



MLTSS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Strategies for Success



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The **NASUAD MLTSS Institute** was established in 2016 in order to drive improvements in key MLTSS policy areas, facilitate sharing and learning among states, and provide direct and intensive technical assistance to states and health plans. The work of the Institute will result in expanded agency capacity, greater innovation at the state level, and state/federal engagement on MLTSS policy.

The **National Association of States United for Aging and Disabilities** represents the nation's 56 state and territorial agencies on aging and disabilities and supports visionary state leadership, the advancement of state systems innovation, and the articulation of national policies that support home and community-based services for older adults and individuals with disabilities.

The **National Association of State Directors of Developmental Disabilities Services** represents the nation's agencies in 50 states and the District of Columbia providing services to children and adults with intellectual and developmental disabilities and their families. NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families.

Mysupport.com is an online platform working with states and health plans to improve the direct support workforce and expand self-directed services. Founded in 2014 by a group of national leaders in the disability and aging community, MySupport offers people with disabilities and families access to a unique provider directory with values-based matching and ongoing outreach to grow the pool of support workers available in a given area.

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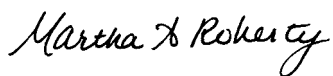
Managed long-term services and supports (MLTSS) is a growing trend across the country. States seeking to modernize and improve their long-term services and supports systems continue to turn to managed care plans to help them achieve their goals. Operating an efficient and effective MLTSS program requires thoughtful program design, capable health plan partners, strong state oversight, and appropriate accountability mechanisms. NASUAD has been deeply engaged in providing technical expertise and assistance to our member states as they plan, design, implement, and evaluate their MLTSS programs. However, our Board of Directors recognized that the states' demand for technical assistance exceeded staff capacity. This recognition led to the creation of the MLTSS Institute in 2016.

The MLTSS Institute is intended to drive improvements in key MLTSS policy issues, facilitate sharing and learning among states, and provide direct and intensive technical assistance to states and health plans. The work of the Institute will result in expanded agency capacity, greater innovation at the state level, and state/federal engagement on MLTSS policy. Creating opportunities for thoughtful policy development, meaningful state interaction, and more effective use of limited state resources is critical to the maturation and success of MLTSS programs.

I am deeply grateful to our visionary Board of Directors, state long-term services and supports leaders, and thought leaders at national health plans who understand that well managed and high quality MLTSS programs benefit us all, and are willing to invest their time and resources to that end.

We are pleased to publish the second paper from the MLTSS Institute focusing on MLTSS programs for people with intellectual and developmental disabilities (I/DD). We hope it will prove useful to states, health plans, providers, and most especially program participants and their caregivers.

Sincerely,



Martha A. Roherty, Executive Director
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EXECUTIVE SUMMARY

Over the past five years, there has been explosive growth in the number of states implementing comprehensive Medicaid managed long-term services and supports (MLTSS) programs; however, most have excluded LTSS services for people with intellectual and developmental disabilities (I/DD). Serving people with I/DD requires unique approaches to program development, implementation, and management. This report highlights the key elements that increase the likelihood of program success, focusing on best practices by both states and health plans. Because there is a long history of activism and self-determination in the I/DD community, early and intensive engagement with participants and their families is critical. Also it is very important to provide adequate time to plan and implement an MLTSS program for people with I/DD.

The report focuses on each lifecycle phase of an MLTSS program, and highlights successful practices in each area:

- Goal setting;
- Program design;
- State infrastructure alignment;
- Procurement and contracting;
- Policies and procedure development; and
- Quality management and oversight.

MLTSS offers both opportunities and challenges for people with I/DD and their families. MLTSS programs for people with I/DD can be planned and implemented successfully if careful attention is paid to each lifecycle phase, and if the feedback of participants, their families, providers, and other stakeholders is acknowledged and acted upon. The result will be increased employment and community integration, improved health outcomes for participants, and budget predictability and innovation for states and health plans.

