

ISSUES FROM THE STATES

Advocating for Improved Consumer Protections in Managed Long-Term Services and Supports

ISSUE BRIEF • APRIL 2015

Written By

Eric Carlson

Directing Attorney, Justice in Aging

Executive Summary

For the past two years, Justice in Aging has provided ongoing assistance to advocates in Florida, Kansas and New Jersey as their states have implemented Medicaid managed care for long-term services and supports (LTSS). This issue brief provides short summaries of the managed care programs in each of those states, and then discusses four specific advocacy issues that have arisen in the states, along with strategies to address those issues. These issues give a flavor of the various problems that can confront consumers and their advocates in a managed care environment.

Limits on Individual Expenditures

Home and community-based services programs are generally limited to the aggregate amount of funds that would have been expended if the HCBS beneficiaries instead had received their necessary services in a nursing facility. In some states, there is also an individual limit — each HCBS beneficiary is limited to the expenditures that he or she would have incurred in a nursing facility.

Neither Florida nor Kansas employ explicit individual limits. In New Jersey, however, each managed care member receiving HCBS is limited to a cost cap

National Senior Citizens Law Center became Justice in Aging on March 2, 2015.

Table of Contents

Executive Summary	1
State Summaries	3
New Jersey	3
Florida	3
Kansas	4
Advocacy Issues	4
Limits on Individual Expenditures	4
New Jersey's Cost Limits	4
Expenditure Limits Motivated by Cost Neutrality Requirements	5
Advocacy Considerations	6
Ombudsman Programs	7
Kansas Ombudsman Program	7
New Jersey Ombudsman Program	10
Florida Ombudsman Program	10
Advocacy Considerations	10
Access to Performance Measure Data	11
Performance Measure Requirements	11
Limits on Access to Information	12
Advocacy Considerations	13
Continuation of Services Pending an Appeal Decision	14
State Protections	14
Advocacy Considerations	15

based on the cost of nursing facility care. An exception can be made if the member is transferred from a nursing facility to a community-based setting, is experiencing a change in health condition that is not expected to last more than six months, or has unique needs that constitute a special circumstances requiring an accommodation. In addition, if a beneficiary's assessed needs exceed the cost limit, he or she can choose to live in the community under the less-than-desired payment amount, upon entering into a risk assessment.

On an individual advocacy level, the member should be aware of both the limits and the exceptions. Individual appeals may be necessary to obtain the necessary service level.

On a policy level, advocates should consider both the pros and cons of a system with explicit cost limits. It may seem initially that a system without explicit limits is best but, as a practical matter, benefits in the other systems are not limitless, but instead are governed by limits that may be invisible to the member — internal guidance of a managed care organization (MCO), for example. Also, if the explicit limits are set at a reasonable level, they may act as a helpful guide as to what level of service is available.

Ombudsman Programs

In 2013, the Centers for Medicare and Medicaid Services (CMS) issued guidance to states for Medicaid managed long-term services and supports. That guidance stated that, while enrolled in an MCO, a member must have access to independent and conflict-free assistance with any disputes with a state or plan. CMS specifically mentions an advocate or ombudsman to assist consumers with such disputes, and notes that any assistance must be provided at no cost to the consumer.

Kansas's managed care program always has included an ombudsman program, although the ombudsman program is still in its relative infancy. Both before and after a program revision, the program has not included representation of members in grievances or appeals. A volunteer component will be launched in 2015 and then expanded through the state in 2016.

Despite the CMS guidance, neither New Jersey nor Kansas have ombudsman programs or comparable advocacy programs that are focused on managed LTSS.

The federal agreement for New Jersey references an advocacy program, but it is limited to managed care members who self-direct services. The federal agreement for Florida also references advocacy organizations, but the reference is to pre-existing organizations not focused on managed care issues.

In states with a clear mandate for an ombudsman program, advocacy should be focused on whether the program is authorized to conduct necessary advocacy for individual members, which should include representation on grievances and appeals. One potential model is the ombudsman program in Wisconsin.

In states without a clear mandate for an ombudsman program, advocacy should focus on obtaining such programs. These states' managed care programs may have been approved prior to the 2013 CMS guidance, but the guidance obviously should apply to states whether or not their programs initially were approved prior to the guidance's release.

Access to Performance Measure Data

Medicaid MCOs are typically required to submit large amounts of performance data to the state, to allow the state and CMS to evaluate the progress of the managed care program, and to make changes as necessary. The state generally shares this information with a quality review organization. The information also could be very useful to any person evaluating the performance of an MCO or an MCO system, including but not limited to advocates for MCO members.

Member advocates in Florida and Kansas requested copies of the performance data from the state, but in some cases much of the data was deleted before the relevant reports were shared. The level of deletion seemed excessive — far beyond that which might be necessary to protect members' privacy.

As necessary, advocates can and should file lawsuits under states public records acts in order to obtain appropriate access to performance data, without imposition of inappropriate deletions. Far better, of course, would be the state in the first instance providing requested data and making deletions only in cases where privacy considerations truly are implicated.

Continuation of Services Pending an Appeal Decision

In Medicaid generally, if a Medicaid program proposes to eliminate all or a portion of a beneficiary's services, the beneficiary is entitled to continuation of those services while he or she pursues an appeal. This protection has been less effective in some managed care settings, as some MCOs have limited the continuation of services to the duration of a pre-existing authorization.

To better protect MCO members, some states have explicitly required that extended benefits not be limited by the length of an original authorization. In New Jersey, for example, in situations where the member requests continued benefits, the contract between the state and the MCOs requires continuation of benefits pending appeal with no limitations related to preexisting authorizations. Kansas has adopted a similar protocol. If the member asks for an MCO appeal or a state fair hearing, the currently authorized HCBS will continue until a decision is rendered in the appeal or fair hearing. If the ultimate decision is unfavorable to the member, he or she nonetheless will not have to pay for the previously-provided services, "unless fraud has occurred."

Advocacy with CMS is on-going to eliminate any ambiguities in the right of an MCO member to obtain continued coverage pending a decision on an appeal or fair hearing. State level advocacy also is vital, particularly as long as the federal standards and guidance are inadequate. The provisions used by New Jersey and Kansas are helpful precedents for state-level advocacy for consumer protections.

