
Putting Consumers First

*Promising Practices for Medicaid Managed
Long-Term Services and Supports*



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Introduction

Across the country, states are pursuing a major shift in the delivery of long-term supports and services (LTSS) for Medicaid beneficiaries who are living with chronic illnesses and disabilities. By 2014, as many as half of states will have shifted from fee-for-service models of LTSS to relying on Medicaid managed care organizations (MCOs) for some or all of LTSS, up from the 16 states that use MCOs for LTSS today.¹ The shift to MCOs, which assume the financial risk of caring for people, creates the potential for both positive changes and negative consequences.

LTSS, sometimes also called long-term-care, include everything from nursing home care to community based supports such as help with chores, personal care, transportation and maintaining a home. These services are essential to help Medicaid beneficiaries, especially seniors and people with disabilities, live with dignity and as much independence and community participation as possible. For people with severe illnesses or disabilities, robust LTSS focused on personal needs and preferences can spell the difference between barely surviving and thriving.

The trend toward managed care is driven by a number of factors. Primary is the cost of LTSS in an era of tight state budgets. LTSS accounts for more than one-third of Medicaid spending – \$127 billion in 2009 – but only 5 percent of that spending comes through capitated managed care.² In capitated managed care, states transfer the cost and responsibility of providing the services to companies that are paid a fixed sum to provide a range of services. Demand is rising for these services as the population ages and as people live with more complex disabilities. Facing fiscal crises, more states are adopting managed care in an effort to control costs.

Another driver of change is the desire to shift the bulk of LTSS spending from nursing homes to the less restrictive home and community settings consumers want and the Supreme Court's *Olmstead* decision³ on the federal Americans with Disabilities Act (ADA) requires. While this can be accomplished through the fee-for-service system as Washington and Oregon have demonstrated, managed care can facilitate the shift. The fee-for-service system's failures are additional drivers of change -- fragmented care, uneven quality of services, and failing to keep people healthy and out of hospitals and nursing homes. States and the federal government are seeking better care and better outcomes at a lower price.

Along with these motives, the federal government is providing financial incentives and flexibility for states to integrate LTSS with medical and behavioral care for people who are eligible for both Medicaid and Medicare. Twenty-three states are pursuing these "dual eligible demonstration"⁴ projects, and many are choosing to use managed care for this integration.

At its best, managed care could reduce fragmentation of care, expand access to community based services and increase the quality and efficiency of services. But there are significant risks for consumers if states or MCOs use managed care to cut services, squeeze out community providers or medicalize support services. Consumers using LTSS are among the sickest and most vulnerable. In some of the 16 states now running Medicaid managed LTSS programs, access to home and community based care has increased and avoidable use of hospitals and nursing homes has decreased.⁵ However, these improvements have not been consistent. Similarly, cost savings have been elusive, with studies of just two states showing overall savings.⁶ The programs vary greatly in size – from just dozens of participants in some states to hundreds of thousands in others – and in which consumers included. No one state offers a model of success in all areas.

Long-Term Services and Supports: The Basics

What are LTSS?

LTSS include a broad range of non-medical social services that help people with mental or physical disabilities live full lives, and prevent or reduce the need for hospitalization or nursing home stays. This includes assistance with daily activities and personal care, such as eating and bathing; chores such as shopping and laundry; transportation; and the provision of wheelchairs and other assistive devices. It also includes rehabilitation and access to peer specialists and recovery services from people who are recovering from mental illness or addiction and are trained to help others. Support for family caregivers through education and respite care is often included as well. Non-traditional supports can also include home modifications, gym memberships or air-conditioners if these are needed to preserve good health and independent living. As part of the shift to managed care, many states are expanding the range of services they cover.

These services may be provided in a variety of settings, including individual residences, group homes, assisted living facilities, adult day care centers and nursing homes. The ADA, as interpreted in the *Olmstead* decision, dictates services be provided in the least restrictive environment possible, typically the person's home or community. Many people with significant disabilities, those who are homeless and others may need help securing appropriate housing to live in the community.⁸

Who provides LTSS?

States or MCOs contract with a variety of for-profit and non-profit organizations to provide LTSS, including independent providers of personal care, home care agencies, nursing homes, rehabilitative centers, recovery organizations, Independent Living Centers, Area Agencies on Aging, and branches of the Arc for people with intellectual and developmental disabilities. To manage their LTSS programs, states are choosing national for-profit companies, local or regional non-profit and for-profit plans, as well as county agencies. Currently, for profit companies serve about 44 percent of people in Medicaid LTSS, private non-profit companies serve 32 percent, and public or quasi-public agencies serve 24 percent.⁹ The national for-profit companies that have more experience running managed care programs include Evercare, which is a division of UnitedHealthcare; AmeriGroup, recently purchased by WellPoint; and Aetna's Schaller Anderson division. More recently, additional commercial insurers, including Molina and Centene, are expanding their involvement, because of the market's burgeoning size.¹⁰

Variations of managed care

States are using a diversity of approaches to revamp the delivery of Medicaid LTSS through managed care. As noted above, some states are integrating LTSS with medical and behavioral care, putting LTSS under the management of the same for-profit, non-profit or public companies that run other Medicaid services. Other states are managing LTSS separately. Many states are mandating participation of Medicaid members, but Minnesota and Wisconsin have shown a voluntary approach can work well. Many are excluding certain subgroups from managed LTSS, such as people with developmental or intellectual disabilities, at least for the short-term. Some are excluding residents in nursing homes. Under the federal dual eligible demonstration projects, 23 states are planning to manage LTSS for consumers enrolled in both Medicaid and Medicare, with the majority using

capitated payments. States also use varying criteria for eligibility, beyond income, ranging from just those who qualify for a nursing home level of care to all people over 65 or with disabilities.

