

**Long-Term Services and Supports Scorecard**  
**Emerging Innovations**

# Emerging Innovations in Managed Long-Term Services and Supports for Family Caregivers

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## About This Paper

Understanding and addressing family caregivers' roles and their needs is a key element of a high-performing LTSS system, because the family (broadly defined) provides the lion's share of Long-Term Services and Supports (LTSS) to people who need help due to a limitation in carrying out daily living activities. This paper is part of a series on promising practices and emerging innovations from the *2017 LTSS State Scorecard*.<sup>1</sup> The 2017 report finds that more recognition and support for family caregivers is needed to advance person- and family-centered care. Managed care plans can lead the way to ensure that their members' family caregivers do not experience burnout, need to quit their jobs to give more care, or compromise their own health and economic security.

The AARP Public Policy Institute (PPI) contracted with Health Management Associates to conduct 15 standardized telephone interviews with 42 individuals in managed care organizations (MCOs) that contract to provide Medicaid managed LTSS in one or more markets. Health Management Associates interviewed administrators that operate plans in 7 states—Arizona, California, Massachusetts, New Jersey, South Carolina, Tennessee, and Wisconsin. They also interviewed administrators that have national, corporate-level responsibility from 4 MCOs that operate Medicaid managed LTSS in multiple states.

Exhibit 1 indicates the plans that participated in the interviews.

The interviews involved plans that operate Medicaid-only managed LTSS contracts and plans that are participating in the Financial Alignment Demonstrations, which include Medicare and Medicaid benefits under a combined contract.<sup>2</sup> All plans interviewed accept full risk for covered services through monthly capitation payments from the state Medicaid program.

To reflect a broad cross section of plans, this environmental scan includes some large, national plans that operate in multiple states as well as smaller plans that have contracts in only one or two state Medicaid markets. After an interview was held with a national plan at a corporate level, the research team had a follow-up interview with state-level leadership within that organization to drill deeper into what that plan was innovating. Plans interviewed for this report represent both for-profit and not-for-profit businesses.

Because this project sought to seek out new and innovative practices, the authors did not randomly sample plans. We selected plans when we had knowledge of their activities or of innovations being developed by state agencies in those markets. Health Management Associates and the AARP PPI were often informed of these activities through their extensive work in this area.

### EXHIBIT 1 Managed Care Organizations with Emerging Innovations

Amerigroup New Jersey Inc.  
 Amerigroup Tennessee Inc.  
 Anthem/Amerigroup (Corporate)  
 Centene Corporation (Corporate)  
 Commonwealth Care Alliance (Massachusetts)  
 Community Care, Inc. (Wisconsin)  
 BlueCross BlueShield of Tennessee  
 Health Plan of San Mateo  
 Inland Empire Health Plan  
 L.A. Care Health Plan  
 Molina Healthcare  
 Select Health of South Carolina (Amerihealth Caritas)  
 UnitedHealthcare (Arizona)  
 UnitedHealthcare (Corporate)  
 UnitedHealthcare (Massachusetts)

**Total = 15 plans with 42 administrators interviewed**

1 Scorecard emerging innovations papers—such as this paper—highlight what LTSS innovations states and organizations are developing, piloting, or testing, whereas promising practices papers focus on concrete programs and policies from states that have performed well according to documented state data. Emerging innovations and promising practices papers are new features of the *2017 LTSS State Scorecard*, and can be located at <http://www.longtermscorecard.org>. 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, June 2017).

2 The [Financial Alignment Demonstrations](https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/FinancialModelstoSupportStatesEffortsinCareCoordination.html) created under the Affordable Care Act promote care coordination for beneficiaries in both Medicare and Medicaid. Accessed at <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/FinancialModelstoSupportStatesEffortsinCareCoordination.html>.



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## Purpose

This *Emerging Innovations* paper highlights examples of how progressive managed care plans are supporting family caregivers who are caring for plan members with long-term services and supports (LTSS) needs. Family caregivers can include relatives, partners, neighbors, and

friends who provide support and assistance to the member. The purpose of this paper is for plan administrators, policy makers, and community-based organizations to learn from each other and to adopt these practices to better care for members and their family caregivers.

## Background

The AARP PPI began thinking about family issues in managed LTSS as early as 2010, during discussions with MCOs about health care reform. In 2011 as we were collecting data to inform the second edition of the *LTSS State Scorecard*, we knew that states were beginning to shift more LTSS to managed care. To drill deeper into the findings of that *Scorecard*, we held an AARP PPI Innovation Roundtable in February 2012 to discuss measuring family caregiver supports across the states—both current data and the need for improvements to that data—to inform the next edition of the PPI’s *LTSS State Scorecard*. At that time, states were beginning to assess the needs of family caregivers in some of their LTSS programs, but more work was needed to understand how states were conducting such assessments, identifying policy barriers, and making recommendations to advance caregiver assessment in the states.

