acute, behavioral health and long-term services and supports for Medicare-Medicaid dual enrollees. Minnesota's FAI focuses on administrative alignment only because the state had a pre-existing integrated care program for dual eligible beneficiaries.

Sources: Publicly available information and Lewis, E., S. Eiken, A. Amos, and P. Saucier. January 29, 2018. *The Growth of Managed Long-Term Services and Supports Programs: 2017 Update*. Truven Health Analytics, an IBM Company. Accessed December 5, 2019, at <https://www.medicare.gov/medicaid/managed-care/downloads/ltss/mltssp-inventory-update-2017.pdf>.

Appendix B. Detailed Description of Approach

The study was based on managed care contracts for all MLTSS programs operating in 2019 that primarily served older adults and adults with physical disabilities. Nine MLTSS programs were excluded from the study for the following reasons:

- The programs primarily serve individuals with developmental disabilities or individuals under age 65:
 - Massachusetts One Care
 - Pennsylvania Adult Autism Program
 - North Carolina Innovations
 - Michigan Managed Specialty Services and Supports
 - New York Fully Integrated Duals Advantage for Individuals with Developmental Disabilities
 - Tennessee Employment and Community First CHOICES.
- The programs recently ended or were slated to end in 2019:
 - Rhode Island’s Rhody Health Options, ended on September 30, 2018 (the state transitioned enrollees back into the fee-for-service system)
 - New York’s Fully Integrated Duals Advantage, ended on December 31, 2019 (the state transitioned enrollees to fully aligned Dual Eligible Special Needs Plans within its Medicaid Advantage Plus Managed LTSS program)
- We could not obtain a managed care contract:
 - California’s Managed Medi-Cal Long-Term Services and Supports

We looked for the most current contract for each of the included programs on state Medicaid program websites and through a general internet search. If we could not find contracts, we contacted the states to request the most current contract. In the cases of Hawaii and Kansas, Medicaid managed care contracts were not available and the states directed us to review the most recent requests for proposal released as part of their procurement cycle. In most cases, we were able to review 2018 or 2019 contracts. For Financial Alignment Initiative demonstration programs, which are not on an annual contracting cycle, we reviewed the most recent versions of the contracts published on the Centers for Medicare & Medicaid Services website, including documents that describe revisions to the contracts.

We then searched the contracts, using the key terms described in the report, and entered the relevant contract language into a data collection template that was organized by contract element and by state. After reviewing the contract language to ensure that it met our criteria, we sent states their respective findings by email for validation. We gave states 2 weeks to respond and sent a reminder. Twelve of the 23 states responded. Most of these states provided supplemental information (outside of the managed LTSS contracts) to demonstrate how their MLTSS programs address the elements. This information is presented in state summaries available on the AARP Public Policy Institute website: www.aarp.org/family-caregivers-in-mltss. In a few instances, states submitted supplemental information that did not meet the study criteria. When this occurred, states were advised that the information was not accepted and it was omitted from the state summaries.

This study was not designed to make a direct comparison to the contract review performed in 2014 for *Care Coordination in Managed Long-Term Services and Supports*.¹ The focus of the earlier study was primarily on care coordination, but it also touched on the care coordination role with family caregivers.

¹ Paul Saucier and Brian Burwell, *Care Coordination in Managed Long-Term Services and Supports*.

That study included three contract elements specific to family caregivers, one of which also was included in the current study: assessment of family caregivers. However, the definition of the element was somewhat stricter in the prior study, requiring that the contract language address four elements: the family caregiver's health and well-being, level of stress and feelings of being overwhelmed, need for training in assisting the member, and any additional services or supports needed to better carry out their roles.

Appendix C. Compilation of Managed LTSS Family Caregiver Contract Specifications across States

Table C1 compiles the results of the contract analysis across the 31 programs in 23 states and the seven elements. The state abbreviations in the table refer to contracts for the following programs:

AZ	Arizona Long-Term Care System
CA	California MediConnect
DE	Delaware Diamond State Health Plan Plus
FL	Florida Statewide Medicaid Managed Long-Term Care Program
HI	Hawaii QUEST Integration
ID MMCP	Idaho Medicare-Medicaid Coordinated Plan
ID MP	Idaho Medicaid Plus
IL HC	Illinois HealthChoice
IL MMAI	Illinois Medicare-Medicaid Alignment Initiative
IA	Iowa HealthLink
KS	Kansas KanCare
MA	Massachusetts Senior Care Options
MI HL	Michigan MI Health Link
MI CH	Michigan MI Choice
MN SC+	Minnesota Senior Care Plus
MN SHO	Minnesota Senior Health Options
NJ	New Jersey FamilyCare
NM	New Mexico Centennial Care
NY MLTC	New York Managed Long-Term Care Partial Capitation
NY MAP	New York Medicaid Advantage Plus
OH MC	Ohio MyCare
OH MCMO	Ohio MyCare Medicaid Only
PA	Pennsylvania Community HealthChoices
RI	Rhode Island Integrated Care Initiative, Phase 2
SC	South Carolina Healthy Connections Prime
TN	Tennessee TennCare CHOICES in Long-Term Care
TX SP	Texas STAR+PLUS
TX D	Texas Dual Eligible Integrated Care Demonstration Project
VA	Virginia Commonwealth Coordinated Care Plus
WI FC	Wisconsin Family Care
WI FCP	Wisconsin Family Care Partnership