State Summaries

New Jersey

In New Jersey, LTSS now is provided through managed care under the terms of a Section 1115 waiver. Managed LTSS became effective (after several delays) in July 2014, as LTSS was added to a pre-existing Medicaid managed care program. Managed LTSS has taken over services that previously were provided under four Section 1915(c) waivers: Global Options for Long-Term Care, AIDS Community

Care Alternatives Program, Community Resources for People with Disabilities, and the Traumatic Brain Injury Waiver. An additional 1915(c) waiver, the Community Care Waiver for persons with intellectual or developmental disabilities, remains outside of managed care.

New Jersey's MLTSS program includes personal care (a state-plan service), respite care, care management, home and vehicle modifications, home-delivered meals, Personal Emergency Response Systems, mental health and addiction services, assisted living, community residential services, and nursing facility care. An exemption is made for persons already residing in nursing facilities as of July 1, 2014; their Medicaid coverage continues in the nursing facilities on a fee-for-service basis.

Five managed care organizations (MCOs) participate in New Jersey Medicaid managed care: Aetna Better Health of New Jersey, Amerigroup New Jersey, Horizon NJ Health, UnitedHealthcare Community Plan, and WellCare.

Florida

Florida's MLTSS program began in August 2013, when the state began implementing the Statewide Medicaid Managed Care program. The transition to managed LTSS took place from August 2013 through March 2014, with designated counties transitioning in specified months.

Florida's MLTSS program is based on a combined Section 1915(b)/(c) waiver. The Section 1915(b) waiver governs the transition to managed care, and the Section 1915(c) waiver authorizes home and community-based services as an alternative to nursing facility care. The MLTSS program covers services that previously had been provided under the following Section 1915(c) waivers: the Aged and Disabled Adult Waiver, the Assisted Living Waiver, the Nursing Home Diversion Waiver, and the Frail Elder Option (Miami-Dade County only). The move to managed care did not lift the enrollment limits that had been, and continue to be, placed upon Section 1915(c) waiver services, and waiver applicants continue to be placed on waiting lists due to the enrollment limitations.

Managed care enrollment is optional for the

Program of All-Inclusive Care for the Elderly (PACE) and for each of the following programs: the Developmental Disabilities Waiver, Traumatic Brain and Spinal Cord Injury Waiver, Project AIDS Care Waiver, Adult Cystic Fibrosis Waiver, Familial Dysautonomia Waiver, and Model Waiver.

Managed LTSS is provided by six MCOs — Amerigroup Florida, Coventry Health Care of Florida, Humana Medical Plan, Molina Complete Care, Sunshine Health Plan, and United Healthcare — and a provider services network, American ElderCare. Only American ElderCare is approved for participation in every one of the state’s eleven Medicaid regions.

Originally, LTSS consumers continued to receive their non-LTSS Medicaid services on a fee-for-service basis, but then those services as well were transferred to managed care. This transfer occurred from May through August 2014.

Kansas

Kansas’ managed care plan, called KanCare, began in January 2013. The program is operated through a Section 1115 waiver and separate 1915(c) waivers, including the Autism Waiver, the Frail Elderly Waiver, the Intellectual/Developmental Disability Waiver, the Physical Disability Waiver, the Technology Assisted Waiver, and the Traumatic Brain Injury Waiver.

KanCare included LTSS from the time of the initial implementation. Implementation was delayed, however, for home and community-based waiver services provided for persons with intellectual or developmental disabilities. These services, provided under the Intellectual/Developmental Disability Waiver, were not transferred to managed care until February 2014. KanCare offers services through three MCOs: Amerigroup of Kansas, the Sunflower State Health Plan, and UnitedHealthcare Community Plan of Kansas. Each is approved for participation across the state.

Advocacy Issues

Limits on Individual Expenditures

New Jersey’s Cost Limits

Federal approval of the New Jersey program states that members “receiving MLTSS will most often receive a cost-effective placement, which will usually be in a community environment.” “Cost-effective” essentially is defined as no more expensive than the corresponding level of institutional care. For example, if a member is deemed to need nursing facility care and receives community-based LTSS instead as an alternative to nursing facility services, the expense of the community-based LTSS cannot exceed the cost of nursing facility services.¹

Under the terms of the approval, exceptions to the limits are available in three situations:

1. The member is transitioning from an institution (a nursing facility, for example) to a community-based setting;
2. The member is experiencing a change in health condition that involves significant additional cost, but which is not expected to last more than six months; or
3. The state has determined that there are “special circumstances” that require an accommodation to meet the member’s “unique needs.”²

If the costs of community-based care exceed the cost of facility care and no exceptions apply, but the member nonetheless refuses the facility care and chooses to live in the community, the member and MCO are directed to complete a risk assessment that details the risk of the community-based setting for the member, and outlines the safeguards in place.³

The approval also addresses the situation in which the facility care is more expensive than communi-

¹ CMS, N.J. Special Terms and Conditions (STC), at pp. 48-49 (version including technical corrections approved 8/14/14).

² CMS, N.J. Special Terms and Conditions (STC), at 49.

³ CMS, N.J. Special Terms and Conditions (STC), at 49.

ty-based care. The MCO may require community-based placements, provided that the service plan adequately protects the member's health and safety.⁴ As implemented, this rule does not apply to members already residing in a nursing facility.⁵

Implementation instruction for these limitations is set forth in the contract between the state and the MCOs. Under that contract, cost-effectiveness is measured by a state-developed "annual cost threshold," which is based on the LTSS –portion of the capitation rate for members living in a nursing facility (or a special care nursing facility, for residents with significantly greater care needs). When a member's HCBS costs reach 85% of the cost threshold, the MCO must convene an interdisciplinary team meeting to discuss the options.⁶

The MCO has authority to deny requested community-based services if the cost of those services would exceed the cost threshold and the actual cost of facility placement (subject to the member's right to remain in the community under a risk assessment agreement). Also, as discussed previously, the MCO has authority to deny facility services if the cost of those services would exceed the cost of adequate community-based services.⁷

The state has issued additional implementation instruction to more clearly define the exceptions to the cost threshold. This guidance slightly expands the exception related to a change in condition lasting less than six months. As non-exclusive examples of qualifying situations, the guidance lists the presence of an acute medical condition that should resolve within six months, and the temporary loss of the member's primary caregiver.⁸

The guidance also authorizes an exception for "complex medical needs which can only be met through private duty nursing."⁹ Examples of such complex medical needs include the following:

- Ventilator management,
- An active tracheostomy accompanied by a need for deep suctioning, or by around-the-clock nebulize treatments with chest physiotherapy,
- Gastrostomy feeding accompanied by frequent regurgitation and/or aspiration, and
- A seizure disorder manifested by frequent prolonged seizures, requiring emergency administration of anticonvulsant medication.