We then conducted a 50-state survey, in collaboration with the Family Caregiver Alliance, examining how well the needs of family caregivers are assessed when states evaluate the needs of older people and adults with disabilities who qualify for home- and community-based services (HCBS) programs under Medicaid.<sup>1</sup> Two of the policy recommendations from this 2013 survey helped inform our continuing work on family issues and managed care:

- *States should examine their assessment tools for people in Medicaid HCBS managed care*

*programs and for those eligible for both Medicaid and Medicare, adding a component to assess family caregiver needs whenever the client’s care plan depends on the caregiver.*

- *If states assign their assessments for publicly funded programs to managed care companies, the assessment tools and data should be publicly available.*

### What Are Long-Term Services and Supports?

Long-term services and supports (LTSS) include a broad range of day-to-day help needed by people with long-term conditions, disabilities, or frailty. This can include personal care (bathing, dressing, toileting); complex care (medications, 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 to family members and other unpaid caregivers.

*Source: 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, June 2017).*

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

This work continued through a first-ever analysis of managed LTSS contract provisions regarding family caregivers and care coordination conducted in collaboration with Truven Health Analytics. In April 2015 we convened another AARP PPI Innovation Roundtable with federal and state officials, health plans, researchers, and advocates to discuss early findings of this research.

After the roundtable, participants asked to continue to discuss emerging issues in family caregiving and promising practices to support person- and family-centered care in managed LTSS. In July 2015 the AARP PPI published *Care Coordination in Managed Long-Term Services and Supports*.<sup>2</sup> We also formed the AARP Learning Collaborative on Family Caregivers and Managed LTSS, so we could continue to learn from each other and move the field forward. The learning collaborative has held almost monthly conference calls for two years.

The research, roundtables, and learning collaborative discussions have informed our ongoing exploration of this important area. In November 2016 the AARP PPI published *Family Caregivers and Managed Long-Term Services and Supports*, the first major research report in this

emerging field of managed LTSS that specifically addresses family caregivers' needs.<sup>3</sup> This paper on emerging innovations is now the first to provide insights directly from MCO leaders themselves.

### What Are Family Caregiver Supportive 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-person and online support groups, and assistive technologies.

*Source: 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, December 2013).*

## Findings

***Family caregiver supports in managed LTSS are an emerging innovation, but key family caregiver services are not yet commonplace.***

Several plan administrators identified family caregiver supports as an area of increased focus this year. They acknowledged the critical role that family caregivers play in providing care that enables individuals to remain in the community, whenever possible. They recognized the value that family caregivers provide in helping to keep the cost of care sustainable, and making it

possible for high-need members to live at home or in the community they prefer. They also noted that family caregivers themselves are in need of supportive services to keep from burning out.

This new focus on person- and family-centered care represents a significant culture change. In 2015, the AARP PPI tried to commission an inventory of family caregiver supports in MCOs. We were not able to initiate the project because most plans were relatively new to managed LTSS. They were focused solely on serving the members

2 Paul Saucier and Brian Burwell, *Care Coordination in Managed Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, July 1, 2015).

3 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, November 2016).

and developing LTSS provider networks. Privacy issues were also a concern. At that time, family caregivers were simply not on the radar.

In the past two years, several forces of change have occurred. Managed LTSS is more established in many states, so several plans have had more experience with, and therefore more interest in, supporting family caregivers to better enable Medicaid consumers with complex and disabling conditions to remain in home and community settings. Collaboration, research, and advocacy around family caregiving have also played a strong role in ushering in this change.

***State policies, managed care contract language, and advocacy are major drivers for family caregiver supports in managed LTSS.***

Plan administrators noted that their innovations often stem from state requirements for a more explicit focus on the assessment of unmet needs and supports for family caregivers. The good news is that these requirements have led to the development of tools and approaches that plans have found worthwhile to introduce in other markets.

State benefit design has a clear impact on most health plans' approach to assessing and supporting family caregivers, and whether these caregivers are providing paid or unpaid supports. Significantly, Medicaid in many states offers options in which some family members can become paid caregivers, often in consumer-directed arrangements, where individuals have more authority to recruit, hire, and train their own LTSS caregivers. The opportunity to be paid for some of the time devoted to caregiving can be a significant support for family caregivers. California leads the nation in terms of the highest number of participant-directing Medicaid beneficiaries and paid family caregivers.

