

Research Report

Family Caregivers and Managed Long- Term Services and Supports

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Executive Summary

Family caregivers are central members of the care team. They can be both providers of care and clients in need of supportive services. Their care and support often make it possible for the member of a managed care plan to live at home rather than in an institutional setting.

In 2013, about 40 million caregivers provided an estimated 37 billion hours of care to adults with self-care needs. The economic value of this unpaid help was approximately \$470 billion—more than six times the amount (\$75 billion) that the Medicaid program spent on all home- and community-based services that year. The emotional, physical, and financial demands of caring for a person with chronic and disabling conditions can take a significant toll; meanwhile, family caregivers often neglect their own health.

Managed care plans have strong financial incentives to consider how the family caregiver can help the member and what supports the family needs to improve quality of life, thus decreasing the overall cost of care. Helping prevent caregiver burnout can delay or prevent more costly placement in a nursing home.

In summary, managed care can lead the way in advancing person- and family-centered care. This report provides the tools and policy recommendations to pave the way. The authors also identify four promising practices and provide innovative solutions and free-of-charge downloadable tools from these programs.

ABOUT THIS REPORT

This is the first major research report in the emerging field of managed long-term services and supports (LTSS) that addresses family caregivers' needs. This report is the result of a year and a half of research and information sharing with experts in the field. The AARP Public Policy Institute hosted a roundtable event in April 2015. We commissioned Truven Health Analytics to research state Medicaid contracts for requirements about care coordination and family caregivers. We published their findings

in July 2015 in a report titled *Care Coordination in Managed Long-Term Services and Supports*. The authors shared the preliminary results from this research at the roundtable. At the request of the roundtable participants, we then formed a Learning Collaborative of monthly phone calls with state and federal officials, health plan administrators, advocates, and researchers. These activities and group of experts helped inform this research report.

KEY FINDINGS AND RESOURCES

Following are some key findings, along with related tools and resources, discussed in the report:

Care Coordination and Services. Most managed care plans have care coordinators available to help members navigate the health and LTSS system, and provide support and monitoring. However, most Medicaid managed care contracts provide little specificity about family caregivers' role in the care coordination process, or about what specific supportive services (such as family meetings or respite care) are available to members' family caregivers. Managed care contracts and plans can specifically recognize, involve, and support members' family caregivers, especially as they relate to care coordinators. This report presents model person- and family-centered provisions for care coordination and caregiver support services in managed LTSS that state Medicaid programs can incorporate into their contracts.

Conversation Starters. Family caregivers sometimes make important care decisions without understanding what their relatives value in daily living. This report contains practical, hands-on questions for “conversation starters” that care coordinators and service providers can use.

New Landmark Federal Rule. A recent federal rule on community living addresses the need for Medicaid home- and community-based service programs to conduct an assessment of caregivers' needs when their care is part of a service plan for

the person with a disability. While this rule applies to only one of the Medicaid home- and community-based service programs, the 1915(i) state plan option, it is a landmark rule for the way it acknowledges caregivers and recognizes the need for providers to better understand the caregiving situation.

Promising Practices. Promising practices are emerging in Medicaid, Medicare, and private managed care plans, as well as specific programs and projects to meet the needs of and support for family caregivers:

- **TennCare** is a leading, prominent state Medicaid program that requires the caregiver's role to be determined, health and well-being assessed, and training and other needs identified. In addition, the program requires that care coordinators give their contact information to the family caregivers. Family caregiver needs assessments are typically performed as part of the member's face-to-face assessment. This report provides citations from the TennCare Family Caregivers' Needs Assessment Protocol as well as the contract language.
- **South Carolina's Healthy Connections Prime** is a Medicare-Medicaid duals demonstration that is recognized for its promising practices in caregiver assessment, services, care coordinator training, and quality measurement of family caregiver supports. Each health plan is required to have a caregiver quality improvement project.
- **UnitedHealthcare** offers family caregiver supports in some of its Medicare Advantage Plans and Medicaid plans, as well as to some large employers with self-funded health plans. Its Solutions for Caregivers program, available in some Medicare Advantage Plans, offers covered services for the family caregiver, including coaching and support over the phone and geriatric case manager services to conduct an in-person assessment and

provide family consultation. Its Solutions for Caregivers Portal for large employers features in-person, phone, and online resources to help working caregivers. In some Medicaid programs, UnitedHealthcare refers caregivers to its Caring for Caregivers program, which provides a community education workshop series that focuses on the needs and health of the caregiver.

- **Cal MediConnect Dementia Project** provides assessment, services, and supports to the family caregivers of people with dementia who are participating in California's Medicare-Medicaid duals demonstration. Working with Alzheimer's Greater Los Angeles and other Alzheimer's groups, this project provides care manager training and support, caregiver education and respite care, support services through referrals, and technical assistance to create systems change. This report provides links to the evidence-based dementia care management toolkit, which can be downloaded at no cost.

RECOMMENDATIONS

With such findings, this report draws the following recommendations:

- 1. Managed LTSS programs should offer appropriate services that address the needs of family caregivers.**

A key component of managed LTSS should be the identification and provision of supports to meet family caregivers' needs and preferences. Involving the family in a meaningful and useful way also should improve the experience of care for both the person and the family and reduce costs. Services and supports should include family caregiver assessments for their own needs; supportive services such as training, support groups, family meetings, counseling, and respite care that are identified in the assessment; home modifications and assistive technologies; and other supportive services and transportation.

- 2. Health plans should recognize and involve family caregivers, especially when the care plan depends on them.**

Family caregivers should be part of the care planning process upon consent of the member

and agreement from the family caregiver. Care coordinators and family caregivers also should have each other's contact information.

States and plans should examine their assessments for members in Medicaid managed LTSS programs—and for those dually eligible for both Medicaid and Medicare—adding a component to assess family caregiver needs whenever the family caregiver is central to the plan of care. Assessing and addressing family caregivers' unmet needs for information, education, and supportive services should be standard practice in all home- and community-based services programs that aim to help beneficiaries remain at home and in the community. All initiatives to assess and address caregivers should reflect multicultural and access needs because of the diversity of family caregivers. The assessment tools and data also should be publicly available.

3. Family caregivers' feedback and involvement can help ensure better quality of care.

Input from family caregivers should be included in the evaluations of health plans, and health plan advisory councils should include family caregivers to inform them of the care experience. Evaluations of the quality and access of LTSS should also include surveys of family caregivers, especially when the member depends on their care.

CONCLUSIONS

Although family caregiver supports are still uncommon in managed LTSS programs, managed care contracts have the power to standardize the person- and family-centered approach. By implementing the report recommendations into new provisions, protocols, or amendments to existing managed LTSS contracts, managed care plans can lead the way to better care for members and their family caregivers.

Introduction

Managed care plans have strong financial incentives to consider not only how the family caregiver can help the member,¹ but also what support the family needs to improve quality of life and reduce the overall cost of care. If family caregivers' needs are not recognized and addressed, they risk burnout from prolonged stress, the physical demands of caregiving, and the high cost of health care and long-term services and supports (LTSS). Helping prevent caregiver burnout can delay or prevent more costly nursing home placement.