Federal authority

The legal underpinning for these changes comes from new state Medicaid plans, Medicaid waivers, and demonstration projects. Many are also occurring in tandem with federal initiatives created or expanded under the Affordable Care Act (ACA) to expand community based care, including Money Follows the Person, Community First Choice and the Balancing Incentive Program.¹¹ Federal regulations govern the changes, and more guidance is expected.

What are the Benefits and Risks of Medicaid Managed LTSS?

If operated in a way that puts consumer interests first, Medicaid managed care has the potential to expand access to the services consumers want and the locations in which they prefer to receive them. Some states have added services, such as home modifications, chores and home-delivered meals in Delaware, or expanded eligibility for previously covered home-based services to more people by ending waiting lists, as Hawaii and Wisconsin did. Several states, including Tennessee and Arizona, have used Medicaid managed LTSS to shift the focus of LTSS from institutional to home and community based care, and in Tennessee's case to overcome opposition from the powerful nursing home industry to this shift.¹²

Managed care can also improve the coordination of services, particularly in states where the same MCOs are responsible for providing acute and behavioral care, and LTSS. This can help to reduce avoidable hospitalizations and nursing home stays by keeping consumers healthier and by reducing perverse incentives for insurers covering acute care or only community LTSS to “dump” consumers in nursing homes paid for by someone else.¹³ Through contracts with MCOs, states with enough oversight staff can also more easily enforce quality standards that can lead to better care. Several studies of individual managed LTSS programs, some run by commercial companies and some by non-profit firms or counties, have shown reductions in use of emergency rooms, hospitals and nursing homes, as well as fewer pressure sores and less functional decline. These improvements, however, are not universal.¹⁴

Managed care also can stabilize state costs, and make budgeting more predictable. A few studies found individual states saved money through managed LTSS while consumer satisfaction remained high. Texas realized savings on acute care as a result of its managed LTSS program.¹⁵ Wisconsin Family Care found savings over two years, compared to fee-for-service LTSS, as use of nursing homes declined and growth in use of home services slowed.¹⁶ A recent study also found that gradual rebalancing of Medicaid LTSS can save states money.¹⁷ Most states, however, have not achieved significant savings in the shift to managed LTSS.¹⁸ For example, Florida's managed care nursing home diversion program cost the state 34 to 54 percent more per person than its fee-for-service community LTSS programs, even after controlling for differences in the populations served and services provided.¹⁹ Experts say developing savings from care management and the shift to community based services takes time because of the need for upfront investments, and savings are not guaranteed.²⁰

State pressure to cut costs and MCOs interest in increasing profits pose the greatest risk for consumers in Medicaid managed LTSS through loss of essential services that could lead to illness

or institutionalization. States could reduce the capitation rates they pay MCOs below the level needed to maintain adequate access to care. For example, to save money, Florida has capped spending on its new managed LTSS program below fee-for-service levels and plans to add people to its waiting list rather than expand community services to meet demand.²¹ For their part, MCOs could try to increase their profits by reducing services or cutting payments to providers. A related risk comes from restrictive rules about what services are “necessary” that are too general to reflect individual needs or may not include non-medical supports that could prevent illness. Plans also may not take into account the different needs of younger people with disabilities, compared with seniors.

Managed care plans may also significantly reduce consumer choice of treatment locations and of providers. Restricted provider networks may interrupt a consumer’s ongoing beneficial treatment with a longtime, trusted provider, if exceptions are not made. Managed care plans may also contract with larger medical providers or build new provider networks while passing over existing networks of experienced community agencies that have long served people with LTSS. This could lead to a shift away from social services, including those designed to improve quality of life and independence, to a focus on medical care. Managed care structures can also challenge hard-fought-for consumer-directed services, such as personal care aides, because they require the managing agency to cede some control to the consumer.

The current state environments also heighten the risk of poor outcomes. Most states cut staff during the recession, and are stretching their capacity to manage projects by taking on many new initiatives. They may have lost staff with critical knowledge about LTSS. In addition, quality LTSS requires a trained home care workforce, but most states face worker shortages and high worker turnover due to low pay and little training. Many states don’t have the community capacity to serve consumers well outside of nursing homes. This is particularly problematic in rural areas. Also, many states have too little affordable, accessible and integrated housing to accommodate all low-income LTSS users who want to live in the community.²²

How Can the Risks Be Minimized and the Benefits Maximized?

Although none of the states currently managing Medicaid LTSS do all things well, there are promising practices from their experiences that, combined with additional steps recommended by LTSS consumers and other experts, can increase the odds that managed LTSS will improve care for consumers.

Designing the program

Adequate planning

A phased approach with extensive input from stakeholders and clear goals will produce the best results. The federal Centers for Medicare and Medicaid Services (CMS) recommends a two-year planning process at a minimum.²³ **Tennessee** took three years to set up its CHOICES program, securing stakeholder buy-in first, and then working with health plans for the better part of a year to ensure all systems were ready and that there were enough providers.²⁴ Advocates say there was not as much consultation prior to recent changes in the program, which have been opposed by advocates and some stakeholders. In **Hawaii**, advocates convinced the state

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A key focus of planning should be ensuring LTSS is person-centered – focused on individual goals and needs and maximizing the consumer’s control, choice and independence. State Medicaid programs must develop expertise in LTSS, including working with experts from state agencies focused on seniors and people with disabilities. Officials need to be sure there are enough skilled community service providers who are culturally and linguistically competent and equipped to serve Medicaid beneficiaries, especially those with disabilities. Officials also need to develop a robust plan for consumer engagement, and assess the ability of MCOs to take on this new business. Key measures of MCO readiness include financial solvency, previous experience in LTSS, high marks in National Committee for Quality Assurance (NCQA) and federal quality ratings, staff training on independent living and recovery learning philosophies, plans for addressing racial and ethnic health disparities and ensuring compliance with the ADA, and systematic consumer engagement. States should also set a medical loss ratio for managed LTSS plans that requires at least 85 percent of premiums to be spent on services and supports.