In general, private duty nursing hours are limited to 16 hours daily, although this limit may be exceeded on a temporary basis.¹⁰

Under the guidance, a member can invite any person (including the member's physician) to participate in an interdisciplinary team considering the member's needs in relation to the cost threshold. If the interdisciplinary team process results in a decision that the cost cap should be exceeded, the MCO submits a request exception to the state. The MCO is responsible for notifying the member of the state's determination and the member's appeal rights.¹¹

Expenditure Limits Motivated By Cost Neutrality Requirements

In addition to its "cost-effective placement" requirement, the federal approval of New Jersey's managed care requires that the program overall be budget-neutral—that total Medicaid expenses be no

⁴ CMS, N.J. Special Terms and Conditions (STC), at 49.

⁵ Contract Between State of New Jersey Department of Human Services, Division of Medical Assistance and Health Services and Contractor § 9.3.2(B)(1) (7/14).

⁶ Contract Between State of New Jersey Department of Human Services, Division of Medical Assistance and Health Services and Contractor § 9.3.4(A).

⁷ Contract Between State of New Jersey Department of Human Services, Division of Medical Assistance and Health Services and Contractor § 9.3.4(A), (B).

⁸ New Jersey Department of Human Services, Division of Medical Assistance and Health Services, Cost Effectiveness Policy Guidance: Exceptions Process, at 1 (Feb. 17, 2015).

⁹ New Jersey Department of Human Services, Division of Medical Assistance and Health Services, Cost Effectiveness Policy Guidance: Exceptions Process, at 1 (Feb. 17, 2015).

¹⁰ New Jersey Department of Human Services, Division of Medical Assistance and Health Services, Cost Effectiveness Policy Guidance: Exceptions Process, at 1 (Feb. 17, 2015); N.J. Admin. Code tit. 10, § 60-5.9.

¹¹ New Jersey Department of Human Services, Division of Medical Assistance and Health Services, Cost Effectiveness Policy Guidance: Exceptions Process, at 2 (Feb. 17, 2015).

more than the Medicaid expenses that would have been incurred in the absence of the managed care program.¹² Such a requirement is mandatory in Medicaid home and community-services waivers, although the statute allows the state (with the federal government's assent) to choose whether to be held to overall budget neutrality, or to the stricter standard of budget neutrality in regards to each Medicaid beneficiary in the program.¹³

Accordingly, the MLTSS programs of both Kansas and Florida are held to overall budget-neutrality requirements.¹⁴ These requirements have an impact on the services authorized and the rates paid for those services.

Advocacy Considerations

During the initial months of MLTSS in New Jersey, the Medicaid program had not issued guidance regarding the "special circumstances" under which cost thresholds can be exceeded. When members were denied exceptions, consumer attorneys requested appeal hearings on their behalf, which forced the state to address the issue. The state postponed the appeal hearings and, in the interim, developed and issued the relevant guidance on the special circumstances.

Although New Jersey's explicit limits on service authorization may seem more restrictive than a system based on overall cost neutrality, the explicit limits may offer some advantage to consumers, as long as the limits are accompanied by a rational system for granting exceptions. A misapplication of explicit limits can be challenged through an appeal process, with relatively clear standards for the judge or hearing officer to apply. Also, assuming that the limits are set at appropriate levels, the existence of the limits sets an expectation that, at a minimum, a service authorization up to the limits could be appropriate.

At first glance, a system without explicit limits might

seem to offer the possibility of higher service levels. In practice, however, the system still operates with limits, only those limits are driven by reimbursement rates and thus are less visible to members and their representatives. The state sets payment rates for MCOs that, in turn, establish payment rates for providers. Then the MCO and the providers respond to those reimbursement rates in how they authorize or perform services. Although many MCOs use assessments and algorithms to determine the level of home and community-based services to be authorized for a particular member, the MCOs often try to keep those algorithms private.

If a state sets explicit limits, the system should include exceptions to those limits as well. Without exceptions, a system would be too likely to force members into nursing facilities, in violation of the requirement of the Americans with Disabilities Act (ADA), as interpreted by the United Supreme Court in the *Olmstead* case, that a state's programs not lead to unnecessarily institutionalization.¹⁵ New Jersey's federal approval, in the section on cost effectiveness, states that nothing in the approval "relieves the State of its responsibility to comply with the Supreme Court *Olmstead* decision, and the Americans with Disabilities Act."¹⁶ Kansas's approval also explicitly incorporates the ADA and, in any case, state programs are subject to the ADA whether or not a federal approval mentions it.¹⁷

Particularly in those states that do not have explicit limits, members and their representatives should beware of MCO policies (such as private algorithms) that the MCOs may be using to limit services improperly. MCOs may not be upfront about the existence of such policies, which requires members and their representatives to be both vigilant and tenacious.

Particularly in those states that do not have explicit limits, members and their representatives should beware of MCO policies (such as private algorithms) that

¹² CMS, N.J. Special Terms and Conditions (STC), at 96.

¹³ See 42 U.S.C. § 1396n(c)(2)(D) (average per capita cost not increased by waiver); CMS, Application for a § 1915(c) HCBS Waiver, HCBS Waiver Application Version 3.5, Appendix B-2 (Individual Cost Limit), Cost Neutrality Demonstration).