Especially for those members with the most complex care needs, providing supportive services to the individual's family caregiver may impact the person's quality of life and costs of health care and LTSS as much as would providing health care interventions. Research documents that high caregiver stress is an important and highly significant predictor of a person's placement in a nursing home.^{2,3,4,5,6}

ABOUT THIS REPORT

This is the first major research report in this emerging field of managed LTSS that addresses family caregivers' needs. It is the result of a year and a half of research and networking. The AARP Public Policy Institute began this work with a roundtable event in April 2015. We published a paper titled *Care Coordination in Managed Long-Term Services and Supports* by Truven Health

Analytics in July 2015. The authors shared at the roundtable the preliminary results from this research about state Medicaid contract provisions regarding care coordination requirements and family caregivers. At the request of the roundtable participants, we then formed a Learning Collaborative of monthly phone calls with health plan administrators, state and federal officials, advocates, and researchers. These activities were critical to informing this work, and the authors want to thank and acknowledge this group of experts.

This report highlights why managed care plans should involve family caregivers more closely in the assessment and care planning process, and address their needs as part of managed LTSS. The report explains why managed LTSS should move toward person- and family-centered care—including a better understanding of values and care preferences of both the member and the family caregiver. It also identifies new federal rules in Medicaid that recognize and support family caregivers, and it highlights some emerging promising practices. Finally, the report recommends ways that states and managed care organizations can better support family caregivers of older people and adults with disabilities enrolled in managed care plans.

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- 1 In this report, the term “member” or “beneficiary” is used to describe an older person or an adult with a chronic, disabling, or serious health condition who is enrolled in a managed care plan.
 - 2 Brenda C. Spillman and Sharon K. Long, *Does High Caregiver Stress Lead to Nursing Home Entry?* (Washington, DC: Urban Institute, 2007).
 - 3 Ichiro Tsuji, Sarah Whalen, and Thomas E. Finucane, “Predictors of Nursing Home Placement in Community-Based Long-Term Care,” *Journal of the American Geriatrics Society*, 43, no. 7 (1995): 761–66.
 - 4 Kristine Yaffe et al., “Patient and Caregiver Characteristics and Nursing Home Placement in Patients with Dementia,” *Journal of the American Medical Association*, 287, no. 16 (2002): 2090–97.
 - 5 Joseph E. Gaugler et al., “Predicting Nursing Home Admission in the U.S: A Meta-analysis,” *BMC Geriatrics* 7, no. 13, (2007): doi:10.1186/1471-2318-7-13.
 - 6 Joseph E. Gaugler et al., “Predictors of Nursing Home Admission for Persons with Dementia,” *Medical Care* 47, no. 2 (2009): 191–98.

Why Focus on Family Caregivers and Managed Long-Term Services and Supports?

The family—broadly defined—is the main source of help for older people and adults with chronic care needs and functional limitations. Family members and friends who take on this caring role are often known as “family caregivers.”⁷ Recognition of and support for family caregivers matters because chronic illness and disability often affect the family as well as the individual. Today, understanding and addressing family caregivers’ needs is viewed as a key component of a high-performing LTSS system (see exhibit 1).⁸

In 2013, roughly 40 million caregivers provided an estimated 37 billion hours of care to adults with limitations in daily activities.⁹ The economic value of this unpaid help was approximately \$470 billion¹⁰—more than six times the amount (\$75 billion) that the Medicaid program spent on all home- and community-based services that year (see exhibit 2).¹¹

FAMILY CAREGIVERS CAN BE BOTH PROVIDERS OF CARE AND CLIENTS IN NEED OF SUPPORTIVE SERVICES THEMSELVES

Family caregivers are inseparable members of the care circle, with much at stake from two perspectives: the caregiver as provider and the caregiver as client.¹² First, the caregiver-as-provider role places them in a critical position to affect outcomes that matter to the managed care organization. They provide fundamental care

Exhibit 1 Findings from the Long-Term Services and Supports Scorecard

Support for family caregivers is a key component of a high-performing system.

“If family caregivers are expected to continue providing support, it is important that their needs are both assessed and addressed with appropriate information, training, respite, and other services tailored to their individual needs and preferences.”

“In a high performing LTSS system, caregivers’ needs—physical, emotional, financial, and work-related—are assessed and addressed. Their strengths are valued, and supports are tailored to their individual values and preferences.”

Source: Susan C. Reinhard et al., *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*, 2nd ed. (Washington, DC: AARP Public Policy Institute, 2014), <http://www.longtermscorecard.org/>.

that a personal care attendant might do, like help with bathing, dressing, and mobility, to keep the plan’s member functioning at home instead of in an institution. Most caregivers also provide complex medical/nursing tasks (such as wound

7 “Family caregiving” 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.

8 Susan C. Reinhard et al., *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*, 2nd ed. (Washington, DC: AARP Public Policy Institute, 2014).

9 Susan C. Reinhard et al., *Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain* (Washington, DC: AARP Public Policy Institute, July 16, 2015).

10 Ibid.

11 Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports in FY 2013* (Cambridge, MA: Truven Health Analytics, June 30, 2015).

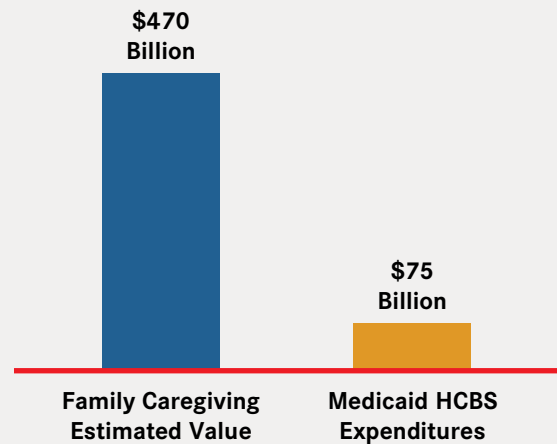
12 Susan C. Reinhard et al., “Supporting Family Caregivers in Providing Care,” in *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*, edited by R. Hughes, vol. 1 (Rockville, MD: Agency for Healthcare Research and Quality, 2007), 1-341-56.

care, administering injections, managing multiple complex medications, and operating specialized medical equipment) that professional nurses and other health care professionals would be expected to do.¹³ They are “providers” who are on the job with no pay.

How well caregivers understand how to do this work matters to the member of the health plan (also known as the care recipient or beneficiary), and therefore to the managed care organization. In their landmark *Home Alone* study, the authors found that family caregivers who provided medical/nursing tasks were frequently worried they would make a mistake because they were carrying out such complex tasks with little preparation or support from health care providers.¹⁴ The more instruction and support caregivers receive to perform essential job tasks, the better they can perform and the better the quality metrics will be. Managed care organizations depend on this unpaid labor force in more ways than they currently recognize.