Consumer engagement in planning, governance and monitoring

Consumers and their advocates bring grounded knowledge about needs and what works. States should directly engage consumer advocates in planning, should establish oversight committees with at least 50 percent consumer representation and should gather additional consumer input through focus groups, surveys and quarterly stakeholder meetings in each region of the state. States should require MCOs to include at least 25 percent consumer representation on their governing boards or to establish regional consumer advisory committees that reflect the diversity of the population to be served. Plans should also conduct community meetings.²⁶

Wisconsin requires one-quarter of each MCO board in its Family Care program to be members or their advocates.

All methods of consumer engagement should be accessible to people with disabilities and culturally and linguistically competent. Consumer advocacy organizations can help states and plans identify consumers willing and able to participate. States and plans should provide staff support and stipends for time and transportation to help consumer and advocates participate. This goes beyond federal requirements for public hearings and comment periods on federal waivers and demonstration projects. But there are precedents. Federal regulations require Medicaid programs to provide Medicaid Medical Care Advisory Committees with “staff assistance from the agency and independent technical assistance” as well as “financial arrangements, if necessary, to make possible the participation of recipient members.”²⁷

In addition, states are employing these consumer engagement strategies:

- **Wisconsin** requires one-quarter of each MCO board in its Family Care program to be members or their advocates.²⁸
- **Massachusetts** requires at least one consumer on the board of each MCO in its Senior Care Options program that provides managed LTSS, acute and behavioral health care for dual eligible individuals. It also requires each MCO to have a consumer advisory committee. Separately, to help guide its new duals demonstration for people with disabilities, the state has proposed an implementation council with at least 51 percent consumer representation.²⁹

- In **Arizona, New Mexico, New York and Tennessee**, regulations or contracts require MCOs to establish member councils or to include consumers on advisory committees in their LTSS plans.³⁰ Advocates suggest these provisions are not uniformly enforced.
- **Tennessee** sponsors quarterly regional stakeholder meetings hosted by the Area Agencies on Aging and Disability. Advocates say these have been effective forums in the past for the state to announce changes and get feedback, but suggest the state could be more receptive to issues that aren't on their agenda. **Texas and Minnesota** also convene periodic stakeholder meetings.³¹
- **North Carolina** requires its non-profit management agencies to provide support to a Consumer and Family Advisory Committee.³²

Integration of LTSS with acute and behavioral health care

To achieve the greatest benefits for consumers and for efficiency, states should integrate all LTSS with acute and behavioral services in the same managed care plans. **Arizona, Massachusetts and Tennessee** integrate LTSS in this way.³³ More states plan to do this in the future through the duals demonstration projects.

If LTSS is managed separately, states can reduce fragmentation of care by requiring LTSS plans to coordinate with other programs and services, including those outside of Medicaid. **Wisconsin** requires Family Care plans to coordinate with other Medicaid services, while **New York** requires Managed LTC plans in its voluntary program to coordinate all services needed by the individual.

Voluntary enrollment

Making plans attractive enough to draw consumers voluntarily is a good way to ensure that consumer needs are being met and quality is high.

- **Minnesota**'s Senior Health Options program has demonstrated that voluntary enrollment can work at a statewide scale for dual eligible seniors, enrolling 36,000 (about two-thirds of those eligible).³⁴ Advocates there report relatively few systemic consumer complaints.
- **Wisconsin** has enrolled 33,000³⁵ consumers in its voluntary Family Care program, even though the program is not yet available statewide. People who qualify for Medicaid and are determined to need the equivalent of nursing home care may choose between Family Care and a self-directed care program.

In both Minnesota and Wisconsin, consumers must actively choose managed care if they want that option. Five more of the 16 states with managed Medicaid LTSS also have voluntary enrollment,³⁶ but consumers are automatically enrolled unless they opt out (passively enrolled). The remaining states mandate enrollment.

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In programs that use passive enrollment or mandate enrollment, additional consumer protections are essential.

- States should phase in the change to managed care, starting with those who need the fewest services, so that problems can be addressed early.
- Consumers should retain the ability to opt out of managed care to a fee-for-service system.

- Within managed care, federal rules require states to give consumers a choice of at least two plans.
- To educate consumers on their choice of plans and providers, states should contract with organizations consumers trust and that have no financial interest in their choice, such as Aging and Disability Resource Centers, Independent Living Centers, Area Agencies on Aging, and Recovery Learning Communities. In **Wisconsin**, the Aging and Disability Resource Centers counsel consumers on their choices.
- States should also use letters, meetings, calls and websites to get the word out, ensuring that the information is linguistically and culturally accessible.
- Consumers should have at least 90 days to make a choice before they are assigned to a plan.
- Assignments should be to the plan that includes the consumer's current providers or best provides for their needs.

Broad range of LTSS

Programs should cover all LTSS included in Medicaid state plans, all LTSS waiver services and other supports, such as home modifications, needed to enable people to live in the community. Programs in **Massachusetts, Arizona, Hawaii and Tennessee** follow this model.³⁷ Care teams should be empowered to provide other services not on the list of benefits, if these are also needed. Care settings should include nursing homes, assisted living facilities, group homes, individual homes and providers' offices. Since as many as half of those getting LTSS in some states have behavioral health needs, peer support and recovery services should be part of the network. There should be no waiting lists or caps on services.

Robust provider network ensuring continuity of care

A diverse and robust network of providers who are culturally and linguistically competent, accessible for people with disabilities, trained in independent living and recovery learning philosophies, and experienced in providing LTSS is essential. The network must also include community providers who can serve consumers in and near their homes.

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Respecting the expertise of long-established aging services networks, several states have protected these providers with special contract provisions. Fair reimbursement for community based providers will also help.