South Carolina, Tennessee, and Texas require plans to use stand-alone assessment tools for family caregivers. These states recognize that identifying and addressing family caregivers' problems, needs, strengths, and resources—through a family caregiver assessment process—is

central to good care for plan members with LTSS needs. Generally, plans develop the tools, but these states require family caregiver assessments to include elements such as measures of caregiver burnout, the need for instruction and services, whether the family caregiver is employed outside of the home, and if the caregiver lives with the member.

Some of these reforms occurred because of research and advocacy efforts by consumer groups such as AARP and family caregiving organizations that have long pressed for assessment of family caregiver needs as part of policy and practice. In fact, TennCare—a leading state Medicaid program in this area—amended its contract with MCOs in 2015 to require family caregiver assessments and identification of caregiver supportive services. This policy change resulted in large part from the *LTSS State Scorecard*, which measures family caregiver assessment as part of a high-performing LTSS system. TennCare added another contract amendment to MCOs in 2016 to ensure that family caregivers have the care coordinator's name and contact information. This change resulted from research and best practices that were shared at the AARP PPI roundtable in April 2015. South Carolina Healthy Connections Prime, a duals demonstration program, then modeled its attention to family caregiver assessment after TennCare. State administrators from both TennCare and South Carolina participated in the roundtable and are active participants in the AARP Learning Collaborative to share lessons learned and to better support Medicaid beneficiaries with LTSS needs and their family caregivers.

States such as California, Massachusetts, New Mexico, and Wisconsin cover the instruction or training of caregivers to better enable them to carry out tasks at home. Massachusetts requires plans to develop family caregiver instruction. Participant-directed or self-directed programs such as those in California and New Mexico allow Medicaid members to hire the person who provides his or her services and to cover caregiver



education. Centennial Care, New Mexico's Medicaid managed care program, offers a self-directed community benefits program option where care plan-related conference or class fees may be covered for both members or unpaid caregivers. See exhibit 2 for a detailed description of caregiver training in Wisconsin's Family Care Program.

Respite is a commonly available benefit under Medicaid LTSS, but the scope and type of respite services vary greatly from state to state. Plan administrators described generous Medicaid respite benefits in some states (e.g., up to 600 hours a year—in home or in residential settings—in Arizona or up to 30 days a year in New Jersey) as well as more limited benefits in other states (e.g., 14 days of respite services in a residential setting only in South Carolina). In addition, a

state's Medicaid respite benefit might be limited to certain populations, rather than available to every member receiving LTSS. Several plans noted it was more difficult to meet caregiver needs when state benefits for services like respite or adult day services were limited in terms of covered units or restricted to narrowly defined LTSS populations.

***Thought leaders within the interviewed plans identified at least three key roles played by family caregivers for members who have complex or disabling conditions.***

These three roles are:

- In-home caregiver,
- Informant and communicator, and
- Advocate.

Each of these roles calls for a strong partnership, with member consent, between the member's care

### EXHIBIT 2

#### Wisconsin's Family Care Benefit Design

Family Care offers three services that support family caregiver and member training:

- **Consultative Clinical and Therapeutic Services for Caregivers** is designed to improve the ability of unpaid family caregivers and paid direct support staff to carry out therapeutic interventions. This service includes the provision of training for caregivers/staff who are or will be providing hands-on care to members with complex needs (beyond routine care) in home- or community-based settings.
- **Consumer Education and Training Services** is designed to help a person with a disability develop self-advocacy skills, support self-determination, exercise civil rights, and acquire skills needed to exercise control and responsibility over other support services. It includes education and training for members, their family caregivers, and/or legal representatives that is directly related to building or acquiring such skills. MCOs must ensure that information about educational and/or training opportunities is available to members, their family caregivers, and legal representatives. Covered expenses may include enrollment fees, books, and transportation related to participation in training courses, conferences, and similar events.
- **Training Services for Unpaid Caregivers** supports education and training services for individuals who provide unpaid care, companionship, supervision, or other supports to members. Training includes instruction about treatment regimens and use of equipment and other services included in the member's care plan, and guidance as necessary to safely maintain the member in the community. Training must be aimed at assisting the unpaid family caregiver in meeting the needs of the member and must be included in the member's care plan. This service can include online or in-person training, conferences, or resource materials on the specific disabilities, illnesses, and conditions that affect the member for whom they care.

Wisconsin also requires that LTSS care managers and/or the interdisciplinary team provide training to members and their families, unpaid direct caregivers, and/or legal representatives regarding prevention of abuse, neglect, and exploitation at the time of the initial assessment and again at each annual reassessment.