¹⁴ Florida Medicaid Section 1915(b) Managed Care Waiver Long Term Care Managed Care Program Proposal (as adopted by CMS), Section D (Cost Effectiveness); Florida Application for a § 1915(c) Home and Community-Based Services Waiver, Florida Long-Term Care Managed Care, Appendix J (Cost Neutrality Demonstration); CMS, Kan. Revised Special Terms and Conditions (STC), at 28 (as revised on or about 1/29/14).

¹⁵ 42 U.S.C. §§ 12131- 65 (ADA's Title II, applying to state and local governments); *Olmstead v. L.C.*, 527 U.S. 581 (1999).

¹⁶ CMS, N.J. Special Terms and Conditions (STC), at 49.

¹⁷ CMS, Kan. Revised STC, at 5.

the MCOs may be using to limit services improperly. MCOs may not be upfront about the existence of such policies, which requires members and their representatives to be both vigilant and tenacious.

Depending of course on the specifics of any limitations, a member may be better off with a system with explicit limits, than with a system of no specific limits but with limits implicitly set by policies, methodologies, or payment structures that may be hidden to the member. An MCO always, or almost always, has some financial incentive to limit services (even if a restriction may be shortsighted in terms of the member's overall health status). Given such incentives, a member may prefer explicit standards with appeal rights, since the lack of explicit limits does not mean that services in practice will be unlimited.

Ombudsman Programs

Federal Guidance

In May 2013, the Centers for Medicare and Medicaid Services (CMS) issued guidance to states for Medicaid managed long-term services and supports. That guidance stated that, while enrolled in an MCO, a member must have access to independent and conflict-free assistance with any disputes with a state or plan. CMS specifically mentions an advocate or ombudsman to assist consumers with such disputes, and notes that any assistance must be provided at no cost to the consumer.¹⁸

Kansas Ombudsman Program

Original Ombudsman Program Requirements

From the beginning of Kansas's Medicaid LTSS managed care program, CMS has required Kansas to operate an ombudsman program to assist consumers. The original Special Terms and Conditions document, effective January 1, 2013, required the state to create

an "independent, conflict-free entity" that would be located outside of the Kansas Department of Health and Environment (which includes Kansas' Medicaid program). This ombudsman program would provide assistance to all member populations, but with "specific focus and outreach activities ... directed towards ... enrollees utilizing LTSS (institutional, residential and community based)."¹⁹ As to activities, the program would "assist ... enrollees in the resolution of problems and conflicts between the MCOs and participants regarding services, coverage, access and rights," and "help participants understand the fair hearing, grievance, and appeal rights and processes at each MCO and proactively assist them through the process if needed."²⁰

In response to these requirements, Kansas created an ombudsman program within Kansas' Department for Aging and Disability Services (KDADS), with a specification that the ombudsman program be organizationally independent from the KDADS commissions that control Medicaid program and reimbursement policy. The program description focused on services provided by the Ombudsman, a single person, but with a requirement that the Ombudsman develop volunteer resources "to assist in one-to-one assistance and other cases."²¹

In addition, Kansas made some provision for employees to assist the Ombudsman. Under the ombudsman plan, if consumer contacts were to exceed the capacity of the full-time Ombudsman, the state could reallocate up to five administrative positions "to assist in providing information and referral services to consumer seeking assistance with issues that may be properly addressed by other entities." In addition, those administrative positions could be "supported by 40 [quality assurance] staff with training and knowledge of the waiver systems." None of these supplemental persons, however, would assist with individual advocacy, and would instead refer consumers to other entities or "identify and transfer appropriate cases to the Ombudsman."²²

¹⁸ CMS, Guidance to States Using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs (May 20, 2013), at 10.

¹⁹ CMS, Kan. Original Special Terms and Conditions (STC), at 28.

²⁰ CMS, Kan. Original STC at 28.

²¹ CMS, Kan. Original STC, Attachment H (Ombudsman Plan).

²² CMS, Kan. Original STC, Attachment H.

Under the plan, advocacy for individual consumers was relatively circumscribed. The state's plan specified that the Ombudsman would "assist in mediating those cases that cannot be handled by state eligibility case workers, hotline staff, or the ADRC, when assistance is needed in starting a grievance or appeal, and when satisfaction cannot be obtained through the grievance and appeals processes." The plan also noted that the Ombudsman would not be "expected to file or represent the consumer in the grievance or appeal."²³

Kansas' ombudsman plan did make some provision for systemic advocacy. The Ombudsman was directed to represent the state on MCO-convened councils and focus groups, and to provide the state with advice on how consumer protections in KanCare could be improved.²⁴

Performance of Kansas Ombudsman Program During 2013

The 2013 annual report of the KanCare Ombudsman provided relatively little information on individual representation. For calendar year 2013, a contact log documented that the ombudsman program had received 1,848 calls, and that 807 of these calls (44%) were based on an identifiable concern relating to KanCare. The four most common issues were billing (174 calls), eligibility (170), change of MCO (141), and pharmacy services (113). Only 36 of the calls concerned grievances or appeals.²⁵

Revised Program Requirements for Kansas

On or about January 29, 2014, CMS revised the standards for KanCare, including a revision of the ombudsman program standards. Under these revised standards, the ombudsman program is required to be autonomous of any MCO or the Kansas Medicaid program and, if the program were to be operated within state government, the state is required to "establish protections such that no undue influence will be

imposed that restricts the ability of the Ombudsman to perform all of the core functions."²⁶

The revised standards, compared to the original standards, provide more detail regarding the minimum job duties. Under those revised standards, the ombudsman program must perform at least the following activities:

- Serve as an access point for complaints and concerns about access to services.
- Help members to understand the grievance and appeal processes, and assist members to navigate those processes and access community legal resources, as needed.
- Develop a protocol for referring unresolvable issues to the state Medicaid program and other state officials as necessary to protect members' safety and well-being.
- Develop and implement training and outreach with MCOs, providers, and community-based organizations, to facilitate cross-organizational collaboration and improve system capacity.
- Assist members to understand and resolve billings issues, and notices of action.²⁷

Thus, in regards to specific problems faced by members, the ombudsman program remains focused more on advice and referral than on (for example) direct assistance with a grievance or appeal.