- **Massachusetts** requires Senior Care Options plans to contract with geriatric social service coordinators from Aging Services Access Points, (the counterpart to Area Agencies on Aging in other states).³⁸
- **New York** enabled many LTSS providers to establish managed care plans.

States should require plans to regularly assess unmet need, build the network, and ensure it is adequate.

- In its duals demonstration proposal, **Oregon** would require plans to conduct a needs assessment before enrolling consumers and then require reassessment annually.³⁹
- States use a variety of techniques to monitor network adequacy, including mapping programs to track the geographic distribution of providers, and calls or visits to providers to

check availability. **Texas, Tennessee and Arizona** are among the states that use “secret shoppers.”⁴⁰

When moving consumers into managed care plans, it is essential to protect continuity of care. States should:

- Require plans to enroll current providers, as **Texas** did for the first three years of managed LTSS.⁴¹
- Permit consumers to continue seeing providers for at least a year, even if those providers don’t join the new plans. In their proposed duals demonstrations, **California and Ohio** plan to give consumers a year to transition from out-of-network LTSS providers to in-network providers.⁴²
- Require plans to allow exceptions to requirements for use of network providers when continuity is essential for the consumer’s health. **Massachusetts** is requiring these “single case agreements” in its duals demonstration.⁴³

Running the program

Preference for home and community based services

Caring for people in the least restrictive setting – often their home – is federal law, and should be an explicit priority in managed LTSS contracts. To help reduce unnecessary use of nursing homes and hospitals and expand community services, states can apply for federal incentive programs such as Money Follows the Person, Community First Choice and the Balancing Incentive Program. In addition, states should use payment methods and performance measures that incentivize community based care, drawing on those that have worked in other states across the country.

***Tennessee** spent Money Follows the Person funds to encourage plans to move people out of nursing homes, coupling this with a capitated rate formula that led to a doubling of people served in the community.*

Tennessee used both strategies to help reduce its extremely high use of nursing homes. It spent Money Follows the Person funds to encourage plans to move people out of nursing homes, coupling this with a capitated rate formula that led to a doubling of people served in the community – most in assisted living – from 2009 to 2011 without additional state costs.⁴⁴

States should take at least some of the following steps⁴⁵:

- Include nursing homes in the capitation rate. Excluding nursing homes may encourage plans to send people who need extensive community services to nursing homes instead, shifting the cost out of the plan and reducing the incentive for enhanced community services.
- Hold plans financially responsible for the full length of any nursing home stay, as **Arizona, Hawaii, New Mexico, Tennessee and Wisconsin** do.
- Pay plans the same rate whether a person with the same level of need is served in a nursing home or in the community, as many states do including **Arizona, Hawaii, New Mexico, and Tennessee**. In some states, such as **Arizona and Tennessee**, that “blended rate” assumes a reduction in nursing home use compared to the previous year’s usage.
- Share with MCOs some or all of the savings resulting from appropriate reductions in the use of nursing homes and increases in community services.

- Include reduction of waiting lists for home and community based services in MCO contracts. Several states, including **Hawaii and Wisconsin** have seen good results from this strategy. However, **Wisconsin** has since reinstated waiting lists because of budget cuts.⁴⁶
- Pay plans more when consumers get care in the community. In **Minnesota**, this has contributed to a significant reduction in nursing home use and increase in community services.

One necessary protection for consumers in these payment incentives is to ensure contracts do not require that MCOs always choose the lowest cost location for care, because truly person-centered care allows the consumer to choose home care over nursing home care even if it is more expensive.

As a further protection, states should continually monitor for any system-wide reduction in use of LTSS, particularly services in the community. **California** proposes to use this measure in evaluating its duals demonstration program.⁴⁷ States should also ensure the percent of LTSS spending occurring in the community remains at same level or greater than it was in the fee-for-service system.

Conflict-free assessment focused on consumer goals

Once consumers choose a managed LTSS plan, their needs and preferences should be comprehensively assessed by someone knowledgeable about LTSS who will not benefit from the decisions made. Plans should not use their employees to conduct the assessments, since the employees are not independent. The plans have an inherent bias toward decreasing care in the same way providers can have a bias toward increasing services.

The assessment should be standardized statewide, (as recommended in the federal Balancing Incentive Program and as it soon will be in **New York and Minnesota**⁴⁸) and should include illnesses, physical and mental functional status, quality of life goals including social, work and transportation needs, and personal preferences. It should consider socioeconomic status, accessibility of services, and existing supports.

- **Washington** uses an assessment tool called CARE,⁴⁹ which includes these components, and is cited as a model in the Balancing Incentive Program Implementation Manual.⁵⁰
- **Wisconsin's** assessment process, built on a comprehensive consumer survey, includes many of these elements.⁵¹

The assessment should be conducted face-to-face in the consumer's home within 30 days of joining a plan. It should lead to an individualized service plan that meets the member's full LTSS needs and is drawn up under the direction of the member and any representative he or she designates. **Arizona** plans are required to conduct home assessments and initiate services within 30 days: plans met this goal for 97 percent of members living in the community in fiscal year 2010.⁵²

Care coordination

Since individual care plans are likely to include multiple components, care coordination both within LTSS and with other parts of the health system is essential to ensure quality care. Each consumer should have a choice among independent, conflict-free care coordinators experienced in working with seniors and people with disabilities but who are not providers, nor employees of the MCO.

Massachusetts, in its duals demonstration project, plans to use an independent living and LTSS coordinator as part of the interdisciplinary care team that will oversee all acute, behavioral and long-term services. As specified in a memorandum of understanding⁵³ between the federal government and the state, the coordinator, chosen from a community based organization, will work with each consumer to help assess LTSS needs, help develop a care plan, and serve as an expert liaison with service providers and the MCO. Advocates who proposed the independent living and LTSS coordinator suggested that candidates would likely be drawn from Independent Living Centers, Recovery Learning Communities, Area Agencies on Aging, The Arc or similar community organizations. A new state law⁵⁴ stipulates that the MCO may not have a financial interest in the organization and the organization may not be a LTSS provider unless the state health secretary grants a waiver.