*Source: Family Care Medicaid 1915(c) Waiver.*

coordinator and the member's family caregiver. Based on interviews with both corporate-level and local leaders within health plans, it was evident that the role of the family caregiver typically begins with the assessment of the member's needs and continues through care planning, care coordination, and service delivery.

All of the plans interviewed affirmed that the member can have whomever he or she chooses to participate in the assessment and care planning process. A few plan administrators noted that the care manager must be attentive to and honor the member's preferences, even if it is to not have family involved in the planning process. They noted, however, that experience has shown that having members engage family caregivers in their care planning process is generally beneficial to both the member and the managed care plan. Overall, the plans indicated that the family caregiver's involvement in care planning and coordination made the care plan stronger and more effective.

***Plans have emerging innovations for family caregivers in six areas.***

### CAREGIVER ASSESSMENT

All plans reported that care managers identified family caregivers' needs. Most plans, however, reported this assessment as an informal process, arising during the formal assessment of the member. Some plans, however, have developed formal family caregiver assessment tools in response to state contract requirements. A growing number of plans reported that they have adopted the use of formal caregiver assessment tools in markets where they are not required.

Examples of family caregiver assessments are as follows:



United Healthcare has developed a national caregiver assessment tool that can be modified to accommodate state requirements. Use of this tool is encouraged, even in states that do not require a separate assessment of family caregivers.

United Healthcare of Arizona uses the required state assessment tool for members, but responses to certain questions in that tool trigger a more in-depth caregiver assessment, which includes a focus on caregiver burnout.



Molina Healthcare voluntarily adopted two screening tools to better support and involve family caregivers.

The American Medical Association (AMA) Caregiver Self-Assessment Questionnaire is required by the South Carolina Medicare Medicaid demonstration contract, but Molina elected to use this tool in all health plans with managed LTSS. To get the best results, the plan is training staff to use the tool to assess caregiver issues, such as family stability and the presence of substance abuse problems, and to identify when respite or other services are needed. Molina also provides a caregiver toolkit that includes a list of community resources, a medication log, checklists to prepare for doctor visits, and many other tools to support individuals and their family caregivers.

The AD8 Dementia Screening Interview promotes early detection of the disease, provides information that may be shared with the person's doctor, and encourages caregiver involvement.



BlueCross BlueShield of Tennessee uses a separate caregiver assessment tool, which includes but goes beyond state minimum assessment elements. The plan collaborated with the state to allow telephonic assessment when the caregiver requests. This allows the caregiver more flexibility and privacy, and the opportunity for candid answers. The tool addresses the caregiver's own health and engagement with a primary care doctor, instruction that the caregiver has had or needs to carry out complex tasks, and whether caregivers are feeling stressed, hopeless, or angry.

### RESPIRE SERVICES THAT GO BEYOND CONTRACT BENEFIT REQUIREMENTS

Respite care addresses one of the most pressing needs of family caregivers. All plans reported the availability of some level of respite or related services, though the amount of covered respite days or hours varied widely across state benefit packages. These services provide relief to caregivers who need a break from caregiving due to stress, the need to take care of their own medical needs, or other family obligations. In addition to in-home and institutional respite, plan administrators described using adult day programs, meal delivery services, in-home monitoring, and personal response systems as ways of relieving some burden for family caregivers. As an emerging practice, many plans reported the ability and practice of offering services beyond the contractual requirements when they determine that a family caregiver needs more support or assistance in the home.

Examples of family caregiver respite are as follows:



Inland Empire Health Plan

**Inland Empire Health Plan**

Inland Empire Health Plan offers in-home respite for caregivers who assist individuals with behavioral health challenges—not a formal benefit under the state’s benefit design—to give caregivers a break. The plan also offers home visitation by doctors for some members, which increases access to primary care for vulnerable populations. The plan believes this benefit provides both a value-added service for members and a burden reliever for family caregivers.



**Community Care, Inc.**

Community Care, Inc. provides alternative sources of respite opportunities for family caregivers who assist members with complex behavioral challenges. Community Care Inc. uses its provider network and self-directed support model to offer and identify alternative respite providers for stressed caregivers.



**Health Plan of San Mateo**

HealthPlan of San Mateo provides respite as a value-added service outside of the state’s respite benefit design, with a focus on providing relief for caregivers supporting members with Alzheimer’s disease and other dementias.



