

Long-Term Services and Supports: Beneficiary Protections in a Managed Care Environment

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Introduction and Summary

A growing number of states are proposing to place the responsibility for providing long-term services and supports (LTSS) to seniors and people with disabilities under managed care organizations (MCOs). These proposals offer both significant risk, and considerable opportunity. Strong beneficiary protections specific to the delivery of LTSS must be incorporated to ensure that states and MCOs develop models that best supports independence and the ability of beneficiaries to remain in or return to community settings

This tool provides ideas for LTSS beneficiary protection that state advocates can use to push for strong protections in managed LTSS programs. To be successful any MCO taking on responsibility for LTSS will need to possess or quickly acquire and incorporate solid and proven LTSS policy and operational components. From the beginning, and at all levels, an MCO will need to work in very close partnership with beneficiaries and advocates to meet very non-homogenous needs.

The tool looks at LTSS consumer protections and opportunities in 15 areas. Each area provides a general summary of its importance and how it fits within LTSS, and then several specific ideas that could be incorporated into developing models. The ideas for protections and opportunities are drawn from current managed LTSS programs, state proposals, advocates recommendations and other sources.

Not all specific protections and opportunities may be appropriate or feasible in any particular state model. The items listed are meant to stimulate thinking among advocates about what protections and opportunities would most fit the unique circumstances in their states. As more states develop managed LTSS programs, we hope to update and expand this tool.

Managed Care Context

Many states have long looked to managed care programs as a way to deliver Medicaid health care services for children and families. When a state contracts with a managed care organization (MCO), the state is responsible for a predictable and stable “per-member-per-month” capitated payment to the MCO. The MCO then is responsible for providing Medicaid covered services such as primary and specialist care and prescription treatments, to its enrolled members. In most states, long-term services and supports (LTSS) have not been included in the benefit packages Medicaid MCOs are required to provider. Instead, they have been provided on a fee-for-service (FFS) basis, in which the state is directly responsible for the billable services provided by eligible providers.

Over the last few years, two very significant trends have emerged. First, states have sought to widen the population of Medicaid beneficiaries served by MCOs to include seniors and persons with disabilities, who generally have much more significant health needs and costs. Many states have sought and received permission from the federal Centers for Medicare and Medicaid Services (CMS) to make enrollment in MCOs mandatory for these Medicaid beneficiaries. Second, [states have increasingly considered expanding the role of MCOs to include a partial or full range of LTSS](#). Most, but not all, states pursuing a Medicaid managed LTSS program are doing so in the context of integrating care for dual eligibles (people who qualify for both Medicare and Medicaid).

These two trends together create a situation of both significant risk, and considerable opportunity, for Medicaid beneficiaries of all ages who have, or are at risk of acquiring, various or multiple mental and physical impairments and chronic conditions.

Risk

The risks arise, in part, because most MCOs have limited experience providing LTSS and working with the populations that have the greatest LTSS needs. Among the biggest risks of shifting responsibility for beneficiaries and LTSS to MCOs:

- Beneficiaries will experience disruptions in continuity of care (COC). Individuals that rely on LTSS often have relationships with trusted providers that extend for decades. The loss of access for even a few days to appropriately experienced medical providers, critical treatments and prescriptions, and personal assistance providers, can compromise functional capacity and the ability to live safely and as independently as possible in the community.
- Home and community-based services (HCBS), and especially personal assistance services, will have to be medically justified. In many states, HCBS consumers and advocates have fought over many decades to develop a web of consumer directed, Medicaid-funded, non-traditional health care services, but consumer direction and independence in the community are not commonly recognized as goals of primary or acute medical care.
- In an effort to decrease costs in the short term, MCOs will deny needed services and/or decrease provider rates to levels that threaten access for beneficiaries.

Opportunity

The opportunities of providing LTSS in a managed care program arise from a recognition that the desire most individuals have to live and receive the supports they need at home or in other small community settings is also usually the most cost-effective strategy for providing care. Opportunities of a managed LTSS program include:

- Potentially improving overall service and care coordination for beneficiaries who receive both LTSS services and medical services for chronic medical conditions, resulting in higher quality of life outcomes as well as cost efficiencies achieved through reduced hospitalizations and emergency room use.
- Potentially shifting the focus and funding from more costly institutional care to less costly HCBS by placing responsibility for both institutional care and HCBS with one managed care entity.

For more background on managed care and the delivery of LTSS see, *“Examining Medicaid Managed Long-Term Service and Support Programs: Key Issues to Consider,”* Kaiser Commission on Medicaid and the Uninsured.

Managed Care Plan Infrastructure

Integration of long term services and supports (LTSS) into the array of services provided by health plans that are primarily medical managed care organizations (MCOs) brings the risk that services, and the management of these services, will revert to a medical or clinical model, reversing gains in the social model of providing care. In a medical model the strong role of consumer choice in designing and directing home and community-based services could be diluted. Managed care’s utilization control tools could direct beneficiaries and prioritize resources to perceived clinical/medical needs and fail to give weight to priorities of consumer direction, individual preferences, social needs, and life goals. To help protect against this risk, MCOs delivering LTSS should demonstrate financing, administrative, and care coordination infrastructures that treat LTSS services on an equal footing and as an equal partner with acute medical services.