Second, the caregiver-as-client perspective acknowledges the risk of family caregivers becoming secondary patients. For nearly four decades, research has documented this “hidden patient” phenomenon.^{15,16,17} Although most family members and close friends who willingly undertake caregiving find it an enriching experience and a source of deep satisfaction and meaning, research shows that those who take on the caregiving role can experience daily struggles, worries, and frustrations. In the *Caregiving in the U.S. 2015* survey, 38 percent of family caregivers said their caregiving situation was highly stressful, and nearly one in five experienced a high level of physical (19 percent) or financial

Exhibit 2
The Estimated Value of Family Caregiving and Medicaid HCBS Expenditures, 2013
 (\$ Billions)



Sources: Susan C. Reinhard, et al., *Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain* (Washington, DC: AARP Public Policy Institute, July 16, 2015); Steve Eiken, et al., *Medicaid Expenditures for Long-Term Services and Supports in FY 2013*, (Cambridge, MA: Truven Health Analytics, June 30, 2015).

(18 percent) strain.¹⁸ The adverse impacts for caregivers are especially severe when caring for someone who has complex health conditions and both functional and cognitive impairments.¹⁹

As they focus on providing care, family caregivers often neglect their own health, forgoing preventive care and attention to symptoms that should prompt medical attention for themselves. The physical demands of the caregiver role take their toll on physical health, while the emotional

13 Susan C. Reinhard, Carol Levine, and Sarah Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* (Washington, DC: AARP Public Policy Institute; New York: United Hospital Fund, October 2012).

14 Ibid.

15 Alfred P. Fengler and Nancy Goodrich, “Wives of Elderly Disabled Men: The Hidden Patients,” *The Gerontologist* 19, no. 2 (1979): 175–83.

16 Steven H. Zarit, Nancy K. Orr, and Judy M. Zarit, *The Hidden Victims of Alzheimer’s Disease: Families under Stress* (New York: New York University Press, 1985).

17 Sharon K. Ostwald, “Caregiver Exhaustion: Caring for the Hidden Patients,” *Advanced Practice Nurse Quality* 3, no. 2 (1997): 29–35.

18 National Alliance for Caregiving and AARP Public Policy Institute, *Caregiving in the U.S. 2015* (Bethesda, MD: NAC; Washington, DC: AARP, June 2015).

19 Lynn F. Feinberg et al., *Valuing the Invaluable: 2011 Update: 2011 Update, The Growing Contributions and Costs of Family Caregiving* (Washington, DC: AARP Public Policy Institute, June 2011).

strain affects mental health. To help them stay healthy and able to continue in their provider role, managed care organizations should view family caregivers as clients who are at risk of becoming patients as well. From this perspective, family caregivers are recognized as individuals who may themselves be vulnerable—and need education and skills training, and supportive services such as respite care.²⁰

The expanded family caregiving role today means everything from arranging, coordinating, and providing LTSS to navigating the complex health care system, communicating with providers, and discussing issues that require shared decision making, to performing more intensive and complex care in the home—all this while holding down a paying job. Most (60 percent) family caregivers caring for ill adults or adults with disabilities worked at a paying job in 2014, placing competing demands on their time.²¹ When working caregivers lack the supports needed to manage their dual responsibilities, some quit their jobs or cut back their work hours to provide care. Leaving a job to take on more caregiving responsibilities not only impacts the day-to-day finances of individuals and their families, but also can have negative longer-term consequences for the family caregiver's financial security.^{22,23}

This framework should guide managed care organizations in how they view family caregivers and why greater caregiver support matters. This report offers more insights and practical recommendations for implementation.

MANAGED LONG-TERM SERVICES AND SUPPORTS ARE CHANGING THE FIELD

The field of LTSS is rapidly changing, with about half of the states moving to Medicaid managed care for their populations needing services and supports (see exhibit 3).

Most managed care plans are relatively new to providing LTSS and have little experience with family caregivers of beneficiaries who need both health care and supportive services. Yet, information is emerging on this topic. Telling new research from the University of Illinois at Chicago demonstrates how family input and involvement impacts member outcomes in Medicaid managed care.²⁴ Among 382 people with disabilities in managed LTSS, family input in health care and LTSS was associated with more positive health-service and LTSS appraisals and fewer unmet LTSS needs.²⁵ The bottom line: family involvement does impact the quality of health care and LTSS. It does make a difference in getting better care.

Older people commonly rely on family or close friends to help them negotiate interactions with health care and social service providers. Family members are often a good source of information and understanding about the beneficiary's health conditions and functioning, serving as the main source for managing continuity of care.²⁶

Because family involvement is often important for good care and shared decision making, managed care plans should inform members of their right to release information to family and other designated persons under the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule.²⁷ Under the law, unless the individual objects, health care providers can share relevant information with

20 Ibid.

21 National Alliance for Caregiving and AARP Public Policy Institute, *Caregiving in the U.S. 2015*.

22 MetLife Mature Market Institute, *The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents* (Westport, CT: MetLife Mature Market Institute, 2011).

23 Chizuko Wakabayashi and Katherine M. Donato, "Does Caregiving Increase Poverty among Women in Later Life? Evidence from the Health and Retirement Survey," *Journal of Health and Social Behavior* 47, no. 3 (2006): 258–74.

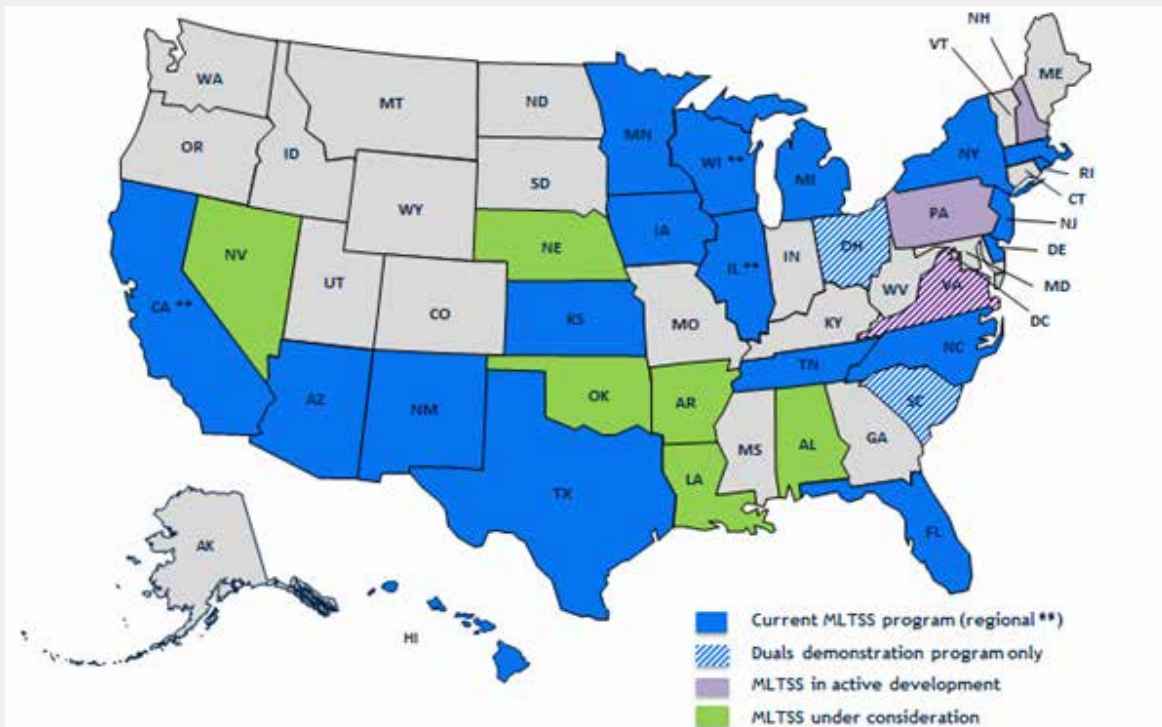
24 Tamar Heller, "Managed Long-Term Services and Supports and Family Caregiving" (presentation, Innovations Roundtable of the AARP Public Policy Institute, Washington, DC, April 28, 2015).