**AmeriHealth Caritas**

AmeriHealth Caritas has a caregiver quality improvement project to increase respite utilization by 10 percent per year to improve the quality of life of enrollees by helping reduce stress and burnout among family caregivers. Strategies include caregiver assessment, engagement through in-home visits, and caregiver education of respite care benefits. South Carolina requires the plans in its dual demonstration to have a caregiver quality improvement project and to track the percentage of enrollees who experience an increase or decrease in the authorization of respite hours. However, plans have the flexibility to determine the parameters of these efforts and corresponding strategies. The plan can also provide additional respite outside of the state institutional respite benefit.

### DIRECT ENGAGEMENT OF FAMILY CAREGIVERS

All states require Medicaid plans to establish member advisory councils to advise plans on their operations of managed LTSS. Some plans have gone beyond the required minimum engagement and have begun to involve members and their families, with more focused attention on understanding the needs of family and other unpaid caregivers.

Examples of direct engagement of family caregivers are as follows:



**UnitedHealthcare**

UnitedHealthcare of Arizona developed eight regional advisory councils, instead of the single council required by the contract, to better promote

local participation by members and family caregivers. The councils also include service providers, area agencies on aging, and small nonprofit community organizations to facilitate broad local engagement.

United Healthcare of Massachusetts has conducted a series of focus groups and surveys for unpaid caregivers in order to develop support tools and programs. The goal is to create education and support opportunities for those that take care of their members, which is integrated into their care management approach.



L.A. Care Health Plan completed a survey of members and families to provide a better understanding of the needs of caregivers in the home. The survey revealed that caregivers generally are seeking peer connections for support and problem solving, access to holistic professional assessment of the members' needs, and increased education for physicians to understand the needs of complex populations.

### FAMILY CAREGIVER INSTRUCTION AND SUPPORT

All plans reported identifying and sharing information about community organizations and programs that can provide information, peer support, or other resources to help family caregivers in their roles. However, some plans have gone beyond linkage and referral to existing resources and have acted to create or expand the availability of caregiver supports.

Examples of expanded family caregiver supports are as follows:



Amerigroup adopted the use of community outreach specialists and housing specialists in multiple states, modeled on the member advocate model required in the Tennessee market. The member advocates work with members and

family caregivers to meet needs in extraordinary circumstances through more effective community linkages.

Amerigroup invited national experts in person-centered planning to train its staff and leadership to promote culture change throughout the plan. This training includes a focus on better supports for members and family caregivers. For example, the plan is mobilizing to support more effective self-advocacy on the part of its members and family caregivers, including in care planning and appeals.

Amerigroup of New Jersey hosts caregiver events twice a year to offer educational workshops for caregivers of members with impaired cognition. These events include interactive relaxation exercises and resource tables from local and county agencies. Workshop topics include Alzheimer's education, fall prevention, and self-directed services. Caregivers complete an evaluation at the end of each event and have communicated the benefits of this event for their families.



Commonwealth Care Alliance has developed an in-house training program that offers a curriculum of caregiver training—both group lecture and in-home, as needed—that addresses topics such as disease management, food preparation, stress management, and self-management/time management skills.



Community Care, Inc. offers unpaid family caregivers a coupon code, so they can access available online caregiver instruction (otherwise developed for paid caregivers). The University of Wisconsin at Oshkosh, in conjunction with the state department of human services, developed this training.

### PARTNERSHIPS WITH COMMUNITY-BASED ORGANIZATIONS AND UNIVERSITIES

All plans report working to identify local community-based organizations and other programs that can provide a broad range of social supports or other important services and instruction for members and their family caregivers. Many plans develop in-house “benefit banks” or other online or printed materials for care coordinators to share with members and family caregivers. As an emerging practice, some plans report initiating more formal arrangements with local organizations to support, expand, leverage, or otherwise improve access to local resources to support caregivers.

Examples of innovative partnerships are as follows:



United Healthcare of Arizona created a member empowerment program, based on input from the member advisory council, to hold mini-conferences for members and family caregivers. The plan brings in support persons, volunteer organizations such as local libraries, and local colleges to provide information and engage members and family caregivers and to educate them through participatory workshops. For example, a local public transportation agency brought adapted buses to a parking lot, so members and their family caregivers could practice getting on and off the vehicles.



L.A. Care Health Plan partners with Alzheimer’s Greater Los Angeles to offer instruction that is hosted in the plan’s family resource centers and other community sites. Alzheimer’s Greater Los Angeles also trains L.A. Care staff on the fundamentals of cognitive impairment, practical dementia care management, caring for the caregiver, and available community supports.