- The MCO must have leadership and management roles dedicated solely to LTSS that are filled by key personnel with demonstrated experience and expertise in LTSS management and systems issues.
- Service authorization decisions must be made by personnel with specific expertise in LTSS and not just medical or clinical expertise. Experience with and understanding of the complex and distinct needs of sub-populations of LTSS beneficiaries are also necessary.
- The MCO must have structures and procedural safeguards to ensure that HCBS services are delivered on an equal footing with medical services. For example, particular HCBS models of practice for various populations (such as recovery in mental health, and independent living for people with various disabilities) should not be overridden by medical approaches to care in which medical providers have final authority over HCBS related decisions.

- MCO governance structures must include beneficiaries who use a range of LTSS.
- MCOs must commit to maintaining and further developing and supporting LTSS provider networks that are effectively integrated within beneficiary communities.
- MCO interdisciplinary care teams must include individuals with expertise in the availability, provision and coordination of LTSS.

HCBS Benefit Packages

The most exciting opportunity presented by an MCO model is the potential that MCOs will be incentivized to provide care at home and in the community instead of in more costly and restrictive institutional settings. For beneficiaries to benefit from this “rebalancing,” the array and duration of HCBS services provided by the MCO must be adequate to assist beneficiaries to achieve personal goals in areas such as community integration, meaningful relationships, employment/education opportunities, home environment, recreation, and health/welfare. The available menu of services must be person-centered in both its scope and its responsiveness to beneficiaries who vary widely in their age, capacities, ambitions, needs, and personal support networks. The benefit package must also make MCOs liable for the full range of LTSS services, including the cost of care provided in institutional settings.

- Contracts must state clearly that MCOs must provide Medicaid state plan services that are no more restrictive in amount, duration, and scope than the coverage provided in the Medicaid fee-for-service setting.
- If the MCO is also responsible for providing Medicare services, contracts must state clearly that MCOs must provide Medicare plan services that are no more restrictive in amount, duration, and scope than the coverage provided in the Medicare or Medicaid fee-for-service setting, whichever is more inclusive.
- MCOs must provide a detailed description for each of the various sub-populations to be served, and of the type of services available to meet their functional needs across the range of their life goals and needs. States must provide overarching documentation on how available LTSS services can meet the functional needs of all beneficiaries in the program.
- MCOs must be financially responsible for the full range of LTSS to ensure that there are no incentives to direct enrollees toward institutions instead of receiving support services while living in community-based settings. For example, MCOs must be at risk financially for nursing facility expenses because if nursing facility services are carved out from LTSS, MCOs would be financially rewarded for shifting complex enrollees with high care needs toward institutions where some other entity would be financially responsible for their care.

- The MCO benefit package must include comprehensive home and community-based services. MCOs should be required to provide these services in sufficient amount, duration, and scope to reasonably be expected to achieve the purpose for which the services are furnished. HCBS must not be subject to arbitrary limits such as wait lists, enrollment caps, or geographic limitations.
- MCOs should be permitted and encouraged to provide alternative supports or services when appropriate to support the individual's long-term care goals and needs. However, contracts must include baseline standards across all MCOs for enhanced and alternative services so individuals can understand the choices available to them, and the extent of services and treatments that are governed by MCO appeal rights.
- MCO benefit packages must include coverage for expenses related to care transitions and changes in beneficiary functional levels, such as moving expenses and home modifications needed for aging in place or after the acquisition of secondary conditions.
- MCOs must identify and support community-based "transition-out" programs to move enrollees when appropriate to community-based settings from nursing facilities and other institutions, and develop such programs where they don't exist or exist only at a rudimentary level. Peer support should be an integral component of such programs.
- For enrollees with a desire to be employed, MCOs must provide services and supports needed to gain and maintain employment as an integral component of improved health, wellness, and independence. There should be a presumption of competitive, integrated employment that is appropriately supported, and Medicaid "buy in" opportunities must be extended to beneficiaries who would otherwise meet the eligibility income threshold but for employment income.
- Any carve out of specific subpopulations should only be for groups that already fully enjoy the benefits of coordinated and integrated care, under the administration of an entity that provides robust home and community-based services.

Provider Choice and Access

Without an adequate provider network, managed care organizations (MCOs) cannot achieve the objectives of providing beneficiaries with appropriate, person-centered, quality long term services and supports (LTSS). Network requirements should be established based on the needs, preferences, and existing provider relationships of beneficiaries in the plan service area. Networks must ensure that a broad range of LTSS is available, and maximize choice among providers of a given service.

- CMS and the state must develop clear standards for LTSS network adequacy.
- To develop standards, CMS, the state and MCOs must undertake a comprehensive LTSS

needs and capacity assessment at the beginning of the demonstration project and update it annually. The needs assessment would provide information on such areas as community health needs, health disparities, existing resources, typical patterns of health care utilization, and barriers to beneficiaries living safely and independently in the community. Plans would then use the information to assess whether their provider networks and points of access are sufficient to meet the needs of beneficiaries in their local communities. Where capacity is under or over-developed, MCOs would develop transitional plans with specific targeted timelines to strengthen or adjust network capacity as needed beyond the stated minimum standards. Such plans may require provider workforce development or redesign to address and eliminate disparities over time.