Background

Services and supports for individuals with intellectual and developmental disabilities (I/DD) have evolved in the United States over the last century. Due to the advocacy of well-intended social reformers such as Dorothea Dix and Samuel Gridley Howe, “state schools” for individuals with I/DD emerged in the mid-to-late 1800s as a resolution to the plight of individuals with disabilities left in prisons or almshouses in deplorable conditions.¹ These state schools were large, often agrarian-focused institutions and continued as the primary tools in states to serve individuals with I/DD from the mid-1800s to a pinnacle of 228,500 individuals in 1967.²

The role of the state-federal partnership in the provision of services and supports for individuals with intellectual and developmental disabilities began to emerge in the early 1960s. This effort sparked the appointment of the President’s Panel on Mental Retardation³ and subsequent passage of two pieces of federal legislation in 1963. The first established funding for states to develop statewide plans to address the societal impact of disability (PL 88-156) and the second, among other provisions, established formula grants for states to construct community-based facilities to serve children and adults with I/DD (PL 88-164).⁴ This state-federal partnership further expanded with the enactment of Medicaid in 1965 and the subsequent addition of Medicaid coverage of Intermediate Care Facilities (ICFs) in 1971.

Also during this time and in the decade to follow, advocates, faith-based and family-driven organizations emerged as key catalysts in the design and development of community-based supports for individuals with I/DD. Families seeking alternatives to large institutions joined together to develop options for children and adults with I/DD in their communities. With the enactment of the Education for All Handicapped Children Act in 1975 (now called the Individuals with Disabilities Education Act) and the continued momentum of grassroots, family-driven community-oriented options, these efforts planted the seeds for much of the community-based infrastructure still in use throughout the country today. In fact, these efforts and those of families demanding the opportunity to keep their children home rather than in clinical settings culminated in the passage of Section 1915(c) of the Social Security Act in 1981, enabling states through a waiver of Medicaid rules to offer home and community-based services (HCBS) as an alternative to institutions.⁵

Oregon was the first state in the union to receive approval from the federal government (then the Health Care Financing Administration or HCFA) to operate a 1915(c) waiver in December of 1981. In 1985, Congress made additional amendments to the statute, including the addition of a statutory definition of habilitation services that recognized day habilitation and supported employment services as reimbursable waiver services for individuals who had previously been institutionalized. The availability of the HCBS authority through 1915(c) of the Social Security Act was a pivotal tool for states under great pressure to reduce the number of people served in large ICFs, which had been the subject of shocking reports revealing overcrowding and inhumane treatment across the country. As a result, state I/DD authorities were the primary early adopters of HCBS despite the fact that the 1915(c) authority has been widely available for all individuals meeting an institutional level of care (nursing facility, hospital or ICF).

Because institutional services are a mandatory benefit, and home and community-based services are optional, funding has long been tilted toward institutional care. Due to the downsizing and closure of state ICFs, long-term services and supports (LTSS) for individuals with I/DD achieved a “balancing” of institutional and community-based funding in 1995, a trend that has continued with more than 76 percent of total LTSS dollars targeted for people with developmental disabilities being spent on community-based services in FY 2015.⁶ Similar balancing in spending was not achieved for all HCBS populations until FY 2013.

As of 2017, every state and the District of Columbia offers an array of services and supports for individuals with intellectual and developmental disabilities. Most states utilize one or more 1915(c) waivers to deliver these services, while a few states utilize 1115 demonstration authorities to offer services that could otherwise be included in 1915(c) waivers. In 2014, 683,000 participants with I/DD were served in 1915(c) waivers across the country.⁷ Additional states also use 1915(i) HCBS as a state plan option or 1915(k) Community First Choice to offer HCBS as well.