The revised standards specify that ombudsman program staff be "knowledgeable about the state's Medicaid programs; beneficiary protections and rights under Medicaid managed care arrangements; the health and support needs of persons with complex needs, including those with a chronic condition, disability, and cognitive or behavioral needs, and the community based systems that support them."²⁸ Also, under the revised standards, services must be delivered in a culturally competent manner and be accessible to persons with disabilities.

The revised standards require reporting a variety of data relating to contacts and assistance, including the

²³ CMS, Kan. Original STC, Attachment H.

²⁴ CMS, Kan. Original STC, Attachment H.

²⁵ KanCare Ombudsman Annual Report 2013, at 2.

²⁶ CMS, Kan. Revised STC, at 29.

²⁷ CMS, Kan. Revised STC, at 30.

²⁸ CMS, Kan. Revised STC, at 30.

following:

- The date of the incoming request as well as the date of any change in status
- The volume and type (email, phone, verbal, etc.) of incoming request for assistance
- Time required for beneficiaries to receive assistance from the Ombudsman, including time from initial request to resolution
- The issue(s) presented in incoming requests for assistance
- The health plan(s) involved in the request for assistance, if any
- The geographic area where the beneficiary involved resides, if applicable
- The current status of the request for assistance, including actions taken to resolve²⁹

As described immediately below, the Kansas ombudsman program has not yet made all of this information available in the quarterly reports shared with the public.

Performance of Kansas

Ombudsman Program During 2014

During the first quarter of 2014, the Kansas ombudsman program had 545 contacts, although only 384 of these contacts were with “consumers,” and only 214 contacts related to a specific MCO. The most common topics in these contacts (considering all contacts, not just consumer contacts) were Medicaid eligibility issues (81 contacts), HCBS eligibility issues (55), billing (51), and pharmacy services (38).³⁰

The second quarter of 2014 saw a slight decrease in ombudsman program contacts: 474 contacts, including

374 contacts with consumers, and 210 contacts related to a specific MCO. The most common topics were Medicaid eligibility issues (73 contacts), durable medical equipment (35), billing (33), and medical services (31).

The third quarter of 2014 showed similar results: 526 contacts, including 412 contacts with consumers, and 256 contacts related to a specific MCO.³² For the first time, the topic of appeals/grievances was the most common (46 contacts). This represented a relatively significant increase from the 22 contacts recorded in each of the first two quarters of 2014.³³ Other common topics in the third quarter were HCBS general issues (45 contacts), medical services (41), billing (40), and durable medical equipment (25).³⁴

In the report for the third quarter of 2014, time data for the first time was made available. Of the 526 contacts, 451 contacts were “resolved” during the quarter. The “average” number of days between contact and resolution was nine days. This figure evidently is the mean rather than the median, since 55% of the resolved contacts (246 of 451) were resolved within a single day or less.³⁵

For the fourth quarter for 2014, the ombudsman program reported 547 contacts, including 437 contacts with consumers, and 210 related to a specific MCO. Of the consumer contacts, only 179 were related to a specific MCO. The 547 contacts resulted in consideration of 704 issues, with the most common being Medicaid eligibility issues (194 contacts), medical services issues (70), HCBS general issues (49), and appeals/grievances (46).³⁶

The ombudsman program currently is staffed by three persons: the state ombudsman, a part-time assistant, and a full-time volunteer coordinator who began work in September 2014. The staff is working with the Center for Community Support and Research at Wichita State University to develop a training

²⁹ CMS, Kan. Revised STC, at 31.

³⁰ KanCare Ombudsman Quarterly Report, First Quarter of 2014, at 2-3.

³¹ KanCare Ombudsman Quarterly Report, Second Quarter of 2014, at 1-2.

³² KanCare Ombudsman Quarterly Report, Third Quarter of 2014, at 1-2.

³³ KanCare Ombudsman Quarterly Report, First Quarter of 2014, at 3; KanCare Ombudsman Quarterly Report, Second Quarter of 2014, at 2.

³⁴ KanCare Ombudsman Quarterly Report, Third Quarter of 2014, at 3.

³⁵ KanCare Ombudsman Quarterly Report, Third Quarter of 2014, at 3.

³⁶ Kansas Foundation for Medical Care, 2014 KanCare Evaluation Quarterly Report, CY 2014, Quarter 4 (Feb. 18, 2015), at 22-23.

program for volunteers. That training is planned to begin by August 2015 — first in Kansas City and then in Wichita. The training is anticipated to expand throughout the state in 2016.³⁷

New Jersey Ombudsman Program

The New Jersey MLTSS program, which was approved effective October 2012, does not have ombudsman requirements that are remotely comparable to the requirements applicable to Kansas. The CMS approval states that each member who self-directs services has “access to an independent advocate or advocacy system in the State,” but does not require that the state create such a system specific to managed care, or establish anything comparable for those members who do not self-direct services.³⁸ The approval is a bit ambiguous in stating that “[t]his function is performed by individuals or entities that do not provide direct services, perform assessments, or have monitoring, oversight, or fiscal responsibilities for the demonstration.”³⁹ The approval states that MCOs “will provide participants with information regarding independent advocacy such as the Ombudsman for Institutionalized Elderly and State staff who approved [level-of-care] determination and did options counseling.”⁴⁰

Florida Ombudsman Program

Florida’s MLTSS program, which was submitted on August 1, 2011 and approved effective July 13, 2013, does not require the state to develop an ombudsman program specific to managed care. The relevant approval from CMS is presented in a question-and-answer format. The question from CMS to the state is: “Describe the state’s strategy to assist beneficiaries entering the long-term managed care program with enrollment, choice counseling, and complaints. Please describe the

state’s ability to provide beneficiary assistance through call centers, ADRC assistance, and the independent advocacy/Ombudsman.”⁴¹ In response, the state cited only to pre-existing programs:

The current recipient support framework, which includes Medicaid Area Offices, Long-Term Care Ombudsman, Aging and Disabilities Resource Centers, aging and disability advocacy groups and the state’s extensive open government and public policy development and adoption process (which affords significant citizen involvement), will continue to serve recipients after long-term care managed care is implemented.⁴²

The state also cited other entities, information sources, or processes that support members, including enrollment brokers (for assistance during the enrollment process), fair hearings, MCO notices of appeal rights and service changes, MCO websites, MCO case management, and MCO customer service lines.⁴³

Advocacy Considerations

States with Existing Ombudsman Programs

Since CMS issued the MLTSS guidance in May 2013, the requirement of a separate MLTSS ombudsman program is well established for programs initiated after that date. As is demonstrated in Kansas, however, the existence of a program denominated as an “ombudsman program” does not necessarily mean that members receive an adequate level of assistance.