- Plans must have an adequate network of all relevant LTSS providers including, center-based adult day health care providers, personal care attendants, home health providers, occupational, physical, and speech therapists, skilled nursing facilities and more.
- MCOs must have an adequate network of providers specializing in care for nursing facilities to care for the population residing in nursing homes.
- Providers must meet relevant Medicare and federal and state Medicaid professional qualification standards, but such standards cannot supplant or interfere with the individual's right to hire, train and supervise personal assistance providers of his or her choice. (See also discussion of Self Direction).
- CMS and the state must ensure that beneficiary access to providers, as measured in the community needs assessments, does not decrease over the course of the demonstration. Criteria must be developed to evaluate the degree to which HCBS entities utilized by the MCO are integrated in the community and are capable of providing necessary services.
- MCOs must be rewarded for increasing their home and community-based service provider capacity, with extra incentives attached to doing so in rural contexts and in other circumstances such as recruiting providers who are fluent in needed minority languages or American Sign Language and whose offices are physically and programmatically accessible.
- MCOs must be required to contract with community-based organizations, such as independent living centers, recovery learning communities, aging services access points, deaf and hard of hearing independent living services programs, the ARC, and similar organizations that serve particular subgroups of the demonstration population.
- LTSS entities, especially smaller ones, must not be disqualified for the sole reason that they lack the billing or other administrative capacity required by the model's operations. Rather, once any LTSS entities meet an MCO's community integration criteria, the MCO must provide technical support to such LTSS entities to assist them in developing any needed administrative capacities.

- Consumers must have the right to obtain assistance from alternative independent organizations specializing in providing LTSS at home where available.
- MCOs must provide beneficiaries with an opportunity to meet with various LTSS providers to determine which provider would best suit their needs. Participants must have the right to change providers immediately if they are not satisfied with the services delivered.
- In addition to meeting specific LTSS network adequacy requirements, MCOs must meet general network adequacy requirement for providing all covered services. Basic principles for determining network adequacy include:
 - Enrollees must have a choice of at least two available and appropriately experienced providers or provider organizations for every category of service identified in the plan benefit package.
 - Time and travel distance standards of no greater than 30 minutes and 30 miles (with exceptions for very rural areas, and possibly for highly specialized expertise or ancillary capacities such as language).
 - Travel time calculations must take into account transportation available in the community for individuals who are unable to drive.
 - A provider is only available if she or he is actively accepting employment or patients.

Care Continuity

Enrollment in an integrated care model will limit the member to particular providers, and likely will also change the availability of services, treatments, and medications, both the kinds of services available and the method of getting them. Such changes can cause significant disruptions in an individual's life, with negative consequences to health and well-being. This is particularly true for LTSS which, by definition, are provided on a regular basis over an extended period of time. At their best, LTSS providers offer companionship along with assistance, and the loss of a long-time provider leaves a significant hole in the life of the person needing assistance.

In order to limit potential disruption, managed care models must implement policies that provide for continuous access to services and providers, as well as safety measures that will come into place when disruptions occur due to various reasons. The protections set forth below are important to assure that a transition to a MCO does not compromise an individual's health or well-being.

- An MCO must automatically extend out-of-network payment to a new enrollee's existing providers for up to one year or until a transition satisfactory to the individual has been

affected (e.g. the provider joins the network or a provider with equivalent specialized expertise and experience, minority language capacity, physical and programmatic accessibility, and/or a willingness to engage in home visits, etc. is identified), to ensure that transition to the MCO does not jeopardize the new enrollee's health or capacity for independent living in the community. The MCO must pay the provider at a rate at least equal to what the provider received previously.

- For situations in which providers are unwilling to accept payment from the plan, the state must establish a mechanism for paying providers during the transition period, and MCO's must establish procedures for effectively fulfilling out-of-network providers' medically necessary prescription, specialist, DME, or other treatment referrals.
- Care continuity protections must apply to all provider categories, including but not limited to personal attendant care, home health services, and durable medical equipment.
- If a provider has been providing services to an individual currently being enrolled into an MCO, and the provider is not already part of the MCO's provider network but meets the MCO's qualification standards, the MCO must be required to offer network admission to the provider.
- States and MCOs must be required to establish processes to encourage providers to enroll in MCO networks.
- If the MCO begins to establish training or certification requirements for HCBS providers, the employment, compensation and benefit packages of existing LTSS providers chosen and trained by individual beneficiaries cannot be made conditional upon meeting these new requirements.
- A community-based provider's lack of a billing capacity should not be an impediment to enrolling in the plan's network. MCOs must work with smaller LTSS providers to help them develop the infrastructure they need to participate in the plan network.
- Because enrollment in an MCO should never require a person to move, an MCO must be required to make payment available to any appropriately certified nursing facility or assisted living facility in which an enrollee is living at the time of enrollment, for services provided to that enrollee. The MCO must provide payment at the network rate if that rate is higher than the standard Medicaid rate.
- MCOs must give due-process notice to both the enrollee and the provider when refusing to make payment to an out-of-network provider who has provided services to the enrollee, or when refusing to authorize such provider to provide services to the enrollee.
- States and MCOs must proactively identify particularly vulnerable beneficiaries before enrollment, such as those requiring constant oxygen administration or dialysis

treatment, and monitor their status with particular care to ensure that appropriate services are provided throughout a transition to managed care and thereafter.