To provide the most seamless care, care teams, including the LTSS coordinators, should have the power to authorize LTSS without prior approval from the MCO so they can move quickly to head off problems that could lead to avoidable hospitalization or nursing home use. **Texas** empowers coordinators to do this in its Star+Plus integrated system.⁵⁵ Coordinators also are responsible for easing transitions from one care site to another and keeping up with any changes in consumer needs. **Arizona and Wisconsin** require coordinators to visit consumers in their homes at least every 90 days⁵⁶ to ensure plans and services are meeting consumer needs.

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Consumer-directed services and support for family caregiving

Consumers should have the option of directing their own personal care services, including hiring and firing personal care workers. This is already practice in 12 of the 16 managed LTSS states.⁵⁷ Plans should train interested consumers in how to direct their own care workers. At the consumer's request, family members should be trained and paid to be personal care workers, as is the case in **Arizona, Hawaii and Tennessee**, among others.⁵⁸ Consumers with complex needs should also be equipped to play a leading role in their own care through the use of shared decision-making tools or self-help models like the Stanford Chronic Disease Self-Management program.⁵⁹ **Arizona and Massachusetts** are among the states that do this.⁶⁰ Plans should also provide respite services for family members who are paid or unpaid caregivers.

Monitoring the program

Quality and performance measures

Aggressive use of performance measures specific to LTSS is essential to ensure the push for savings doesn't jeopardize the quality of care. States should incorporate these into contracts with managed care plans and tie payments to quality through incentives or penalties. Given the goals of LTSS, the measures need to address consumer quality of life, including choice of where they live, participation in care decisions, and ability to maintain relationships; consumer satisfaction; degree to which service needs are met; changes in functional status; disparities in quality by race, ethnicity and extent of disability; care coordination; and rebalancing of care from institutions to the community. Measures need to incorporate the different needs and goals of people with physical and mental disabilities at various stages of life.

Work to devise national standards is underway both inside and outside the government.⁶¹ In the meantime, states should at least track preventable hospitalizations and nursing home placements, grievances, extent to which care plan services are provided, and trends in services denied. In addition, they should survey all consumers about whether their goals are being met using a LTSS-specific tool, and conduct in-person interviews with a subset of consumers. **Florida and North Carolina** are among the states that conduct face-to-face interviews with consumers. States should also measure the effectiveness of consumer engagement in program planning and operations. Results of all quality assessments should be publicly disclosed.

Wisconsin is a leader in some aspects of quality assessment. Its external quality review organization checks care plans against provider encounters. It also uses a consumer survey called PEONIES,⁶² considered a promising practice by the Center for Health Care Strategies.⁶³ The survey includes questions in 12 areas, including whether the consumer is living in his or her preferred setting, making his or her own decisions, working or pursuing interests, participating in the community, maintaining relationships, being treated with respect, and comfortable with his or her own health. The impact of the survey would be greater if the state required MCOs to use it.

Other consumer protections and oversight

States should establish and adequately fund independent ombudsmen with extensive knowledge of LTSS, preferably by contracting with an organization already trusted to represent consumers. Alternatively, the state could train, empower and fund federally required long-term-care ombudsmen, who now focus on care in nursing homes, to take on this broader role. These ombudsmen should help individual consumers and feed information about systemic problems to state and plan officials and consumer advisory committees.

Wisconsin contracted with Disability Rights Wisconsin to operate an ombudsman program for people 18 to 59 getting Medicaid LTSS.

- **Wisconsin** consumer advocates pressed for an ombudsman when their state proposed to expand managed LTSS in 2006. The state enhanced the role of its federally required institutional long-term-care ombudsman to include complaints from people 60 and older receiving community based services. In addition, the state contracted with Disability Rights Wisconsin to operate an ombudsman program for people 18 to 59 getting Medicaid LTSS. Disability ombudsmen across the state handle individual cases while a program manager identifies systemic problems in Medicaid LTSS and has been able to secure some statewide improvements.⁶⁴
- **Hawaii** contracts with a non-profit advocacy organization to serve as ombudsman for its managed care programs.⁶⁵
- **New York** is proposing an ombudsman modeled on the Wisconsin program to serve its managed LTSS and duals demonstration programs, and advocates are working to strengthen the proposal.⁶⁶

States should also run simple, accessible systems for resolving consumer disputes with managed LTSS plans and continue services while any dispute is pending. States should provide accessible materials, vetted by consumer advocates, that explain the grievance system and how to navigate the managed care plan.

States should enforce compliance with managed care contracts, using mechanisms authorized under federal and state law, including annual assessments of quality and reports on grievances and appeals.

- **Tennessee** and **Arizona** are known for aggressive contract oversight.
- **Delaware** requires MCOs to notify the state and get approval before making any reductions in service.⁶⁷

States should also enforce plan and provider compliance with the ADA, including the *Olmstead* decision; Section 504 of the Rehabilitation Act of 1973,⁶⁸ which prohibits organizations receiving federal funds from denying services to people with disabilities; the Mental Health Parity and Addiction Equity Act of 2008,⁶⁹ and federal and state requirements for cultural and linguistic competency. This robust oversight requires the state to hire and support enough staff with experience both in LTSS and in contract management.⁷⁰

Finally, transparency is imperative. States should follow **Minnesota's** recent example: making all contracts public and requiring plans⁷¹ to publicly report on their finances, reserves, provider rates, and patient outcomes.