Table C1
Results of Contract Analysis

Contract Element	Finding	State Programs	Count of Programs
Family Caregiver Assessment			
Are family caregivers assessed on their health and well-being and/or other areas such as training and support needs?	Yes	HI, NM, PA, SC, TN, WI FC, WI FCP	7
	No	AZ, CA, ID MMCP, ID MP, IL HC, IL MMAI, IA, KS, MA, MI HL, MI CH, NJ, NY MLTC, NY MAP, OH MC, OH MCMO, RI, TX SP, TX D, VA	20
	Other	DE, FL, MN MSHO, MN MSC+ (Elderly Waiver participants only)	4
Inclusion of Family Caregivers in Development of Service Plan and/or Coordination of Care			
Does the contract reference the inclusion of family caregivers in the development of the member's service plan, care coordination, or the care team?	Yes	AZ, CA, DE, FL, HI, ID MMCP, ID MP, IL HC, IL MMAI, IA, KS, MA, MI HL, MI CH, MN SC+, MN SHO, NJ, NY MLTC, NY MAP, OH MC, OH MCMO, PA, RI, SC, TN, TX SP, TX D, VA, WI FC, WI FCP	30
	No	NM	1
	Other		0
Services and Supports for Family Caregivers			
Does the contract cover services and supports for family caregivers?	Yes	AZ, CA, DE, FL, HI, ID MMCP, ID MP, IL HC, IL MMAI, MA, MI HL, MI CH, MN SC+, MN SHO, NJ, NM, NY MLTC, NY MAP, OH MC, OH MCMO, PA, RI, SC, TN, TX SP, TX D, VA, WI FC, WI FCP	29
	No	IA, KS	2
	Other		0
Consumer Direction that Allows Payment of Family Caregivers			
Does the contract allow payment to family caregivers in the program's consumer direction option (if available)?	Yes	AZ, DE, FL, HI, NJ, NM, PA, RI, SC, TN, WI FC, WI FCP	12
	No	CA, ID MMCP, ID MP, IL HC, IL MMAI, IA, KS, MA, MI HL, MI CH, NY MLTC, NY MAP, OH MC, OH MCMO, VA	15
	Other	MN SC+, MN SHO, TX SP, TX D	4
Loss of Caregiver Triggers Beneficiary Reassessment			
Does the contract require a member to be reassessed upon loss of the caregiver? With loss defined broadly as a change in status that affects the caregiver's ability to provide care to the member (e.g., death, hospitalization, illness, employment, or financial strain)?	Yes	DE, FL, MI HL, MI CH, NJ, OH MC, OH MCMO, PA, RI, SC, TN, TX SP, TX D	13
	No	CA, HI, IL HC, IL MMAI, IA, KS, MA, NM, NY MLTC, NY MAP, VA	11
	Other	AZ, ID MMCP, ID MP, MN SC+, MN SHO, WI FC, WI FCP	7

Contract Element	Finding	State Programs	Count of Programs
Inclusion of Family Caregivers in Health Plan's Member Advisory Committee			
Does the contract require family caregivers to be included in the health plan member advisory committee?	Yes	AZ, CA, IL HC, IL MMAI, IA, KS, MA, MI HL, NJ, NM, OH MC, PA, RI, SC, TN, TX SP, TX D, VA	18
	No	DE, FL, HI, ID MMCP, ID MP, MI CH, MN SC+, MN SHO, NY MLTC, NY MAP, OH MCMO, WI FC, WI FCP	13
	Other		0
Quality Assessment/Performance Improvement Processes that Include Family Caregivers			
Does the contract require quality measures related to family caregivers and/or for them to be included in the program's quality assessment/performance improvement processes?	Yes	AZ, FL, ID MMCP, ID MP, IL HC, IL MMAI, KS, MA, MI HL, NM, NY MLTC, OH MC, RI, SC, TN, TX D, VA, WI FC, WI FCP	19
	No	CA, DE, HI, IA, MI CH, NJ, NY MAP, OH MCMO, PA, TX SP	10
	Other	MN SC+, MN SHO	2

How to Interpret the Finding	
Yes	"Yes" indicates the language was found in the contract.
No	"No" indicates the language was not found in the contract.
Other	"Other" indicates the state provided supplemental information (not found in the contract) that met the criteria for the element. For example, one state provided additional information from its managed LTSS program handbook that confirms the member can select family and/or friends to be paid caregivers in the consumer direction program.

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