- For at least 120 days from enrollment of a new member, an MCO must honor all existing authorizations for services or supplies, and must not terminate such an authorized service or supply without due-process notice to the enrollee, and an individualized plan to transition the beneficiary to other services or supports as needed is in place. In the event an appeal is filed to maintain existing services, aid paid pending must be provided until the appeal is decided, even if the previous authorization period for the services has ended.
- Any existing grounds for state exemptions from mandatory managed care enrollment, and the procedures for pursuing such exemptions, must continue to be honored and made available, and beneficiaries must be notified about how to obtain an exemption.

Person-Centered Care Planning

The Affordable Care Act mandates “person-centered” delivery of LTSS, an approach to care planning which recognizes that beneficiaries are not merely passive recipients of medical care, but the individuals who can best determine what it means to be well and what is needed to achieve wellness. Person-centered planning recognizes that the person receiving services is the primary expert in his or her own goals and needs. In order for this to be more than an empty slogan, it must be accompanied by substantive standards, including a comprehensive person-centered functional assessment. Furthermore, while MCOs must meet baseline standards for LTSS services available within the managed care benefit package, specific delivery of LTSS should be customizable according to the needs and preferences of the individual.

A person-centered approach is not limited to health status, but also encompasses values of independence, control, and autonomy. It begins by identifying the strengths, preferences, needs (clinical and support), and desired outcomes of the individual. Counselors’ (options counselors, support brokers, and others who are administratively independent from MCO employees who ultimately authorize the individualized service plan) role in the person-centered process is to enable and assist LTSS consumers to identify and access a personalized mix of paid and non-paid services. The individual’s personally defined outcomes, preferred methods for achieving them, training supports, therapies, treatments, and other services needed to achieve those outcomes become part of a written person-centered services and support plan. The person-centered plan also supports individuals’ ability to self-direct services. (See discussion of Self Direction).

- Individuals must be offered choices with respect to their services and supports, and must hold decision-making authority over which of the available services and supports to employ and which of the available providers to work with. Enrollees should not face any penalty or reduction in benefits for exercising freedom of choice.

SPECIAL REPORT

- Individuals must have control over who is included in the planning process.
- Individuals must have choices about the extent of involvement of their personal care provider(s) in their individual care team and appeal processes (ranging from no involvement to acting on individual's behalf for all care decisions).
- Individuals must have the right to choose to designate someone (e.g. a trusted family member or friend) to serve as their representative for a range of purposes or time periods. If a representative is needed at a point in time when an individual is too impaired to make a choice, the representative should be someone who has a history of close involvement with the person.
- Care planning meetings must be held at a time and place that is convenient and accessible to the individual.
- MCOs must provide information that allows individuals to understand and make informed decisions about service options, including providing information about Olmstead rights to all individuals who use LTSS.
- Mechanisms must be in place to minimize conflict of interests in the facilitation and development of the plan.
- States and MCOs should develop appropriate standards, requirements and guidance to ensure quality services and outcomes, but should also allow informed consumers to opt-out of general requirements where appropriate. For instance, an individual who is skilled in instructing his or her providers should be allowed to waive prior training or certification requirements for care providers.
- States and CMS must jointly establish requirements for the person-centered plan itself. For instance:
 - The person centered plan should integrate all elements of needed medical, clinical, and community living supports. An integrated care team with both clinical and LTSS expertise will have responsibility for developing and implementing the plan.
 - The plan must be prepared in person-first singular language and be comprehensible to the consumer and/or representative.
 - In order to be strength based, the positive attributes of the individual must be documented at the beginning of the plan.
 - The plan must identify risks and the measures taken to reduce risks without restricting the individual's autonomy to undertake risks in order to achieve goals.
 - Goals must be documented in the individual's and/or representative's own words, with clarity about the amount, duration, and scope of services and supports that will be provided to assist the individual to achieve his/her goals.

SPECIAL REPORT

- Specific person(s) and/or any provider agency(ies) responsible for delivering services and supports must be identified.
 - The plan should include a discussion of acute care preferences and anticipate care transitions needed for a return to the community from any temporary emergency room, hospitalization, or nursing home admission, as well as transitions requested by any individual who desires and is capable of a less restrictive community placement.
 - Other non-paid supports and items needed to achieve the goal must be documented. The plan must include the signatures of all people with responsibility for its implementation, including the individual and/or representative, and a timeline for plan review.
 - The plan must identify the person and/or entity responsible for monitoring the plan and everyone involved (including the beneficiary) must receive a copy of the plan.
 - The plan should include strategies for resolving conflict or disagreement within the process, and include clear conflict-of-interest guidelines for all planning participants, as well as a method for the beneficiary to request revision of a plan, or appeal the denial, termination, or reduction of a service.
- MCOs must have procedures in place to monitor and follow up implementation of individual's person-centered plans. This process includes mechanisms to ensure that paid and unpaid services and supports are delivered, and that integrated care teams monitor progress toward achieving individuals' goals, and review the care plan according to the established timeline. The MCO must also provide a feedback mechanism for the individual to report on progress, issues and problems.
 - CMS and states must ensure that the time it takes to do adequate person-centered planning is considered in setting reimbursement rates, and must consider the quality of person-centered planning when evaluating MCO performance.
 - States, CMS and MCOs must incorporate person-centered principles in their policy, mission/vision statements and operations documents.
 - States, CMS and MCO staff and leadership must receive training in the principles of person-centered planning.