In recent years, administration of HCBS by the Centers for Medicare & Medicaid Services (CMS) has steered states toward ensuring that HCBS are administered in ways that connect those served to the broader community and to people without disabilities. This effort has included the promulgation of new HCBS regulations and related policy guidance issuances. These efforts were complemented by enactment of the Workforce Innovation and Opportunity Act of 2014 (WIOA) and settlement agreements between states and the U.S. Department of Justice (DOJ) that clarify application of the Americans with Disabilities Act (ADA) to publicly administered services to individuals with disabilities.

CMS issued rules governing community settings in 2014. The CMS HCBS rules support “full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.”⁸

In addition to CMS efforts to increase the integration of individuals receiving HCBS, the DOJ has undertaken legal actions in states during the past decade related to access to community-based services.

“The ADA and its Title II regulations require public entities to ‘administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.’ The preamble to the ‘integration mandate’ regulation explains that ‘the most integrated setting’ is one that ‘enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.’”⁹

Medicaid Managed Care

Medicaid is a critical source of health and long-term services and supports (LTSS) for individuals with a wide range of disabilities. At the federal level, the Medicaid program is administered by the CMS. Each state designs their Medicaid program within broad federal requirements. As a result, Medicaid programs vary from state to state. There are required services and eligibility groups that each Medicaid program must offer, but as it stands today, states have many choices about optional services, optional programs, and methods for payment and service delivery. States offer LTSS to individuals with disabilities and older adults, and these programs are a key vehicle to provide home and community-based services and supports.

From the Medicaid program's inception in 1965 until the 1990s, services were delivered primarily on fee-for service (FFS) basis in which providers are paid a set rate for each service delivered. Beginning in the 1990s states began turning to managed care organizations (MCOs) for the delivery of health-related services within Medicaid for children and non-disabled adults and this trend has continued and expanded. Medicaid enrollment in comprehensive MCOs increased by 45 percent over two years—from almost 35 million in 2013 to 50.9 million in 2015.¹⁰

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At its most basic level, Medicaid managed care (MMC) is a tool providing for the delivery of Medicaid health benefits and additional services through contracted arrangements between state Medicaid agencies and managed care plans that accept a set per member per month (capitation) payment for these services. States selecting managed care service delivery must assess their Medicaid policy goals to ensure that this approach is appropriate to meeting the needs of the intended population(s). Early uses of managed care were focused primarily on cost control and quality improvement in acute health services. However, for Medicaid managed care programs that deliver LTSS—called Managed LTSS programs or MLTSS—recent goals have included increasing budget predictability, consumer satisfaction, the ability to tailor services/supports to individual needs, increasing access to HCBS, and system balancing.

Medicaid managed care programs are not monolithic. Within the Social Security Act (SSA), the law that authorizes the Medicaid program, there are a number of authorities states can use to implement managed care. These authorities include Sections 1932(a), 1915(a), 1915(b), and 1115. Each of these authorities have slight variations on what they permit in terms of service delivery, enrollment and eligible populations. Regardless of the statutory authority used, states and managed care plans must meet certain requirements regarding payments, enrollee protections (including choice of managed care plans, information requirements, and appeal and grievance rights), quality and many other factors.¹¹

MMC may be voluntary or mandatory, depending on the state's design and statutory Medicaid authority. This means that individuals can either (1) elect to receive their services through a managed care arrangement (voluntary) or (2) be required to receive their services through managed care (mandatory). When programs are mandatory, states (except under some limited exceptions) must offer individuals a choice of managed care plans.

Most MMC programs utilize risk contracts. A *risk contract* means a contract under which the contractor: (a) assumes risk for the cost of the services covered under the contract; and (b) incurs loss if the cost of furnishing the services exceeds the payments under the contract.¹² Risk contracts must include payments that are actuarially sound as defined in 42 CFR 438.4¹³ and must provide for oversight to ensure the managed care plans operate in accordance with their contractual obligations, consistent with both state and federal law.