25 Ibid.

26 Lynn F. Feinberg, *Moving toward Person- and Family-Centered Care* (Washington, DC: AARP Public Policy Institute, March 2012).

27 The Lewin Group, *Geriatric Services Capacity Assessment, Resources for Integrated Care* (Falls Church, VA: 2016), https://resourcesforintegratedcare.com/Older_Adults/GCC/Tool/Care_For_Geriatric_Consumers.

Exhibit 3
States with Medicaid Managed LTSS Programs, August 2016



Source: Camille Dobson, NASUAD, emailed to authors with permission on 8/26/16.

a family caregiver or other individual involved in a person's care.^{28,29} HIPAA should not be a barrier to talking with family caregivers.

Despite the impact of family involvement on member outcomes, an AARP Public Policy Institute study conducted by Truven Health Analytics found that while the importance of family caregivers is often acknowledged in contracts, most such contracts provide little specificity about their role in the care coordination process.³⁰ Specifically, out of the 19 state-managed LTSS contracts for older people and adults with physical disabilities examined, the study found the following:

- Most (15) state contracts do acknowledge family caregivers with regard to needs

assessments. However, rather than asking the caregiver about their own needs, the contracts usually reference them as a source of information about the member for the care coordinators (as long as the member consents). Some of these contracts refer to a family caregiver as someone whose training needs should be assessed by the care coordinator.

- Nine contracts address the provision of care coordinator contact information to family caregivers upon consent of the member or when the family caregiver is the legal representative.
- In only three contracts, the training of family caregivers is a covered benefit and is included in the member's plan of care when needed.

28 United Hospital Fund, *HIPAA: Questions and Answers for Family Caregivers* (New York: 2014), <http://www.nextstepincare.org/uploads/File/Guides/HIPAA/HIPAA.pdf>.

29 Claire Noel-Miller and Jane Sung, "How HIPAA Can Maintain Privacy, Enable Exchange of Electronic Health Records and Improve Patient Care at the Same Time," *AARP Blog*, June 10, 2016, <http://blog.aarp.org/2016/06/10/how-hipaa-can-maintain-privacy-enable-exchange-of-electronic-health-records-and-improve-patient-care-at-the-same-time/>.

30 Paul Saucier and Brian Burwell, *Care Coordination in Managed Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, July 2015).

Why Should Managed Long-Term Services and Supports Move toward Person- and Family-Centered Care?

PERSON- AND FAMILY-CENTERED CARE SUPPORTS INDIVIDUALS AND THEIR FAMILIES

The movement toward person- and family-centered care is transforming the delivery of health care and LTSS. This approach is intended to address the needs of the “whole person” and to deliver health care and LTSS that address an individual’s needs goals, preferences, cultural traditions, family situation, and values. This care both recognizes and supports family needs and preferences, integrating family caregivers as partners in care when appropriate.³¹

The National Strategy for Quality Improvement—developed by the Agency for Healthcare Quality and Research and known as the National Quality Strategy—provides a road map toward the “Triple Aim” of better care, healthier people, and affordable care.³² The strategy calls for more transparent, accountable, and higher-quality care through broad partnerships that extend beyond individual providers and settings and that actively involve individuals *and their families*. The strategy also calls for using quality measures to help achieve person- and family-centered care.

Health and social service providers must consider not only how the family caregiver can help the beneficiary of the health plan, but also what supports the family member needs to continue in his or her caregiving role. Recent research finds that only one in three (32 percent) family caregivers say a doctor, nurse, or social worker has asked them about what they needed to care for their relative. Half as many (16 percent) family caregivers say a health provider had asked what they need to care for themselves.³³

Assessing and addressing both the individual’s and the family caregiver’s information, care, and support needs—and his or her experience of care—are key elements of person- and family-centered care to ensure coordination and continuity of care in health care and LTSS. Assessment of caregiver needs is critical whenever a health plan member identifies family or friends as caregivers and when members rely on family caregivers to implement the service plan through home- and community-based services, hospital discharge planning, and care coordination.

CARE COORDINATION IS IMPORTANT FOR MEMBERS AND THEIR FAMILY CAREGIVERS

Most managed care plans have care coordinators to help people with multiple chronic conditions and complex needs navigate the health and LTSS systems and to help with ongoing support and monitoring. As states shift to managed care, effective care coordination for people who need services and supports and their families is critical. Managed care state contracts and plans can recognize, involve, and support members’ family caregivers, specifically as the contracts relate to care coordinators (see the authors’ model provisions in exhibit 4).³⁴

In current practice, the member’s assessment and plan of care typically identify the availability of a family caregiver, describe the type and amount of family supports to be provided, and minimize the amount of paid care needed if a family caregiver is present. A recent review on how the Medicaid program treats services provided by family members suggests that some states (frequently through managed care organizations) compel

31 Feinberg, *Moving toward Person- and Family-Centered Care*.

32 Department of Health and Human Services, *Working for Quality: 2013 Annual Progress Report to Congress: National Strategy for Quality Improvement in Health Care* (Agency for Health Care Research and Quality: Washington, DC, 2013).

33 National Alliance for Caregiving and AARP Public Policy Institute, *Caregiving in the U.S. 2015*.

34 Saucier and Burwell, *Care Coordination in Managed Long-Term Services and Supports*.

Exhibit 4
**Model Person- and Family-Centered Provisions for Care Coordination in
Managed Long-Term Services and Supports**

- With consent of the member, the medical record and the service plan identify family caregivers.
- With consent of the member, the care coordinator invites family caregivers to participate in the service planning process.
- The care coordinator identifies family caregivers' specific problems, needs, strengths, and resources.
- Family caregivers receive information, including contact information of the care coordinator.
- The care coordinator identifies and addresses education and training needs of family caregivers and equips them with necessary resources and referrals to learn specific caregiving skills (e.g., administering medication, operating equipment, managing chronic conditions, handling problem behaviors in persons with dementia).
- The care coordinator refers family caregivers to respite care and other supportive services (such as counseling or family meetings) as appropriate because the plan covers these services.
- The care coordinator identifies community resources not covered by the plan for referral to family caregivers.

unpaid assistance from a family caregiver even though the caregiver has the right to decide when she or he wishes to provide unpaid care to the beneficiary.³⁵ Services provided by family caregivers should be included in the care plan only if family caregivers have willingly agreed to provide these services and have indicated their ability to carry out the actual tasks.