A process for monitoring person-centered planning activities by plans must be implemented at the federal and state level and incorporated as an integral component of quality improvement activities. This monitoring information must also be available to the independent ombudsman office. (See discussion of Independent Ombudsman).

Self Direction

Self direction is a way of delivering HCBS that allows individual beneficiaries to directly control a range of services and supports (with the help of representatives, if desired) based on that individual's own preferences and needs, and with the goal of maximizing independence and the ability to live in the most integrated community-based setting. Approaches to participant direction may include employer authority over personal assistance workers and budget authority over HCBS service delivery, or both. Although self-direction is an optional delivery mechanism for most Medicaid funded programs, programs that propose to integrate LTSS into Medicaid and Medicare managed care must be required to prioritize the preservation and further enhancement of self-directing options.

Self-direction should be part of an overall person-centered planning process, and necessarily encompasses specific principles and protections around respect for enrollee choice and the right to appoint and work with a representative that are listed in the section on Person Centered Planning.

- MCOs must continue to offer self-directed HCBS options that were in place prior to implementation of managed care. This includes a continuation of individuals' specific employer and budget authority, for instance:
 - Hiring, firing, training, and supervising personal assistance workers. This includes recruiting, interviewing and setting or negotiating work schedules and tasks, and evaluating job performance.
 - Controlling and using funding that would otherwise be controlled by an agency. This includes setting wages and benefits for workers within program guidelines, and purchasing goods and services to reach an individual's goals (e.g. assistive technology, home modifications, laundry services, and wellness supports).
- Self direction must be available to all individuals regardless of age, disability, functional limitations, or cognitive abilities.
- MCOs must provide objective information, training, and decision-making tools to assist individuals who use HCBS services to understand self direction and implement it to the extent they choose.
- Individuals must have access to full information, and assistance as needed or desired, to make informed decisions about all aspects of participant direction. Individuals should be provided with appropriate supports such as financial management services and training to facilitate participant direction.
- Individuals must be permitted to choose to hire family and friends as HCBS providers. MCOs must support flexible hiring, training, and worker qualifications that respect self direction and help to expand the long-term service work force.

- Individuals must have the right to take risks and the responsibility to develop or help develop a back-up plan for assumed risks and for emergencies.
- Individuals exercising budget authority should have the opportunity, but not the obligation, to budget for and save funds for emergency needs (e.g., emergency vehicle repairs or travel related to family illness) and large purchases (e.g. home or vehicle modifications) with the intention of supporting independence and avoiding unnecessary institutionalization.
- Individuals' self directed budgets and plans are developed to include other services and supports as obtained, such as housing, and allows funds to be used in combination with those resources realized from other programs.
- Individuals who use HCBS must have a central role in the ongoing development of quality measures for HCBS, including the determination of appropriate worker qualifications, training, and individual outcome measures.

Assessments

The overall assessment process is vital for an individual to receive necessary and appropriate care. Ideally, an assessment will be usable for both determining eligibility for and planning of services. It must include all aspects of an individual's life relevant to whether the enrollee will be able to live in a house, apartment, or other community-based setting.

- States must develop, and require MCOs to use uniform assessment tools and processes that must be used for both determining eligibility and planning services. Processes must include requirements that the tool be administered by persons who are knowledgeable about LTSS, and specifically the scope and availability of HCBS services and supports that are or could be made available in the state and locally.
- States must establish conflict-of-interest standards for the persons conducting assessments, including the requirement that a person developing an assessment should not be a service provider for the individual, related by blood or marriage to the individual or to a service provider for the enrollee, a person financially responsible for the individual, or a person empowered to make financial or health-related decisions for the individual.
- MCOs must be required to conduct assessments in person, unless the individual has indicated a preference for a telephonic assessment. The individual should be providing the option of an in home or in office assessment.
- States must require that MCOs perform assessments when there is a significant change in an individual's condition or circumstances, at the individual's request, or at least once every 12 months.

- States must develop uniform assessment instruments and processes that must be used for both determining eligibility and planning services.
- States and MCOs must require that assessments include information related to the individual's ability to remain in, or move to, a house, apartment, or other community-based setting, and their interest in doing so.
- The assessment must include services and supports currently available to the individual, as well as those that are not currently available but are needed.

Care Transitions

Care transitions are especially important to persons needing LTSS because a transition often determines where the person will live. If the beneficiary receives adequate support before and during the transition process, he or she will more likely be able to return to, or move to, a house, apartment, or other non-institutional setting. On the other hand, poor transitions are likely to result in hasty institutional placements, or badly supported attempts to return to the community and further institutionalization, which for some individuals means that they will never live at home again.