Conclusion

The major push to expand managed LTSS in Medicaid across the country provides opportunities to expand home and community based services, integrate LTSS with medical and mental health care, and increase quality and efficiency, all of which could improve the lives of seniors and people with disabilities in Medicaid. In the long-term, increased efficiency and the shift to community based care might slow growth in Medicaid spending and therefore help avoid programmatic cuts.

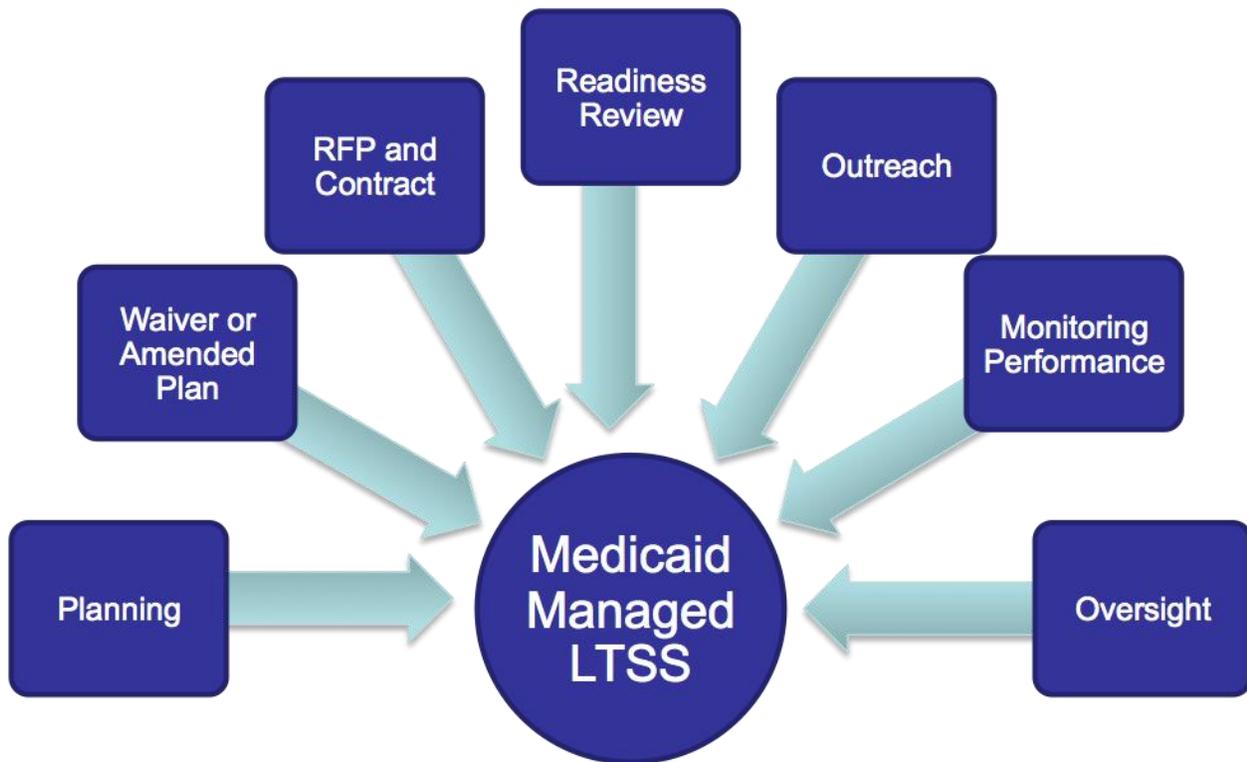
However, a rush toward savings or profits could jeopardize services that are essential to help seniors and people with disabilities live with dignity and as much independence and community participation as possible. States should proceed with caution.

To help minimize the risks and maximize the benefits, consumer advocates and state officials should draw on promising practices in other states and policy recommendations of seniors, people with disabilities and other experts.

Appendix A:

Avenues for Consumer Engagement to Shape Managed LTSS

The development of Medicaid Managed LTSS in any state creates openings for consumer engagement. To mitigate the risks and maximize the potential benefits of the program, consumer advocates must get involved when the program is first planned and stay involved as it unfolds.



Intervention Points: Following are common openings for engagement, although states may seek to restrict consumer involvement in some aspects of the process.

- **Initial planning** – gather allies; consult experts; meet with state officials, managed care organizations (MCOs) and providers; involve legislative champions; develop consumer principles and recommendations; begin discussions with officials at the US Centers for Medicare & Medicaid Services (CMS)
- **Development of waiver applications or Medicaid state plan amendments** – comment on state drafts, bring allies and consumers to hearings, engage Legislative oversight committees, comment to CMS officials
- **Development of requests for proposals and contracts with MCOs** – meet with state officials, review drafts, talk with MCO officials, check MCO experience in other states
- **State review of plan readiness** – identify areas of concern, seek to participate in state review, review readiness reports, assess provider network adequacy using secret shoppers

- **Consumer outreach materials and consumer handbooks** – meet with state officials, review materials, review draft contracts for enrollment brokers if used, work with community based organizations to educate consumers
- **Performance reviews**, including external quality reviews and consumer surveys – give input to state officials on measures and questions, review reports, monitor quality outcomes, monitor grievances and appeals
- **Oversight** – seek appointment to state advisory committees and MCO boards or advisory committees, support other consumer representatives, engage with ombudsmen, review plan reports to state, use secret shoppers to test cultural and linguistic competency and compliance with disability access laws, inform federal officials of major problems

Potential Allies: Seeking common ground with other interested parties can help strengthen consumer advocates' voices at every intervention point. Coalition building is always challenging and requires learning about and acknowledging shared interests and differences. Bridging the priorities and perspectives of seniors and people with disabilities adds another layer of complexity. Even the language of the independent living movement and that of advocates for frail seniors is different in describing their visions of quality care. To come together may require many discussions, including community forums to explore commonalities. Developing shared principles is an important tactic.