Moreover, in Medicaid policy, the family caregiver's own support needs for education, skills training, and supportive services are often overlooked. Yet, the needs of the family caregiver are central to the care of the beneficiary.

In a person- and family-centered care approach, the assessment process should be an opportunity to ask the family caregiver how he or she is doing, and what information and assistance are needed to carry out caregiving tasks and manage stress. The approach also facilitates continuity of care and respects the values and preferences of both the individual and the family caregiver.

Asking questions of the family caregiver as part of the assessment process—and listening to family

needs and worries—are fundamental principles of good care planning, especially when the plan of care depends on a family caregiver, such as when an older adult has Alzheimer's disease.³⁶ In one study, more than one in four dual eligible beneficiaries who received home- and community-based services through Medicaid waiver programs had Alzheimer's disease or another form of dementia and relied on their family caregivers for everyday help.³⁷

Family caregiver supportive services can include identifying the primary caregiver and other family members or friends involved in care provision, assessing the family's situation, and addressing caregiver's own unmet needs, including information about managing chronic or serious health 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). Supportive services may include counseling, short-term therapy groups to increase coping skills, family meetings, in-person and online support groups, and assistive technologies.³⁸ All caregiver supportive services

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

36 Lynn F. Feinberg, *Moving Toward Person- and Family-Centered Care*.

37 Edith G. Walsh et al., "Cost Drivers for Dual Eligible Beneficiaries: Potentially Avoidable Hospitalizations from Nursing Facility Skilled Nursing Facility, and Home and Community Based Services (HCBS) Waiver Programs," Final Task Report, Research Triangle Institute, Research Triangle Park, NC, 2010.

38 Kathy 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, December 2013).

should be offered in a culturally and linguistically competent manner.

Investing resources to proactively identify, assess, and address family care needs can improve quality of life for the person and family and reduce more costly and intensive services. In one state study, the availability and use of a caregiver assessment process and family caregiver supportive services resulted in a delay in the use of Medicaid LTSS for the care recipient over a one-year period.³⁹

PLANS CAN MAKE A WISE INVESTMENT IN A “CONVERSATION STARTER”

Family caregivers sometimes make critical daily care decisions without an understanding of what their relatives value and find most meaningful in daily living. Caregiving requires an understanding not only of the beneficiary’s personal values and

care preferences, but also of what he or she values most in life. A better understanding of values and care preferences provides a foundation that complements quality initiatives and assessment practices, in part because of the complexity and intimate nature of LTSS decisions.⁴⁰

Incorporating questions for members about what they value and prefer in everyday care, coupled with questions for family caregivers about their perceptions of what matters most to their relative, can be a “conversation starter” for care coordinators and service providers in a person- and family-centered assessment and care planning process (see exhibit 5).

Research has shown that persons with mild to moderate cognitive impairment are able to participate and respond reliably and accurately to these types of questions.⁴¹

**Exhibit 5
Questions for the Conversation Starter**

Environment and Social Network	Personal Autonomy
<p>How important is it to</p> <ul style="list-style-type: none"> ● Be with family and friends? ● Be safe from crime? ● Have reliable help? ● Choose particular family members/friends to help with care? ● Keep the same doctors? ● Feel safe at home even if activity is restricted? ● Be in touch with others in case of emergency? ● Be a part of family celebrations or rituals? ● Be able to practice religious or spiritual beliefs? ● Avoid being a physical or financial burden on family? ● Keep in touch with distant family and friends? ● Have the family caregiver be the one to help out? ● Avoid family conflict? ● Have some money to leave to family? 	<p>How important is it to</p> <ul style="list-style-type: none"> ● Come and go as one pleases? ● Organize daily routine in one’s own way? ● Do things for oneself? ● Make one’s own financial decisions? ● Spend money how one wants? ● Use services that one can pay for oneself? ● Have something to do? ● Live in one’s own home? ● Feel useful?

Source: Carol J. Whitlatch, Lynn F. Feinberg, and Shandra S. Tucke, *The Values and Preferences Scale*, ©Benjamin Rose Institute, 2005. Adapted by permission.

39 Bridget Lavelle et al., *Expanding Eligibility for the Family Caregiver Support Program in SFY 2012: Updated Findings* (Olympia, WA: Washington State Department of Social and Health Services, 2014), http://leg.wa.gov/JointCommittees/ADJLEC/Documents/2014-05-19/Expanding_Eligibility_FCS_Report.pdf.

40 Carol J. Whitlatch, Lynn F. Feinberg, and Shandra S. Tucke, “Measuring the Values and Preferences for Everyday Care of Persons with Cognitive Impairment and Their Family Caregivers,” *The Gerontologist* 45, no. 2 (2005): 370–80.

41 Lynn F. Feinberg and Carol J. Whitlatch, “Are Persons with Cognitive Impairment Able to State Consistent Choices?,” *The Gerontologist* 41: 374–82.

What New Federal Rules Support Family Caregivers in Medicaid?

Policy makers have begun to respond to the evolving role of family caregivers and how they fit into the care team. At the federal level, two new Medicaid rules begin to address these issues.

FEDERAL RULE ON COMMUNITY LIVING REQUIRES CAREGIVER ASSESSMENT

A recent US Centers for Medicare & Medicaid Services (CMS) rule on community living addresses the need for Medicaid home- and community-based services programs to conduct an assessment of caregivers' needs when their assistance is part of the care plan for the person with a disability.⁴² This rule marks the first time that CMS has formally recognized the importance of assessing family caregivers through new requirements for person-centered care planning. The new CMS rule relates to only one of the Medicaid home- and community-based service programs, the 1915(i) state plan option, which allows states to expand these services and target them to specific populations.⁴³ However, while it is a landmark rule for the way it acknowledges caregivers, this provision of assessing family caregivers' needs should be a standard in all home- and community-based services programs, especially when the family caregiver is a major provider of care.

NEW FEDERAL RULE ON MANAGED CARE REGULATIONS ACKNOWLEDGES FAMILY CAREGIVERS

Recently, CMS released the final rule that updates Medicaid regulations for managed care organizations. The new requirements give states flexibility in program design and administration to deliver managed LTSS to older people and adults with disabilities. While the final rule falls short in strengthening Medicaid's focus on person- *and* family-centered care, where appropriate, CMS does allow states to develop their own assessment standards in managed care and to consider the "critical importance of caregivers in supporting enrollees as they develop education, outreach, and support strategies."⁴⁴

CMS also added representatives of beneficiaries or enrollees to the list of individuals who should be part of the state stakeholder group and to the managed care plan member advisory committee, stating, "family members or other individuals that represent enrollees are always a critical stakeholder component."⁴⁵

Again, while the rule should go much further, the mere language in the rule is notable for how it acknowledges caregivers and the role they play.