- Prior to an individual's discharge from a hospital or a nursing facility, an MCO must present him or her with the full range of appropriate and available options, including HCBS. Likewise, an MCO must ensure that its participating providers, particularly hospitals and nursing facilities, present enrollees with the full range of appropriate and available options once the individual's condition has sufficiently stabilized and prior to discharge. An individual's preferences must be honored, pursuant to applicable service planning procedures.
- Prior to an individual's discharge from a hospital or nursing facility, an MCO must ensure that an individual's service needs have been appropriately assessed and that a transition plan has been prepared. Accordingly, an MCO must require that its participating hospitals and nursing facilities ensure that an individual's services needs have been appropriately assessed prior to discharge and that a transition plan has been prepared. Development of transition plans should follow service planning requirements, particularly those relating to an individual's participation and appeal rights.
- MCOs must ensure that appropriate LTSS are available immediately upon discharge.
- MCOs must pay retainer payments or employ similar mechanisms to ensure that LTSS providers are available to re-start services when an individual returns from a hospitalization or nursing facility stay. This obligation must apply equally when the LTSS provider is an assisted living facility or similar setting; in that case, the state obligation applies both to service costs and to room and board expenses.

- When an individual is living in a participating assisted living facility or similar setting, and then is hospitalized or admitted to a nursing facility, the assisted living facility or similar setting must honor the individual's rights under the admission agreement and/or relevant state legal protections to retain possession of the living unit in the assisted living facility. As necessary, the assisted living facility or similar settings must offer a room hold. MCOs must require that participating providers adopt and follow such policies, and alter any existing contractual requirements that state a contrary policy.
- MCO benefit packages must include coverage for expenses related to care transitions such as moving expenses and home modifications.
- As necessary, states and MCOs must offer a benefit that would allow individuals to retain their house, apartment or other community-based setting during a hospitalization or nursing facility stay, in situations where expenses (or other factors) associated with the hospitalization or nursing facility stay otherwise would not allow individuals to maintain the house, apartment, or other setting.
- MCOs must find and support community-based "transition-out" programs to move individuals when appropriate to community-based settings from nursing facilities and other institutions, and develop such programs where they do not exist or exist only at a rudimentary level. Peer support should be an integral component of such programs.

Appeals and Grievances

Individuals in MCOs may disagree with decisions the MCO and its providers make about what services are needed and whether coverage for those services will be provided. They may also have concerns about treatment by providers or members of their care team. Individuals must have the ability to appeal decisions made by the MCO and to file complaints about problems encountered in dealing with the MCO and its network.

- Existing Medicaid due process rights – including the right to notice and to appeal a MCO decision – must apply to decisions by a MCO to deny, reduce or terminate LTSS. If the MCO is also covering Medicare benefits, the rights associated with that program must also be included and efforts must be made by CMS, the state and the MCO to create an integrated appeals and grievance process.
- Aid paid pending must be provided to individuals who appeal, within required timeframes, a reduction or termination of LTSS services. MCOs must be prohibited from limiting the period of aid paid pending to a current authorization period. Aid paid pending must continue until the resolution of an appeal.
- Decision-makers in the appeals process must be trained to evaluate the necessity of LTSS, taking into account the non-medical goals and benefits of these services.

- Individuals enrolled in the MCO must have the right to file grievances about the service and treatment provided by the MCO, its contractors and its providers.
- The state must collect, and share publicly, data on the rate of denials (including partial denials) of requested services, the number of appeals and grievances filed and the number of appeals that result in the reversal of a MCO decision.
- The state must establish an independent ombudsman to assist individuals through the appeals and grievance process. (See discussion of Independent Ombudsman).

Ombudsman

A key beneficiary protection, particularly for LTSS services, is the availability of an independent, conflict-free entity to serve as an ombudsman for participants. The ombudsman would provide individuals with free assistance in accessing their care, understanding and exercising their rights and responsibilities, and in appealing adverse decisions made by their plan. Through this individual assistance the ombudsman can also identify systemic problems and work with state and plan officials to raise and resolve issues. Although the ombudsman can address any issues that arise for MCO members, it is anticipated that most issues would involve LTSS and the ombudsman should have particular LTSS expertise.

- The ombudsman must be able to provide advice, information, referral and direct assistance in dealing with the MCOs, providers and the state agency. The ombudsman must provide individuals with assistance navigating the program, including:
 - Understanding benefits, coverage or access rules and procedures, and participant rights and responsibilities;
 - Making enrollment decisions;
 - Exercising rights and responsibilities, including Olmstead rights around community integration;
 - Accessing covered benefits;
 - Resolving billing problems;
 - Appealing MCO denial, reduction or termination of service decisions;
 - Raising and resolving quality of care and quality of life issues;
 - Ensuring the right to privacy, consumer direction, and decision-making; and
 - Understanding and enforcing an individual's civil rights
- The ombudsman should be accessible to all individuals through telephonic helplines and,

where appropriate, in-person appointments.

- MCOs must be required to notify individuals of the availability of the ombudsman in enrollment and other marketing materials including annual notices summarizing grievance and appeal procedures, and all notices of denial, reduction or termination of a service, whether sent in writing or in another alternative format.
- The ombudsman must be permitted to participate in participant advisory committee meetings with MCOs and state officials. The ombudsman should prepare reports to the state, at least annually. These reports should be made public.
- The ombudsman must have established channels of access to senior officials at the MCO and the state. A schedule of periodic meetings between the ombudsman and plans and the ombudsman and the state must be established to discuss patterns and systemic issues.
- The ombudsman must be funded by the state. Funding must be sufficient to carry out these services.
- The ombudsman must have expertise in the on-the-ground delivery of LTSS. If the plan is integrating Medicaid and Medicare benefits, experience with the Medicare program is also necessary.
- The ombudsman should be housed in an independent organization with an established record of beneficiary representation. The organization must have credibility with the senior and disability communities and the capacity to foster formal links with both communities.