Inland Empire Health Plan *Inland Empire Health Plan*

Inland Empire Health Plan sponsors and leads the Inland Empire Disabilities Collaborative, which builds cooperative relationships across a network of entities engaged in supporting and serving individuals with disabilities to strengthen and expand system capacity and effectiveness. The collaborative includes more than 900 service providers from regional organizations that serve people with disabilities and older adults. This effort includes a strong partnership and collaboration with PossAbilities of Loma Linda University and the Community Access Center.

The plan also joined local county agencies, community-based organizations, and medical/professional colleges in sponsoring professional case conferences and instruction developed and presented by the UCLA Geriatric Workforce Enhancement Program. Programs are targeted to paid caregivers (which includes a large number of family caregivers in California through the state’s In-Home Supportive Services program), with a focus on identification and care for individuals with dementia. A goal is to develop online educational materials that can be used over time to better prepare family caregivers.



*BlueCross BlueShield of Tennessee*

BlueCross BlueShield of Tennessee has linked with the local Area Agencies on Aging and Disability (AAADs) to provide family caregivers supports such as stress management and to facilitate connecting to similar types of supports. This is an important partnership because the AAADs locally administer the National Family Caregiver Support Program under the Older Americans Act.

### FOCUS ON DEMENTIA AND BEHAVIORAL HEALTH

One area of focus of Medicaid managed LTSS plans is increasing supports for family caregivers

who are caring for members with dementia and/or challenging behavioral health needs. These family caregivers are considered most at risk of high levels of stress and burnout, and needing information and training on how to reduce and manage difficult behavioral symptoms and how to best provide hands-on assistance as needs change over time.

Examples of innovations in this area are as follows:



**Amerigroup of New Jersey**

Amerigroup of New Jersey includes behavioral health specialists as part of the multidisciplinary team that supports the LTSS care coordinator. The plan also partners with local health educators and providers to offer training sessions in communities on Alzheimer's disease and other dementias.



**Community Care, Inc.**

Community Care, Inc. developed online resources for care coordinators to use to assess caregiver burnout, especially related to dementia care. The

plan also develops in-house experts for dementia care and connects families to other organizations for supports regarding dementia such as local “memory cafes.”



Illinicare, Centene's Illinois subsidiary, encourages regular in-home family meetings. A behavioral health specialist can attend these meetings and offer support for members and caregivers as needed.



**Inland Empire Health Plan**

Inland Empire Health Plan recently revised the interdisciplinary care team (ICT) meeting structure and frequency to ensure inclusion of multidisciplinary care team representatives from various disciplines, including LTSS and behavioral health staff. Inland Empire Health Plan's goal was to increase participation by health plan members, their caregivers, the primary care provider, and specialists and have a meaningful ICT discussion with the right people at the right time.

## Opportunities and Recommendations

The findings of this environmental scan lead to six areas of opportunities and recommendations.

### COLLABORATE ON CARE ACT IMPLEMENTATION

***Widespread enactment of the CARE Act across the states presents an opportunity for hospitals and plans to better work together in discharge, instruction on complex care tasks, and transition planning from hospital to home.***

Only a minority of plan administrators interviewed were familiar with the CARE Act in their states. At the time of the interviews, about 35 states and territories had enacted the

CARE Act; by July 2017, this number had risen to 39 states and territories.

The CARE Act requires hospitals to:

- Identify family caregivers (with the patient's permission) and record those names in the medical record;
- Notify the family caregiver as soon as possible before the patient is discharged from the hospital; and
- Instruct the caregivers on how to perform complex medical/nursing tasks that they are expected to carry out at home, after the family member leaves the hospital.<sup>4</sup>

4 Susan C. Reinhard and Elaine Ryan, *From Home Alone to the CARE Act: Collaboration for Family Caregivers* (Washington, DC: AARP Public Policy Institute, August 2017).

These medical/nursing tasks include wound care, managing medications, giving injections and tube feedings, monitoring blood sugar, preparing special diets, and operating medical equipment, among others.

Hospitals could find health plans particularly effective in facilitating family caregiver engagement in planning, since care coordinators from managed care plans already have established relationships with family caregivers and knowledge of the range of plan benefits for the member and the family, often beyond traditional home health benefits, that can be beneficial to successful transitions.<sup>5</sup> Plan administrators universally described having strategies—such as involving the LTSS care coordinator—to engage with or wrap around a hospital’s discharge planning process.

Most plans also noted that it is particularly challenging to effectively support preparing for successful transitions at hospital discharge if LTSS members are eligible for Medicare as the primary payer for hospital services. In many cases, the plan has no formal way of knowing when someone has been admitted to a hospital, but rather must rely on notification from the individual or family members. This lack of integration can delay and diminish preparation for effective transitions. Improved communication with hospitals and use of electronic medical records could also assist managed LTSS plans in overcoming delays in notification regarding hospitalization for dually eligible members who are covered by both Medicare (hospitalization) and Medicaid (LTSS).