42 *Federal Register* 79, no. 11 (2014): 2948–3039, <http://www.gpo.gov/fdsys/pkg/FR-2014-01-16/pdf/2014-00487.pdf>.

43 Lynn F. Feinberg, "Setting the Pace for Identifying Family Caregiver Needs in Home and Community-Based Services," *AARP Blog*, March 5, 2014. <http://blog.aarp.org/2014/03/05/setting-the-pace-for-identifying-family-caregiver-needs-in-home-and-community-based-services/>.

44 Final Rule, 81 Fed. Reg. 27,497, § 438.71(b)(2), beneficiary support system, p. 476, <https://www.federalregister.gov/articles/2016/05/06/2016-09581/medicaid-and-childrens-health-insurance-program-chip-programs-medicare-managed-care-chip-delivered>.

45 Final Rule, 81 Fed. Reg. 27,497, §§ 438.70 and 438.110, p. 590, <https://www.federalregister.gov/articles/2016/05/06/2016-09581/medicaid-and-childrens-health-insurance-program-chip-programs-medicare-managed-care-chip-delivered>.

What Are Some Promising Practices?

Although family caregiver support is not common practice in managed LTSS, promising practices are emerging. Below are examples that include state Medicaid managed LTSS programs in Tennessee and South Carolina, a large national health plan, and a dementia care project in California.



TENNESSEE

TennCare is a leading, progressive state Medicaid program in assessing and addressing family caregivers' needs. Although Tennessee implemented its managed care demonstration in 1994, it launched its TennCare CHOICES program in 2010 to provide LTSS to older adults and adults with physical disabilities through three managed care organizations. Tennessee amended its contract with the managed care organizations in 2015 to require that at initial member enrollment and at least annually thereafter, the caregiver's role be determined, health and well-being assessed, and training and other needs identified.⁴⁶ In 2016, TennCare added an additional requirement that the care coordinator must ensure that the identified family caregivers have the care coordinator's contact information.⁴⁷

Family caregiver needs assessments are typically performed as part of the face-to-face assessment:

- At least once every 365 days as part of the annual review,
- Upon a significant change in circumstances, and

Exhibit 6 TennCare Family Caregivers' Needs Assessment Protocol

"[A]t each face to face visit..., the Care Coordinator shall, as part of the ongoing needs assessment, inquire about the primary caregiver's overall well-being and ability to continue providing the level of supports outlined in the plan of care. If a caregiver expresses concern about his or her overall well-being and/or ability to continue providing their current level of care for the member, the Care Coordinator shall complete a full caregiver assessment and update the member's plan of care and/or risk agreement, as necessary."

Source: TennCare Needs Assessment Protocol, cited by Patti Killingsworth, "State of Tennessee: Family Caregivers in MLTSS" (Presentation at the Home and Community-Based Services Conference, Washington, DC, September 1, 2015).

- As the care coordinator deems necessary (see exhibit 6).⁴⁸

Based on the identified needs of the caregiver, a plan is developed to address the health and well-being of each caregiver and sustain his or her ability to provide care to the member. Included as part of the plan of care is caregiver education, training, and other supportive services that aim to assist the caregiver to provide care for the member (see exhibit 7).

Family caregivers are defined broadly to include those who are "routinely involved in providing

⁴⁶ Saucier and Burwell, *Care Coordination in Managed Long-Term Services and Supports*.

⁴⁷ E-mail communication with Patti Killingsworth and the authors, July 6, 2016.

⁴⁸ Patti Killingsworth, "State of Tennessee: Family Caregivers in MLTSS" (presentation at the Home and Community-Based Services Conference, Washington, DC, September 1, 2015).

Exhibit 7
TennCare CHOICES Contract Language

“At a minimum ... the caregiver assessment shall include:

- (1) an overall assessment of the family member(s) and/or caregiver(s) providing services to the member to determine the willingness and ability of the family member(s) or caregiver(s) to contribute effectively to the needs of the member, including employment status and schedule, and other caregiving responsibilities;*
- (2) an assessment of the caregiver’s own health and well-being, including medical, behavioral, or physical limitations as it relates to the caregiver’s ability to support the member;*
- (3) an assessment of the caregiver’s level of stress related to caregiving responsibilities and any feelings of being overwhelmed;*
- (4) identification of the caregiver’s needs for training in knowledge and skills in assisting the person needing care; and*
- (5) identification of any service and support needs to be better prepared for their caregiving role.”*

Additionally, the care coordinator or support coordinator shall ensure that all identified caregivers have the care coordinator or support coordinator’s name and contact information.

Source: TennCare Contract. Contract language for items 1–5 was part of the January 1, 2015, amendment, with an effective date of July 1, 2015. The additional requirement was added for January 1, 2016.

unpaid support and assistance to the member.”⁴⁹
Assessment of the caregiver’s unmet needs and supportive services can be conducted with the member’s primary caregiver, another caregiver, or both.



SOUTH CAROLINA

South Carolina Healthy Connections Prime modeled its family caregiver assessment and supports after TennCare, and it is also recognized for its promising practices in this area. South Carolina’s duals demonstration program, called Healthy Connections Prime, is for adults ages 65 and older with both Medicare and Medicaid coverage. Implemented in 2015, this new program integrates all the services of Medicare, Medicare Part D, and Medicaid into a single set of

benefits that health plans fully manage. Healthy Connections Prime is a demonstration project under the CMS Financial Alignment Initiative for Medicare and Medicaid enrollees.

Following are some notable elements of South Carolina’s Healthy Connections Prime program:

Assessment. University of California San Francisco researchers found that South Carolina’s contract was among the most prescriptive among the duals demonstration states for family caregiver identification, assessment, and supports and services.⁵⁰ The contract requires that caregiver status and abilities should be assessed using the state’s comprehensive assessment tool and should include the caregiver’s capacity, qualifications, and risks.⁵¹ The plan of care should include risk assessments, which can include caregiver

49 Ibid.

50 Brooke Hollister and Susan Chapman, *Dementia Care Coordination Workforce and Practices in Seven Dual Demonstration States* (San Francisco, CA: UCSF Health Workforce Research Center on Long-Term Care, November 20, 2015).

51 Contract between US Department of Health and Human Services Centers for Medicare & Medicaid Services in Partnership with the South Carolina Department of Health and Human Services and <Entity>, September 5, 2014, www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/SouthCarolinaContract.pdf.

competencies and risks associated with burnout or the ability to no longer perform duties.⁵²

Services. The health plans must provide a range of health promotion and wellness informational activities, including caregiver supports, for enrollees' family members or friends. Healthy Connections Prime covers adult day health services, transportation, home- and community-based services such as home-delivered meals, and respite care. To provide temporary around-the-clock relief for caregivers, the program will pay for respite care in an institutional setting for up to 14 days per year.⁵³ South Carolina does not offer an in-home respite benefit in its home- and community-based waiver, but the state has a small in-home respite benefit, provided by \$2 million in state-only funds.