Below is a short checklist of the most likely potential allies:

- **Geriatric providers** – doctors and other providers trained in serving seniors
- **Community providers** of LTSS
- **Referral and advocacy agencies**, such as Area Agencies on Aging, Aging and Disability Resource Centers, Independent Living Centers and Councils, and Recovery Learning Communities for people with mental illness or substance use disorders
- **Unions and associations** representing LTSS workers
- **Organizations representing** seniors, people with physical, mental, intellectual and developmental disabilities, people with substance use disorders, homeless individuals and low-income consumers
- **Mission-driven managed care plans** (typically non-profit plans)
- **National advocates**, including Community Catalyst, National Senior Citizens Law Center, Disability Rights Education & Defense Fund, AARP, National Health Law Program, and Families USA

Selected Resources

CMS web toolkit: [Managed Long-Term Services and Supports: Resources for State Policy and Program Development](#). *Includes tutorial and state contracts*

National Senior Citizens Law Center web toolkit: [Long-Term Services and Supports: Beneficiary Protections in a Managed Care Environment](#)

AARP Public Policy Institute: [Keeping Watch: Building State Capacity to Oversee Medicaid Managed Long-Term Services and Supports](#). July 2012

Kaiser Commission on Medicaid and the Uninsured: [Examining Medicaid Managed Long-Term Services and Support Programs: Key Issues to Consider](#). October 2011

Families USA: [Evaluating Managed Long-Term Care Proposals in Your State: Key Areas for Advocacy](#). June 2012. *Checklist and recommendations*

Center for Health Care Strategies: [Medicaid Rate-Setting Strategies to Promote Home- and Community-Based Services](#). May 2012

Center for Health Care Strategies: [Managed Long-Term Care Supports and Services: Performance Measurement Resources](#). March 2010

CMS/Truven Analytics: [The Growth of Managed Long-Term Services and Supports Programs: A 2012 Update. July 2012](#). *Overview and state by state listing*

Community Catalyst: [Best Practices for Meaningful Consumer Input in New Health Care Delivery Models](#). September 2012.

¹ Saucier, Paul et al. [The Growth of Managed Long-Term Services and Supports \(MLTSS\) Programs: A 2012 Update](#). Truven Health Analytics and CMS. July 2012.

² Eiken, Steve et al. [Medicaid Expenditures for Long-Term Services and Supports: 2011 Update](#). Thompson Reuters. October 2011. Saucier, Paul. [Managed Long Term Services and Supports presentation](#). National Health Policy Forum. May 2012.

³ <http://www.ada.gov/olmstead/index.htm>

⁴ [Financial Alignment Initiative for Medicare-Medicaid enrollees](#).

⁵ Saucier, May 2012.

⁶ Saucier, July 2012.

⁷ This paper does not address unique systems of care for people with intellectual or developmental disabilities, nor the Program of All-Inclusive Care for the Elderly.

⁸ Resources on housing policies for LTSS users include: CMS. [New Housing Resources to Support Olmstead Implementation](#). June 2012.

⁹ Saucier, July 2012.

¹⁰ Lind, Alice et al. [Profiles of State Innovation: Roadmap for Managing Long-Term Supports and Services](#). Center for Health Care Strategies. November 2010.

¹¹ [Money Follows the Person](#), [Community First Choice](#) and [Balancing Incentive Program](#)

¹² Lind, 2010; Mahaney, Rosanne. Diamond State Health Plan Plus presentation. [National Health Policy Forum. October 2012](#). Killingsworth, Patti. Rebalancing in Tennessee Through Implementation of Managed Long-Term Services and Supports presentation. Academy Health Long-Term Care Interest Group Policy Seminar. February 2012.

¹³ This has been an issue for some people getting services from both Medicaid and Medicare through separate plans, since Medicare only covers nursing home stays after hospitalization, and only for a short stay. Separately, this has been a problem in state Medicaid programs where nursing home services are excluded from capitated plans.