### **FORM COMMUNITY PARTNERSHIPS TO ADVANCE PERSON- AND FAMILY-CENTERED CARE**

***There is significant opportunity to develop more direct relationships between plans and key community resources to scale up evidence-based caregiver interventions and foster co-***

### ***development of supports more specifically tailored to the needs of family caregivers.***

All plans stressed the importance of community resources for providing supports to family caregivers. The supports ranged from finding support groups for family caregivers, obtaining information on diseases, securing instruction for caregivers, and finding help to address needs like housing and transportation. Most plans described the role of care coordinators as linking family caregivers to community resources. Plans often described their efforts to catalogue information about community resources and to equip staff, members, and caregivers with information about the availability of community resources, sometimes through online resources and very often through providing written materials to family caregivers in the home.

This form of linking was often described as making referrals to services, but it generally did not appear to involve a warm handoff—for example, the care coordinator introducing the caregiver to the community support worker—or even having the care coordinator make an appointment for the family caregiver to follow up on the referral. Plans did not generally describe having a direct business relationship with these community resources—for example, through contracts and memorandums of understanding. Rather, plans were organizing information and making the availability of community resources known to family caregivers.

Some plans described going beyond information and referral. They described efforts to more directly partner or collaborate with community-based organizations to facilitate access to services for members and their family caregivers, adopting the principle of person- and family-centered care. Some plans also described creating new or expanded opportunities for family caregivers to access resources by collaborating with the local organization on referrals and linkage, partnering in the development of a curriculum, sponsoring

5 Lynn F. Feinberg, *Patient and Family Advisory Councils in Hospitals: Building Partnerships to Improve Care* (AARP Public Policy Institute, November 2017).

events, paying for family caregivers to participate in these opportunities, or fostering community awareness and growth in system capacity.

### **COLLABORATE LOCALLY WITH THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM**

***Since most plans are not familiar with the National Family Caregiver Support Program (NFCSP) under the Older Americans Act, there is great opportunity for better leveraging these services and supports in managed LTSS to target family caregivers in need.***

Established in 2000, the National Family Caregiver Support Program provides grants to states and territories to fund a range of supports to help family caregivers care for relatives or close friends in their homes for as long as possible.<sup>6</sup> However, available programs and services vary among states and communities, reflecting both limited federal resources and variation in local priorities. Services include informing family caregivers about available services; assisting family caregivers in gaining access to supportive services; individual counseling, support groups, and family caregiver training; respite care; and supplemental services on a limited basis.

Three plans identified the local NFCSP program as an important partner or resource in providing family caregiver supports, while one plan described an extensive, statewide collaborative relationship with the local aging and disability resource centers to provide caregiver supports. In a few interviews, plan administrators did not know about family caregiver support programs in their local communities, but stated that the organization(s) had not been open to working more closely with their plan (e.g., taking referrals from the plan), often citing limited NFCSP resources. However, the large majority of plan administrators interviewed did not know whether their local plans referred family caregivers to or had collaborative, contracted relationships with the agencies that run the family caregiver support programs in local communities.

### **COLLABORATE TO BOLSTER PROMISING CAREGIVER SERVICES AND SUPPORTS**

***State officials, plan administrators, and community-based organizations have great opportunities to work together toward overcoming significant barriers such as a lack of home care workers and demand for family caregiver instruction, counseling, and respite care.***

In some markets, plans described a lack of sufficient system capacity, especially regarding respite services. Some possible reasons were in-home service agency challenges with 24-hour staffing, and administrative burden perceived by providers in terms of respite admissions.

Several plan administrators noted that, when state plan benefits are not comprehensive or generous regarding family caregiver needs for education or respite, health plans are fiscally challenged to invest in sufficient family caregiver support.

### **ENHANCE STRATEGIES FOR PLANNING FOR THE FUTURE**

***Because many family caregivers fear what will happen if they can no longer provide care or will need more support in the future, plans could adopt practices to support person- and family-centered care across the continuum of care, and be more explicit regarding potential alternatives for supplementing family caregiver supports in planning for the future.***

The fear of what happens when family caregivers are no longer able to provide hands-on care is often one of the most stressful aspects of caring for someone with chronic conditions or disabilities. At least one plan observed that individuals and families may press for more services than they need in the near term, in case they need more support in the future when the family-provided care is unavailable.