The state contracted with the University of South Carolina's Office for the Study of Aging to conduct trainings for the Healthy Connections Prime care coordinators.⁵⁴ Social workers can earn continuing education units for the trainings, which include identifying and addressing abuse and neglect, interviewing skills, and building and updating care plans. In partnership with the South Carolina Alzheimer's Association, the university also conducts dementia care training.⁵⁵

Quality. South Carolina is a standout in its quality measurement of family caregiver supports. The state requires health plans to track the percentage of enrollees receiving home- and community-based services who experience an increase or decrease in the authorization of respite hours (each reported separately).⁵⁶ In addition, each health plan is required to have a caregiver quality improvement project (see exhibit 8).⁵⁷

Exhibit 8 South Carolina Caregiver Quality Improvement

"... caregiving [is] a topic that we want our health plans to address... each of the plans has to come up with at least one quality improvement project that centers on caregiving ... we think that that's another nuance that they're not necessarily thinking about ... as they should especially as their members over time will age in place. They need to think ahead, of the role of the caregiver in helping to support the member and helping them to maintain that high quality of life."

(South Carolina Key Informant)

Source: Brooke Hollister and Susan Chapman, *Dementia Care Coordination Workforce and Practices in Seven Dual Demonstration States* (San Francisco, CA: UCSF Health Workforce Research Center on Long-Term Care, November 20, 2015).



UnitedHealthcare's Solutions for Caregivers is a promising program that is offered to some of its Medicare members and its larger employers. UnitedHealthcare also offers family caregiver supports to meet the needs of some of its Medicaid populations.

Solutions for Caregivers for UnitedHealthcare Medicare Advantage Plans.^{58,59} Under these plans, Medicare members have toll-free telephone access to geriatric experts and coaching on family issues

52 Ibid.

53 Ibid.

54 University of South Carolina School of Public Health, http://www.sph.sc.edu/news/osa_training.html.

55 Hollister and Chapman, *Dementia Care Coordination Workforce and Practices in Seven Dual Demonstration States*.

56 Contract between US Department of Health and Human Services Centers for Medicare & Medicaid Services in Partnership with the South Carolina Department of Health and Human Services and <Entity>.

57 Hollister and Chapman, *Dementia Care Coordination Workforce and Practices in Seven Dual Demonstration States*.

58 Some, not all, UnitedHealthcare Medicare Advantage members have Solutions for Caregivers.

59 UHC MA Coverage Summary for Solutions for Caregivers, https://www.unitedhealthcareonline.com/ccmcontent/ProviderII/UHC/en-US/Assets/ProviderStaticFiles/ProviderStaticFilesPdf/Tools%20and%20Resources/Policies%20and%20Protocols/UnitedHealthcare%20Medicare%20Coverage/Solutions_Caregivers_UHCMA_CS.pdf.

and the stress of caregiving. These experts can help identify services—such as meal delivery, transportation, and housekeeping—to fit a family’s caregiving needs.

Geriatric care managers are also available for one in-person assessment or up to six hours of caregiver consultation hours over the phone per calendar year. Care managers can conduct an at-home assessment to review the current situation and plan for future care. They can write a care plan to help the caregiver understand the care needs and help him or her select services. They can review local support services within the community with suggested next steps for the caregiver to consider. They can implement care planning and coordination from community-based private and public agencies to best meet the member’s needs. They can also review residential facilities such as assisted living or skilled nursing facilities (see exhibit 9).

Exhibit 9
Covered Benefits: Solutions for Caregivers in UnitedHealthcare Medicare Advantage Plans

Telephonic Care Resource Center Services

- Coaching and support
- Personalized research and identification of services

Geriatric Case Manager Services

- One in-person assessment
- Care plan
- Care coordination

Source: UHC MA Coverage Summary, March 24, 2015.

Solutions for Caregivers for Large Employers.

In January 2016, UnitedHealthcare launched the Solutions for Caregivers Portal for large employers with self-funded health plans at no additional charge for employees to use the online services.⁶⁰ It features in-person, phone, and online resources to help caregivers save money and

provide help to the people for whom they are caring. Caregivers can enter the website—<http://www.uhcforcaregivers.com>—as a guest, or they can create a personalized site. They have access to expert information to create a plan of care, customized resources to meet caregivers’ own needs, and discounted products and services. For those who have case management services as a benefit or who chose to purchase those services, a team of clinicians is available to help family caregivers.

Caregiver Support in Medicaid Programs. Given differences in programs and benefit design, UnitedHealthcare offers caregiver supports that align with the needs of the Medicaid population it serves. As part of a managed LTSS comprehensive assessment process, care coordinators work with the individual and his or her support network to assess the existing support system. Through this process, UnitedHealthcare identifies caregivers who may benefit from additional support and refers them to its Caring for Caregivers program. Caring for Caregivers provides a community education workshop series that focuses on the needs and health of the caregiver. This tool lets caregivers know they are not alone and that there are people and available resources in their community to provide respite services for them.

Additionally, UnitedHealthcare offers mindfulness training for caregivers in several regions. Mindfulness is a self-care practice that helps lower stress, strengthen resiliency, and cultivate the ability to respond consciously and with compassion.



The Cal MediConnect Dementia Project is a promising practice that provides critical assessment, services, and supports to the family caregivers of people with dementia who are participating in the state’s Medicare-Medicaid duals demonstration. Cal MediConnect provides coordinated medical, behavioral health, long-term

60 “UnitedHealthcare’s ‘Solutions for Caregivers’ Provides Comprehensive Resources to Help People Care for Aging or Disabled Family Members,” January 7, 2016.

institutional, and home- and community-based services through managed care organizations to dually eligible beneficiaries in seven counties of the state.

Overview. The California Department of Aging receives funding for this project from the US Administration for Community Living through the Alzheimer’s Disease Supportive Services Program.⁶¹ Working with Alzheimer’s Greater Los Angeles and other Alzheimer’s groups, the Cal MediConnect Dementia Project provides:

- Care manager training and support,
- Caregiver education and respite care,
- Support services through referrals to Alzheimer’s Greater Los Angeles, and
- Technical assistance to create systems change.⁶²

Assessment. The state Department of Aging expects that about 13 percent of individuals who will be auto-enrolled in Cal MediConnect will have been diagnosed with Alzheimer’s disease or a related dementia, with an additional 13 percent likely to have undiagnosed dementia.⁶³ The state recognizes the need for supports for people with dementia and also for their family caregivers. The health risk assessment of the person with dementia must include a process to identify appropriate involvement of caregivers in care coordination.⁶⁴

Toolkit. This project developed a dementia care management toolkit that includes a tool for identifying family caregivers, a validated caregiver stress and strain instrument, a caregiver needs assessment, standardized care

Exhibit 10 Promising Practice: Dementia Care Management Toolkit

The Cal MediConnect Dementia Project developed an evidence-based toolkit for care managers and family caregivers who are caring for people with dementia. A few of the resources include:

- A tool for identifying family caregivers,
- A caregiver stress and strain instrument,
- A caregiver needs assessment, and
- Plain language fact sheets.