Ideally, an independent ombudsman program will be able to provide direct representative with grievances and appeals, and not be overly reliant upon volunteers. Kansas falls short in each instance, as its ombudsman

³⁷ Kansas Foundation for Medical Care, 2014 KanCare Evaluation Quarterly Report, CY 2014, Quarter 4 (Feb. 18, 2015), at 21.

³⁸ CMS, N.J. Special Terms and Conditions (STC), at 41 (version including technical corrections approved 8/14/14).

³⁹ CMS, N.J. STC, at 41. The state has given a grant to the Community Health Law Project to perform this work.

⁴⁰ CMS, N.J. STC, at 41.

⁴¹ Florida Medicaid Section 1915(b) Managed Care Waiver Long Term Care Managed Care Program Proposal, Effective Dates 7/10/13 – 6/30/16, at 52.

⁴² Florida Medicaid Section 1915(b) Managed Care Waiver Long Term Care Managed Care Program Proposal, Effective Dates 7/10/13 – 6/30/16, at 52.

⁴³ Florida Medicaid Section 1915(b) Managed Care Waiver Long Term Care Managed Care Program Proposal, Effective Dates 7/10/13 – 6/30/16, at 52-53.

program is not authorized to provide direct assistance and based to a significant extent on a volunteer model. (The Kansas ombudsman program currently is in the process of developing its volunteer component.)

One strong model is seen in Wisconsin, where a state-funded ombudsman program assists members in two Medicaid MLTSS programs.⁴⁴ The Wisconsin MLTSS ombudsman program is operated by Disability Rights Wisconsin under a contract with the Wisconsin Department of Health Services. The program has a goal of providing at least one advocate for every 2,500 members under age 60.⁴⁵ The available advocacy services must include all of the following:

- Information and assistance in obtaining needed services
- Information and assistance in pursuing complaints and appeals
- Negotiation and mediation
- Case advocacy assistance in interpreting relevant law
- Individual case advocacy in administrative hearings and court proceedings relating to program benefits⁴⁶

States without Existing Ombudsman Programs

These states by and large have managed care programs that were approved prior to issuance of the CMS MLTSS guidance. In these states, consumers and their advocates should seek program amendments to add an ombudsman requirement. Amendment might be easiest as a practical matter when the relevant waiver program is up for renewal but, on the other hand, there is no need to wait for the scheduled renewal, since waivers can be amended at any time.

Access to Performance Measure Data

Performance Measure Requirements

Medicaid MCOs are typically required to submit large amounts of performance data to the state, to allow the state and CMS to evaluate the progress of the managed care program, and to make changes as necessary. The Kansas requirements are relatively typical: the contract between the State of Kansas and each MCO lists 81 reports that the MCO must submit to the state, and specifies whether the data must be submitted weekly, monthly, quarterly, annually, or otherwise.⁴⁷

These 81 reports, as might be expected, cover a wide range of an MCO's operations. Some reports relate to contacts with members — for example, a grievance and appeal report, or a report on service authorizations, service denials, and pending service authorizations. Other reports relate to contact with members, but with more of an aggregate focus, such as a report on network adequacy, and a report on utilization of service by service type and average service utilization. Still other reports are focused on systems operations more broadly; this category includes financial statements and various reports on claims processing.⁴⁸

This information could be very useful to any person evaluating an MCO's performance, including but not limited to advocates for MCO members. Indeed, state-based consumer advocates working with Justice in Aging have sought and obtained copies of some of these reports, in order to better understand how the MCOs are performing and where changes to the system may be advisable. In general, requests for these reports are submitted through the state's public records act. These public records acts are open-government provisions that, in general, give the public access to any govern-

⁴⁴ The Family Care program, a managed-care option within the state's Medicaid program, covers long-term services and supports (LTSS) such as nursing facility care, personal care services, and home health services. The IRIS program — IRIS is the acronym for "Include, Respect, I Self-Direct" — is a Medicaid waiver program that funds self-directed services for Medicaid beneficiaries in their own homes.

⁴⁵ Wis. Stat. § 46.281(1n)(e); see also Wis. Stat. § 16.009(4) (authority of long-term care ombudsman program; ability to serve for persons of at least 60 years old who are not served by MLTSS ombudsman program).

⁴⁶ Wis. Stat. § 16.009(2)(p)(1)-(5); see also National Association of States United for Aging and Disabilities, Business Opportunity for Community-Based Organizations: MLTSS Ombudsman (Dec. 17, 2014).

⁴⁷ Attachment H to Contract Between Kansas Department of Health and Environment and [MCO] for Managed Care for Medicaid and CHIP Programs (KanCare).

⁴⁸ Attachment H to Contract Between Kansas Department of Health and Environment and [MCO] for Managed Care for Medicaid and CHIP Programs (KanCare).

ment documents that are not protected from disclosure by privacy laws or other limitations set by state law.

The Kansas advocates obtained copies of the LTSS Oversight Report for each MCO; these reports list information regarding care coordination staff, LTSS enrollment, care coordination contacts (for new members, transition members, on-going members, and annual reviews) and the Money Follows the Person program (which assists in transferring persons from nursing facilities to community-based settings). Useful information included the ratio of HCBS to nursing facility services, which ranged from 2.1 to 1.9 to 1.2 within the three MCOs participating in KanCare. These data suggest which MCOs are better at providing non-institutional options for members, and which need to work harder to develop LTSS options outside of a nursing facility.

Other useful information from the Kansas LTSS Oversight Report included the average number of members per care coordinator, which ranged from 74 to 122 to 128, depending on the MCO. It should be noted that the MCO with the lowest rate of care coordinators was not the same MCO with the heaviest rate of nursing facility usage, so the rate of care coordinators did not necessarily correlate with a higher rate of HCBS.