All plans reported being highly focused on providing a person-centered care planning process for each member using LTSS. Person-centered planning has long been a centerpiece of Medicaid HCBS and supports delivery. With

<sup>6</sup> See <https://www.acl.gov/programs/support-caregivers/national-family-caregiver-support-program>.



the introduction and expansion of managed LTSS, a person- and family-centered approach to planning is being encouraged by states, even for individuals using institutional settings of care. Many plan administrators noted the importance of understanding the member's goals and preferences regarding care, and all plans acknowledged the importance of, where possible, supporting and extending the ability of family caregivers to continue to provide in-home supports. All noted that care plans are updated if situations or needs change. However, the vast majority of plan administrators did not discuss any specific or routine attention paid to preplanning alternative strategies if and when current family caregivers might no longer be able to continue in their role.

### **ENSURE THAT PLANNING, SERVICES, AND SUPPORTS REFLECT THE CULTURALLY SPECIFIC NEEDS OF FAMILY CAREGIVERS**

*Although many health plans are involved in addressing cultural competency—for example, by hiring bilingual care coordinators—the broader issue of how cultural differences can impact demand and which kinds of supports are acceptable to subpopulations of family caregivers is important to address in order to provide more effective access to family caregiver supportive services.*

While plans routinely provide written materials in multiple languages and have systems in place to assist with translation services as needed, some plans noted that they continue to struggle with the ability to provide culturally sensitive in-home supports. A few plans reported encountering reluctance on the part of family caregivers and/or members to use paid respite or other services offered through the care planning process, especially in some age groups or subpopulations. Plan administrators often attributed this occurrence to differences in cultural norms and

preferences within and across communities or age groups. For example, reluctance on the part of some caregivers to accept any assistance may occur because they do not believe others could do as good a job in supporting their loved ones or are unwilling to admit they need help. It might reflect situations where the members themselves resist outside help, a dislike of certain options (e.g., even temporary admission to an institution), or perhaps a general reluctance to have strangers in the home.

A few plans noted that their efforts to offer more organized education, even in partnership with community-based organizations, had received only lukewarm response in terms of participation in some communities. Administrators speculated on several potential causes for low take-up by family caregivers:

- Family caregivers may have little available time to attend classes, especially if that requires finding someone else to be with the member or taking time off from paid employment to attend.
- Family caregivers may not perceive a need for training, especially if they have been assuming caregiving tasks over many months or even years.
- Where managed LTSS is new, family caregivers might be resistant to accepting education from the plan, or, especially for self-directing members, there may be a preference for member-provided training of caregivers.

Direct family caregiver and member engagement, including focused engagement within subpopulations, could prove effective in supporting more effective strategies by managed care plans to tailor training, services, and supports that meet the needs of members and their family caregivers.

## Conclusion

Not all family caregivers need help, but many do. Medicaid's managed LTSS plans recognize the importance of advancing person- and family-centered care. Plan administrators report that family caregivers play an important role as both paid and unpaid caregivers. They understand that family caregivers often provide supports that are critical to the health and well-being of members. They also acknowledge that those who take on this unpaid role risk the stress, physical strain, competing demands, and financial hardship of caregiving, and thus are vulnerable themselves. State Medicaid benefits and managed care contract language on plan performance expectations have a definite impact on assessing and supporting family caregivers.

Emerging innovations in the support of family caregivers include:

- The use of formal family caregiver assessment tools to identify risk of caregiver burnout, to encourage caregivers to identify their own needs, and to help care managers recognize the need for additional instruction or supports;
- Plan flexibility to go beyond state benefit limits, when needed, to sustain effective family caregiver arrangements;
- More focused engagement of family caregivers to provide input to plan operations and to identify areas of needed supports and

culturally appropriate services through focus groups, surveys, and family advisory councils;

- Plans going beyond linkage and referral of existing resources to creating or expanding the availability of effective family caregiver services and supports;
- Plan initiatives to improve supports for those caring for someone living with dementia, behavioral health conditions, or challenging behaviors; and
- Effective partnerships among health plans, community-based organizations, and universities to provide targeted education and support groups.

These innovative practices and strategies are helping to reform the delivery of LTSS by recognizing and supporting both the plan member and the family caregiver. Meanwhile, policy makers, plans, community-based organizations, and hospitals have important opportunities to collaborate on overcoming challenges—such as improving cultural competency, reducing benefit restrictions on critical services, and improving the ability to leverage federally supported family caregiver supportive services and the CARE Act—to advance person- and family-centered care in managed LTSS.

EMERGING INNOVATIONS



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