These resources are free of charge and can be downloaded from the following website:
<http://www.alzgia.org/professionals/dementia-care-management-toolkit/>.

Source: Alzheimer’s Greater Los Angeles.

plans, and plain language fact sheets that can all be downloaded and used free of charge (see exhibit 10).⁶⁵ Care managers can use the tool for recognizing a family caregiver to help identify the member’s authorized representative and/or the person assisting with the most hands-on care. The questions/prompts serve to facilitate conversation.⁶⁶ The caregiver stress and strain instrument asks the caregiver how he or she feels as a result of providing care.⁶⁷ The care needs assessment tool asks about challenging behaviors of the beneficiary as well as functional, safety, and caregiver needs.⁶⁸ The standardized care plans

61 Contract #90 DS2002-01-00.

62 Debra Cherry, “Dementia Cal MediConnect Project” (presentation at the AARP Roundtable on MLTSS & Family Caregiving, Washington, DC, April 2015).

63 Lora Connolly, *California Coordinated Care Initiative: An Opportunity to Improve Access and Services for Persons with Dementia and Family Caregivers* (Sacramento: California Department of Aging, March 2016).

64 All Plan Letter 14-010, page 4. September 10, 2014.

65 Alzheimer’s Greater Los Angeles, “Dementia Care Management Toolkit,” <http://www.alzgia.org/professionals/dementia-care-management-toolkit/>.

66 Alzheimer’s Greater Los Angeles, Tool for Identifying an Informal or Family Caregiver, <http://www.alzgia.org/wp-content/uploads/2016/01/Dementia-Care-Toolkit-Identifying-Caregiver.pdf>.

67 Alzheimer’s Greater Los Angeles, Caregiver Stress/Strain Instrument, <http://www.alzgia.org/wp-content/uploads/2016/01/Dementia-Care-Toolkit-Caregiver-Stress-Instrument.pdf>.

68 Alzheimer’s Greater Los Angeles, Care Needs Assessment Tool, <http://www.alzgia.org/wp-content/uploads/2016/01/Dementia-Care-Toolkit-Care-Needs-Assessment.pdf>.

are derived from the evidence-based ACCESS Project and contain recommendations for care managers on a range of care issues relevant to family caregivers.⁶⁹ The fact sheets have helpful information for family caregivers on keeping the home safe; anger, frustration, and fighting; getting lost; bathing; medications; and dealing with problem behaviors, such as hallucinations.⁷⁰

Evaluation. The University of California, San Francisco Institute for Health and Aging is the independent evaluator for this project. To date, about 500 family caregivers have attended training events.⁷¹ Through the family caregiver measures, evaluators have found the family caregivers to be very satisfied with the training and/or services, have an increased knowledge about dementia and home- and community-based services, and have increased feelings of perceived self-efficacy for caregiving tasks.⁷²

The project has also trained hundreds of care managers in managed care organizations on the fundamentals of cognitive impairment, Alzheimer’s disease, and related dementias; practical dementia care management; caring for the caregiver; and resources and supportive services. Preliminary results from the Cal MediConnect Dementia Project have shown that satisfaction among care coordinators participating in the dementia care training has been high and that trained care managers report that they are more likely to identify, assess, and assist family caregivers.⁷³ This training is particularly important because many of the health plans are relatively new to serving people with LTSS needs.

69 Barbara G. Vickrey et al., “The Effect of a Disease Management Intervention on Quality and Outcomes of Dementia Care,” *Annals of Internal Medicine* 145, no. 10 (2006): 713–26.

70 Alzheimer’s Greater Los Angeles, Plain language fact sheets, <http://www.alzcla.org/wp-content/uploads/2016/01/Dementia-Care-Toolkit-plain-language-fact-sheets.pdf>.

71 Connolly, *California Coordinated Care Initiative*.

72 Ibid.

73 Hollister and Chapman, *Dementia Care Coordination Workforce and Practices in Seven Dual Demonstration States*.

Recommendations

Given the above findings, the authors make the following recommendations:

1. Managed LTSS programs should offer appropriate services geared to the needs of family caregivers.

Recognizing and addressing family caregivers' needs and preferences—and involving the family in a meaningful and practical way—should be a key component of managed LTSS to promote better care, improve the experience of care for both the person and the family, and reduce costs. Services and supports should include:

- Assessments of family caregivers' needs to help maintain their own health and well-being, target caregiver support services, and sustain their ability to provide care;
- Provision of caregiver supportive services based on identified unmet needs, including education and skills training; support groups, family meetings, and counseling; and respite care;
- Ensuring that family caregivers who provide medical/nursing tasks have multiple opportunities to learn how to administer medications, including injections, provide wound care, and perform other kinds of complex care;
- Home modifications and assistive technologies; and
- Other supportive services and transportation.

When a family caregiver assessment is conducted, family members should be asked about their own health and well-being, their level of stress and any feelings of being overwhelmed, training needs, and any additional services and support needs. Plans should provide the needed services and supports identified during the assessment process.

2. Health plans should identify and engage family caregivers, especially when the care plan depends on them.

States and plans should examine their assessment tools for beneficiaries in Medicaid home- and community-based services managed care programs—and for those eligible for both Medicaid and Medicare—adding a component to assess family caregiver needs whenever the member's service plan depends on the family caregiver. Assessing and addressing family caregivers' unmet needs for information, education, and supportive services should be standard practice in all home- and community-based services programs that aim to help beneficiaries remain at home and in the community. States and plans should ensure that all initiatives to assess and address caregiver needs reflect the multicultural and access needs of the diverse population of family caregivers. The assessment tools and data should be publicly available, as part of generally accepted principles of transparency.

If the member consents, and the family caregiver agrees, family caregivers should be part of the care planning process. Care coordinators and family caregivers should have each other's contact information to facilitate communication.

3. Family caregivers' feedback and involvement can be critical to ensuring quality of care.

Evaluations of health plans should include feedback from family caregivers, and health plan advisory councils should also include family caregivers to better understand their care experience. Evaluations of the quality and appropriateness of LTSS should also include surveys of family caregivers, especially when the service plan depends on them.

Conclusions

A person- and family-centered approach is critical to assessment, care planning, and service delivery.

Involving family caregivers who are willing and able to provide services, along with support for their own care needs, should be a key component of coordination and continuity of care in health care and LTSS.

While family caregiver support is still relatively uncommon in managed LTSS, managed care contracts can be the means for standardizing the person- and family-centered approach.

These important recommendations can be added as provisions or amendments to managed LTSS contracts to better support family caregivers. Innovative approaches and solutions will be needed to finance and deliver LTSS and to explicitly recognize and support family caregivers. Managed care plans can lead the way.

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