Meaningful Systemic Stakeholder Involvement

A person centered care delivery system should include meaningful consumer engagement at all levels of the system. Consumer and advocacy groups that participate in planning systems for managed care should be provided with support, within conflict-of-interest guidelines, to promote beneficiary awareness of and expectations for HCBS, advocate for an appropriate balance between medical and LTSS supports, and translate consumer concerns into specific policy recommendations, action plans, and goals. After integration has been implemented, consumer involvement should extend into ongoing monitoring through representation in standing advisory groups at both a state and local plan level.

- The state must have a stakeholder advisory board that includes Medicaid-eligible beneficiaries to advise it on all aspects of the planning, implementation and operation of the managed care program. The advisory board should continue through program implementation. Individuals with a range of LTSS service needs and their representatives and advocates must be included.

- Each MCO must have a standing consumer advisory committee that includes seniors, younger persons with disabilities, and family members of individuals enrolled in plans. A range of disabilities should be represented and users of a range of LTSS must be included. The advisory committee will advise the MCO on all policies and practices affecting the experience of care, have access to information regarding the MCO's policies and practices as well as grievance and quality measure information, and make recommendations for changes in policy or practice to be presented to the MCO's governing board.
- Every MCO must convene meetings with its members at least quarterly to document fully all grievances raised by individuals at the meetings, to keep comprehensive minutes of all member meetings that are made available to all individuals, and to provide written responses to all articulated grievances prior to the convening of the next member meeting. The MCO's should notify all members at least 15 days prior to each meeting regarding the date and location of the meeting, and offer to assist with transportation to the meeting if the member cannot travel independently. Telephone access or other provisions should be made for participation by people who cannot travel.
- Individuals participating in state or MCO stakeholder processes should be connected to advocacy organizations with the necessary expertise to assist them in understanding state and federal laws, contracts and guidance that spell out CMS, state and MCO requirements. These organizations can also help stakeholders identify and recommend solutions to systemic problems in the MCO.
- All of the above meetings should be held in locations that are physically accessible. Accommodations such as sign language interpreters must be available for individuals requesting them.
- To ensure meaningful consumer participation, there must be transparency at the state and plan level. Agreements between and among CMS, the state and the MCO must be made public. Results of readiness reviews, evaluations and quality measures must also be made public. MCOs, as they are performing a state function, must be subject to state freedom of information act laws.

Civil Rights

For LTSS, as for all covered services, providers are required by law to ensure access to equally effective services regardless of the individual's disability (broadly defined under the Americans with Disabilities Act of 1990 [ADA]), age, sexual orientation or gender identity, and linguistic, cultural or racial background. With regard to disability, this means pro-active planning to ensure that the MCO, as well as its provider network and subcontractors, can meet requests from individuals for reasonable accommodations and policy or procedural modifications that are needed for quality health care. Moreover, the civil rights mandate to act without discrimination extends to the needs and preference of HCBS consumers. For example, an individual who has

multiple chronic conditions and is Deaf may choose to hire a Deaf personal assistance worker. The MCO should be prepared to provide American Sign Language interpretation or other effective communication aids to both the individual and the personal assistance worker in where it is reasonable to provide such assistance. For LTSS to be truly person-centered, MCOs must go beyond minimum civil rights requirements.

- CMS and the state must have an affirmative plan, with data requirements, periodic monitoring obligations, and enforcement measures, to ensure that MCOs are in compliance with all relevant civil right laws.
- MCOs must be required to conduct a staff review of their provider networks, using available facility site review tools, to ensure that the provider network is physically accessible, and providers make reasonable modifications of policies, practices, and procedures (programmatic accessibility) to meet the array of disability-related needs of all beneficiaries, such as height-adjustable examination tables, assistance with filling forms or undressing, or extended appointment times or diagnostic equipment and other accommodations. Providers must be advised of their accessibility obligations under the Americans with Disabilities Act and other applicable Federal and state statutes and rules. Beneficiaries and MCO employees must be able to find information about the accessibility of individual providers and provider sites in order to be able to choose physically and programmatically accessible providers.
- Plans must survey, identify and commit to preserving providers that deliver unique or specialized LTSS for people with disabilities or high-needs senior populations, including those that have uncommon linguistic or cultural abilities (e.g., Spanish sign language).
- All levels of the MCO must demonstrate a clear commitment to and understanding of the unique importance of LTSS, including the integration mandate of the Americans with Disabilities Act as interpreted by the Supreme Court in the Olmstead decision.
- MCOs must be part of the state's Olmstead plan, participate in any Olmstead committee, and have their own plan for delivering services consistent with the Americans with Disabilities Act and the integration mandate.
- As recipients of federal funds, the MCOs must develop language access plans to address the needs of Limited English Proficient (LEP) individuals in every aspect of the organization's interaction, from enrollment to initial assessment to grievance and appeal procedures. The communication needs of LEP individuals and people with visual, hearing, or other communication impairments must be especially accounted for when giving notices related to, assessing for, or providing home and community-based services.
- MCOs must incorporate HHS Office of Minority Health [cultural competency standards](#) (CLAS) into all levels of the organization and services delivery system.
- MCOs and providers should gather data about, and take into account, the needs and preferences of lesbian, gay, bisexual and transgender beneficiaries.