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- ¹⁴ Saucier, May 2012. Summer, Laura. [Examining Medicaid Managed Long-Term Services and Support Programs: Key Issues to Consider](#). Kaiser Commission on Medicaid and the Uninsured. October 2011; Saucier, Paul and Wendy Fox-Grage. [Medicaid Managed Long-Term Care](#). AARP Public Policy Institute. November 2005.
- ¹⁵ Lewin Group. [Medicaid Managed Care Cost Savings – A Synthesis of 24 Studies](#). Updated March 2009
- ¹⁶ APS Healthcare. [Family Care Independent Assessment: An Evaluation of Access, Quality and Cost Effectiveness For Calendar Year 2003 – 2004](#). October 2005.
- ¹⁷ Kaye, Stephen. [Gradual Rebalancing Of Medicaid Long-Term Services And Supports Saves Money And Serves More People. Statistical Model Shows](#). Health Affairs. June 2012.
- ¹⁸ Saucier, July 2012.
- ¹⁹ Nohlgren, Stephen. [Florida’s Shift to Private Managed Care Means Longer Medicaid Waiting Lists, Study Finds](#). Tampa Bay News. January 31, 2012; The State Could Consider Several Options to Maximize Its Use of Funds for Medicaid Home and Community-Based Services. Florida Legislature Office of Program Policy Analysis and Government Accountability. March 2010.
- ²⁰ Summer, 2011.
- ²¹ Summer, Laura and Joan Alker. [Proposed Medicaid Long-Term Care Changes Raise Host of Questions About Impact](#). Georgetown University Health Policy Institute. January 2012.
- ²² Recommendations on workforce and housing are outside the scope of this paper. Sources on these topics include: [National Direct Service Workforce Resource Center](#); [Eldercare Workforce Alliance](#); [PHI – Quality Care through Quality Jobs](#); [New Housing Resources to Support Olmstead Implementation](#).
- ²³ <http://www.medicaid.gov/mltss/index.html>
- ²⁴ Lind, 2010.
- ²⁵ Lind, 2010.
- ²⁶ Nagasako, Elna. [Best Practices for Meaningful Consumer Input in New Health Care Delivery Models](#). Community Catalyst. September 2012.
- ²⁷ 42 CFR 431.12
- ²⁸ Saucier, July 2012.
- ²⁹ [Massachusetts Senior Care Options contract](#); MassHealth presentation. [Integrating Medicare and Medicaid for Individuals with Dual Eligibility](#). November 2012.
- ³⁰ Saucier, July 2012.
- ³¹ Saucier, July 2012; Interview with Tennessee advocates.
- ³² Saucier, July 2012.
- ³³ Lipson, Debra J. et al. [Keeping Watch: Building State Capacity to Oversee Medicaid Managed Long-Term Services and Supports](#). AARP Public Policy Institute. July 2012.
- ³⁴ [Redesigning Integrated Medicare and Medicaid Financing and Service Delivery for People with Dual Eligibility in Minnesota](#). Minnesota Department of Human Services. April 2012.
- ³⁵ [Family Care, Partnership and PACE Enrollment Data](#). Wisconsin Department of Health Services. June 2012.
- ³⁶ Saucier, July 2012.
- ³⁷ Lind, 2010.
- ³⁸ [Massachusetts Senior Care Options contract](#).
- ³⁹ [Oregon State Demonstration to Integrate Care for Dual Eligibles](#).
- ⁴⁰ Lipson, 2012; Conversation with Thomas J. Betlach, director, Arizona Health Care Cost Containment System. October 2012.
- ⁴¹ Summer, October 2011.
- ⁴² [California Proposal for Demonstration to Integrate Care for Dual Eligibles](#); [Ohio Proposal for Demonstration to Integrate Care for Medicare-Medicaid Enrollees](#)
- ⁴³ [Massachusetts-CMS memorandum of understanding](#). August 2012.
- ⁴⁴ Lind, 2010; Killingsworth, Patti. Rebalancing in Tennessee Through Implementation of Managed Long-Term Services and Supports. Academy Health Long-Term Care Interest Group Policy Seminar. February 2012.
- ⁴⁵ Gore, Suzanne and Julie Klebonis. [Medicaid Rate-Setting Strategies to Promote Home-and-Community-Based Services](#). Center for Health Care Strategies. May 2012; Hendrickson, Leslie and Laurel Mildred. [Flexible Accounting for Long-Term-Care Services: State Budgeting Practices that Increase Access to Home and Community-Based Services](#). SCAN Foundation. January 2012; Engquist, Gretchen et al. [Medicaid-Funded Long-Term Care: Toward More Home- and Community-Based Options](#). Center for Health Care Strategies. May 2010; Lipson, 2012.
- ⁴⁶ Kwak, Jung. 2012. Long-Term Care Reform Initiatives presentation. American Society on Aging. March 2012.
- ⁴⁷ [California Draft Programmatic Transition Plan](#) for Dual Eligible Demonstration. August 2012.
- ⁴⁸ [Uniform Assessment System](#) in New York; [MNChoices](#).
- ⁴⁹ [Comprehensive Assessment Reporting Evaluation Tool](#).

⁵⁰ [Balancing Incentive Program Implementation Manual](#).

⁵¹ [Wisconsin's Family Care contract 2011](#).

⁵² [Arizona Long Term Care System \(ALTCS\) Performance Measure](#). Division of Health Care Management. August 2011

⁵³ [Massachusetts-CMS memorandum of understanding](#). August 2012.

⁵⁴ Massachusetts [Chapter 224](#) of the Acts of 2012.

⁵⁵ Lind, 2010; [Texas Star+Plus contract](#).

⁵⁶ Lind, 2010; [Wisconsin's Family Care contract 2011](#); [Arizona Long Term Care System contract 2011](#).

⁵⁷ Saucier, July 2012.

⁵⁸ Lind, 2010; Barth, Sarah. [Mileposts in Approaching Managed Long-Term Services and Supports](#) presentation. National Council on Aging and Friday Morning Collaborative. April 2012.

⁵⁹ [Stanford Chronic Disease Self-Management](#) program.

⁶⁰ Burwell, Brian et al. [Care Management Practices in Integrated Care Models for Dual Eligibles](#). AARP Public Policy Institute. October 2010.

⁶¹ The Agency for Healthcare Research and Quality, National Quality Forum Measurement Application Partnership, Centers for Medicare & Medicaid Services, Long-Term Quality Alliance, National Council on Disability and the Consortium for Citizens with Disabilities are among those working on LTSS-specific quality measures.

⁶² [PEONIES](#).

⁶³ Barth, Sarah. April 2012.

⁶⁴ [Wisconsin Family Care and IRIS Ombudsman Program](#): conversation with Wisconsin ombudsman.

⁶⁵ [Hawaii QUEST Expanded Section 1115 Draft Annual Report](#). April 3, 2012.

⁶⁶ [New York State Medicaid Redesign Team Waiver Amendment](#). August 2012.

⁶⁷ Lind, 2010; Lipson, 2012; Mahaney, 2012.

⁶⁸ [Section 504 of the Rehabilitation Act of 1973](#).

⁶⁹ [Mental Health Parity and Addiction Equity Act of 2008](#); Consumer Rights to Mental Health Treatment: State Responsibility for Enforcing the Federal Parity Act; Bosco, Jennifer. [Consumer Rights to Mental Health Treatment: State Responsibility for Enforcing the Federal Parity Act](#). Community Catalyst. May 2012.

⁷⁰ See Lipson, 2012, for an extensive discussion of the needed capacities.

⁷¹ [Minnesota Executive Order 11-06](#).