Limits on Access to Information

The usefulness of the grievance/appeal data has been limited, at least for the time being, by states' policies of providing the relevant report only after first deleting information regarding the circumstances of the appeal or grievance. The Kansas Grievances and Appeals Report includes both aggregate information and individual information. The aggregate information includes each of the following pieces of information:

- Number of grievances/appeals reviewed
- Number of grievances/appeals resolved
- Number of grievance/appeals considered invalid
- Average length of time to complete each griev-

ance/appeal

- Total number of state fair hearings requested
- Number of upheld decisions at state fair hearing level
- Number of overturned decisions at state fair hearing level
- Number of health plan appeals reversed in the member's favor
- Number of health plan appeals reversed in the provider's favor
- Number of state fair hearings withdrawn

The form also includes the most common reason that a resident prevailed in a health plan level appeal ("medical necessity met" for each of three MCOs) and the top five issues leading to a grievance or appeal (which differed from MCO to MCO).⁴⁹

The deletions in data are seen in the portion of the reports that list individual grievances or fair hearings. In the copies provided to a Kansas advocate, the grievance report includes the provider type, the reason for the grievance, the date a grievance was received, the date the grievance was completed, and the number of business days required to resolve the grievance. The reason for the grievance is chosen from one of several categories — for example, "billing and financial issues," and "quality of care."⁵⁰

For each grievance, however, much of the information has been blacked out. Some of the deletions are admittedly necessary to protect privacy — this includes columns listing the member's Medicaid identification number and the member's name. The same cannot be said, however, for the columns for "Grievance Reason Narrative," "Details of Resolution," "Provider Name," and "Type of Waiver Member." Much or all of that information could be released without implicating any privacy rights of a member. It is possible that "Grievance Reason Narrative" or "Details of Resolution" might involve private information in some circumstances, but that is not a reason to delete each and every item in those columns.⁵¹

The appeal data (related to appeals determined

⁴⁹ Grievance and Appeal Reports, January through March 2013, for Amerigroup Kansas, Inc., Sunflower Health Plan, and United-Healthcare Community Plan of Kansas, Section II.

⁵⁰ Grievance and Appeal Reports, January through March 2013, for Amerigroup Kansas, Inc., Sunflower Health Plan, and United-Healthcare Community Plan of Kansas, Grievance Report.

⁵¹ Grievance and Appeal Reports, January through March 2013, for Amerigroup Kansas, Inc., Sunflower Health Plan, and United-Healthcare Community Plan of Kansas, Grievance Report.

within the MCO) show a similar pattern. As produced by the state, the reports include columns for the relevant dates, the number of days needed to resolve the appeal, the type of service denied, the reason for the appeal, the provider type, and the determination (either “upheld,” “overturned,” or “pending”). The blacked-out information includes not only the member’s name and identification number, but also the “Appeal Narrative,” the “Reason [Why] Appeal Was Upheld or Reversed or Withdrawn,” “Provider Name,” and “Type of Waiver Member.”⁵²

Likewise, a similar pattern is seen in the data from state fair hearings (when state hearing officers adjudicate disputes). In the copies provided to advocates, a limited amount of data is made available: the relevant dates, the type of service denied, the reason for the fair hearing, the provider type, and the determination. The blacked-out information includes (again) the member and his or her identification number, and also the “State Fair Hearing Reason Narrative,” the “Reason MCO Decision Was Upheld or Overturned,” “Provider Name,” and “Type of Waiver Member.”⁵³

Florida advocates encountered similar issues. Florida MCOs are required to submit a “Denial, Reduction, Termination or Suspension of Services Report.” Florida advocates requested a copy of this report from the state for each MCO, and the state provided those reports — but only after first deleting virtually all of the information. Each report contains six columns, and the state blacked out the first five: the member’s name, the member’s identification number, the requested service, the date of denial, and the date a notice of action was sent to the member. Furthermore, the remaining column — “Reason for Denial” — was blacked out in part, in most cases leaving only the generic description of “Service is not medically necessary.”⁵⁴

Advocacy Considerations

Additional systemic advocacy is needed to make performance measures more available and useful to members of the public, including but not limited to consumers and their representatives. Governments and MCOs frequently claim that managed care provides higher quality care at a lower cost but, if those claims are to be given credence, the data must be shared in a way that makes analysis possible. Results should be recorded with enough specificity to allow for meaningful distinctions, and deletions should be limited only to those items that truly infringe on a member’s privacy interests. Release of a provider’s name, in almost all instances, does not intrude on a member’s privacy, given that the member’s name and identification number is not released. Also, details about the reason for the action, or the rationale for a ruling, do not invade any privacy interests, but are vital to understanding how a system is operating. It is not particularly useful to know, for example, that a service authorization was denied on the grounds that it was deemed “not medically necessary.” The denial is much better understood, and useful for the purposes of evaluating an MCO, if the basics of the denial are accompanied with information about the service involved and the factors that led to a determination that the service was unnecessary. Notably, medical regulations require that fair hearing decisions (whether or not related to managed care) be available to the public.⁵⁵

Performance measure systems are designed primarily to produce data for analysis by MCOs, states, the federal government, and third-party evaluators. To argue against public access to the performance measure data, an MCO or government might argue that necessary data analysis and program course correction already is being performed. Many current managed care waivers are subject to on-going evaluation. In Kansas,

⁵² Grievance and Appeal Reports, January through March 2013, for Amerigroup Kansas, Inc., Sunflower Health Plan, and United-Healthcare Community Plan of Kansas, Appeals Report.

⁵³ Grievance and Appeal Reports, January through March 2013, for Amerigroup Kansas, Inc., Sunflower Health Plan, and United-Healthcare Community Plan of Kansas, Fair Hearing Report.

⁵⁴ Sunshine State Health Plan, Denial, Reduction, Termination or Suspension of Services Report, July 31, 2014. The blacking out of information is not the sole problem with this report. The report methodology offers four denial codes: admitted to acute care, out of network provider, service is not medically necessary, and “other” (with instructions to include a description of “other” reasons for service denial). The description “service is not medically necessary” is not particularly illuminating as to the circumstances surrounding a denial, and the report requires no additional explanation.