Financing

Whenever risk-based, capitated models are used, payment structures must encourage appropriate utilization of care and reward the provision of preventive care, intensive transition supports, and home and community-based services. Rates should be adjusted for health status of the population using a variety of measures to facilitate this goal. MCOs must ensure that the rates they pay network providers are high enough to create and maintain adequate and sustainable networks.

In addition, nothing in the rate structure should discourage the provision of home and community-based services. For example, entities should not receive a higher rate when enrollees have been admitted to nursing homes. There must be some risk for the integrated model associated with that admission. Finally, the rate structure should encourage participation of non-profit and safety net providers by offering access to capital necessary to begin offering LTSS as part of a MCO benefit package and by utilizing risk-sharing strategies that level the playing field between non-profit and larger, for-profit entities.

- Financial incentives must focus largely on maintaining and fostering independence among people in community settings and moving people in institutional settings to the community to the extent possible and desired by the individual. MCOs must be at equal risk for institutional and home and community-based placement of people with LTSS needs.
- States must be required to ensure LTSS expenditures, as a percentage of total expenditures, remain at or above current percentages, and that community LTSS expenditures, as a percentage of total LTSS expenditures, remain at or above current percentages.
- Rates paid to MCOs must be risk adjusted to account for the unique needs of MCO enrollees. Rating categories should be based on the type and severity of diagnosis among enrollees. [See this paper for more.](#)
- The rate setting process must include a method for predicting the long term services and supports needs of individuals that enroll in the MCO. Data on functional impairments must be collected to support the development of this method.
- MCOs must be at limited financial risk until CMS and the state are assured that the rate setting and risk adjustment processes are sound. Risk corridors should be used to ensure that costs that are not predicted by the rate setting process are not ultimately born by individuals in the form of decreased access to providers and services.
- CMS and states must develop opportunities for non-profit, community-based MCOs and LTSS providers to participate on equal footing with their larger, private, for profit counterparts.

- Any quality incentive payments to providers or plans must be fully transparent and based on meeting or exceeding quality targets that include consumer-centric measures.
- MCOs must not be incentivized to cut home and community-based provider rates as a means of achieving savings. Requirements in contracts that set minimum rates will help prevent provider rates from dropping to levels that threaten access. Rate disputes between plans and providers must not impede access to needed services.
- CMS and state must collect and make publicly available, data on rates paid to MCOs and rates MCOs pay to providers, including but not limited to LTSS providers.

State and Federal Oversight and Monitoring

Structures must be in place to ensure that MCOs are performing contracted duties and delivering high quality services. Oversight and monitoring should be a coordinated and complementary effort by CMS, state agencies, an independent advocate for enrollees, and stakeholder committees. Where the MCO is also providing Medicare benefits, Medicare must also be involved.

- States must have an oversight and monitoring plan that clarifies what role each of the relevant agencies will play. In most states, numerous agencies have been involved in the delivery of long term services supports. Expertise from each of these agencies should be leveraged in a managed LTSS program, but roles need to be delineated and a clear lead agency ultimately responsible for the program should be identified.
- States must restructure and rehire as necessary to ensure that staff have expertise in overseeing, monitoring and contracting with MCOs.
- The oversight and monitoring plan must include activities to monitor MCO performance over time as well as activities that can quickly identify and resolve current problems.
- Specific activities for overseeing and monitoring delivery of LTSS must be developed. For example:
 - A dashboard that monitors the delivery of HCBS. Beneficiaries would have the ability to call into the state-run dashboard if a personal care attendant did not report to work and the state would have the ability to send a replacement worker immediately. The dashboard would track over time the MCOs ability to provide timely access to HCBS.
 - Secret shopper surveys that test the adequacy of LTSS networks.
 - Audits of MCO operations related to LTSS delivery.
 - Review and analysis of LTSS encounter data submitted by MCOs.

- States must utilize stakeholder groups and independent ombudsman in its monitoring and oversight plan.
- MCO performance and quality data collected via the states oversight and monitoring efforts must be made publicly available in a timely and regular way.

Quality Measurements, Data and Evaluation

In light of the fact that many MCOs have limited or no experience providing home and community-based services (HCBS), and the reality that there are very few reliable and tested HCBS quality measures that reflect outcomes, it is especially important to advocate for the development and use of quality measures that are created in accordance with a set of core principles and with input from beneficiaries, advocates, and other stakeholders. As MCOs take over responsibility for delivering LTSS, states, health plans, advocates and beneficiaries require this data to be able to track whether beneficiary needs are being met over time and across MCOs. Ultimately, if similar outcome measures are used across programs and service settings (e.g., community versus institutions), data can be used by consumers to make better choices, and by advocates and policy makers to assign resources to programs and settings with better outcomes.

The importance and depth of this subject requires lengthier treatment, and a separate tool devoted to quality measurements, data, and evaluation is forthcoming.

SPECIAL REPORT

This is the print version of an online toolkit for advocates that can be accessed at, <http://dualsdemoadvocacy.org/resources/ltss>. This information is current as of June 12, 2012. Any new information and resources that become available will only be updated online.



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