⁵⁵ 42 C.F.R. § 431.244(g).

for example, the Kansas Foundation for Medical Care (KFMC) has a contract with the State of Kansas to evaluate the KanCare program, through analysis of the data submitted by MCOs. KFMC issues reports both annually and (for a smaller subset of data) quarterly.

The KFMC evaluation reports offer some information that is not available from the reports by the state in response to public records requests. For example, the most recent KFMC report, for the quarter ending December 31, 2014, includes a section discussing grievance data. The report notes that the state's grievance and appeals data "includes detailed descriptions of the grievances that were resolved within the quarter" — these descriptions, as discussed above, are deleted from the reports shared with the public under public records act requests.⁵⁶

The report from KFMC gives some indication of the deleted information. The report notes that the classification of grievances varied widely across MCOs. Using the "transportation" category as an example, the report notes that percentage of transportation grievances related to "timeliness" varied from zero percent to 44% to 64% across the three MCOs, and the percentage related to "availability" ranged from zero % to 31% to 79%. Some variation could be expected from MCO to MCO, but the extremely wide ranges and the recording of zero percent for some measures suggests that the variances were due in large part to discrepancies in classification rather than in how services were provided.⁵⁷

The KFMC report also notes certain specifics related to transportation that are not available in the reports made available by the state in response to public record requests. KFMC indicates concern regarding the number of safety-related transportation issues, "including reckless and careless driving, driver texting, accidents, and speeding."⁵⁸

The KFMC report uses information about specific providers that has been deleted from the report copies made available through public records requests. According to the KFMC report, one MCO had 183 grievances relating to billing, involving 140 providers. One medical center was listed in 11 of those grievances, and also

had been listed multiple times in reports from previous quarters. This type of information, however, would not be available from the reports provided by the states to the public, due to the deletion of provider names.

Thus, performance measures should be provided to the general public without the types of deletions seen in the responses made by Kansas and Florida to the public requests. Much of the deleted information is not private and does not reveal anything about a particular person. It is not sufficient that some of this information may ultimately be released to a certain extent in reports assembled by evaluator organizations such as the Kansas Foundation for Medical Care. It also is not sufficient that requestors of records retain the right to sue the state in response to excessive deletions — the state should respond appropriately in the first instance, rather than responding inappropriately and inviting a lawsuit.

Continuation of Services Pending an Appeal Decision State Protections

In Medicaid generally, if a Medicaid program proposes to eliminate all or a portion of a beneficiary's services, the beneficiary is entitled to continuation of those services while he or she pursues an appeal.⁵⁹ This is an important protection — Medicaid programs can make mistakes or be guilty of poor judgment, and the right to aid pending appeal is a relatively inexpensive way of lessening the chance that a beneficiary will suffer from an inappropriate loss of services.

These protections have been less effective in some managed care settings, as some MCOs have limited the continuation of services to the duration of a pre-existing authorization. If, for example, home and community-based services originally had been authorized through July 31, and a beneficiary appeals a termination scheduled to take effect on June 30, the MCO might not continue the HCBS beyond July 31, even if the appeal decision is not issued until August,

⁵⁶ Kansas Foundation for Medical Care, 2014 KanCare Evaluation Quarterly Report, CY 2014, Quarter 4 (Feb. 18, 2015), at 11.

⁵⁷ Kansas Foundation for Medical Care, 2014 KanCare Evaluation Quarterly Report, CY 2014, Quarter 4 (Feb. 18, 2015), at 12.

⁵⁸ Kansas Foundation for Medical Care, 2014 KanCare Evaluation Quarterly Report, CY 2014, Quarter 4 (Feb. 18, 2015), at 12.

⁵⁹ 42 C.F.R. §§ 431.230(a), 438.420(b).

September, or a subsequent month.⁶⁰

To better protect MCO members, some states have explicitly required that extended benefits not be limited by the length of an original authorization. In New Jersey, for example, in situations where the member requests continued benefits, the contract between the state and the MCOs requires continuation of benefits pending appeal with no limitations related to preexisting authorizations, and with a broad statement in the “Duration” subsection that “The Contractor shall continue the enrollee’s benefits while an appeal is pending.”⁶¹

Kansas has adopted a similar protocol, as documented in its standard template for use by MCOs in their notice to members of any reduction, suspension, or termination of home and community-based services. If the member asks for an MCO appeal or a state fair hearing, the currently authorized HCBS will continue until a decision is rendered in the appeal or fair hearing. If the ultimate decision is unfavorable to the member, he or she nonetheless will not have to pay for the previously-provided services, “unless fraud has occurred.”⁶²

Advocacy Considerations

There is no reason why the right to continued services should not be as strong in a managed care setting as it is in a fee-for-service setting. Advocacy with CMS, led by the National Health Law Program, is on-going to eliminate any ambiguities in the right of an MCO member to obtain continued coverage pending a decision on an appeal or fair hearing. Giving the importance of the services, they should not be reduced or terminated without the member having the opportunity to have the issues heard by a hearing officer or other comparable decision-maker.

State level advocacy also is vital, particularly as long as the federal standards and guidance are inadequate. The provisions used by New Jersey and Kansas are helpful precedents for state-level advocacy for consumer protections.

Justice in Aging thanks The Retirement Research Foundation and the Atlantic Philanthropies for support of both this issue brief, and the underlying advocacy and education that has informed the issue brief.

⁶⁰ See 42 C.F.R. § 438.420(b)(4) (obligation to continue services if “[t]he original period covered by the original authorization has not expired”).

⁶¹ Contract Between State of New Jersey, Dep’t of Human Services, Div. of Medical Assistance and Health Services and Contractor (v. 3), at § 4.6.4(C)(6), (7) (July 2014).

⁶² Kansas Dep’t for Aging and Disability Services, MCO Notice of Action Template.

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

WASHINGTON

1444 Eye Street, NW, Suite 1100
Washington, DC 20005
202-289-6976

LOS ANGELES

3660 Wilshire Boulevard, Suite 718
Los Angeles, CA 90010
213-639-0930

OAKLAND

1330 Broadway, Suite 525
Oakland, CA 94612
510-663-1055