Under risk contracts, managed care plans typically receive a set per member per month payment (also called a capitated payment), and, in exchange, ensure that the individual receives all needed covered services as well as service coordination, connection to available resources, and other additional benefits beyond what a FFS approach would have covered. The state makes the payment regardless of whether the particular beneficiary receives services during the period covered by payment. The capitation payment is not the same as an individual's service costs. Some individuals' service costs will be higher

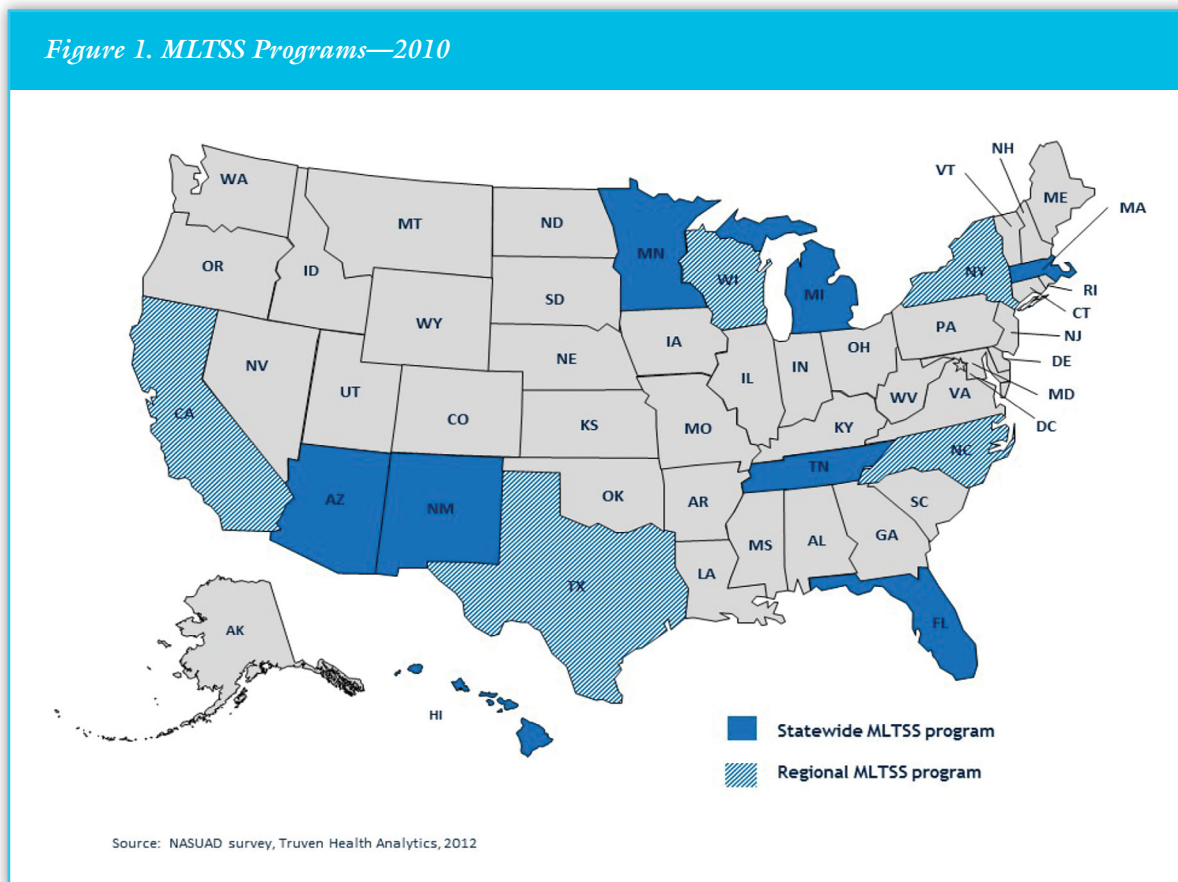
than the capitation rate, while others will be lower, depending on their needs as identified through the person-centered planning process. The managed care plan typically bears this risk, though specific contracts may include risk mitigation strategies that minimize risk for the managed care plan, share the risk between the state and managed care plan, or may include provisions that would re-assign an individual to a higher capitation rate if certain services are utilized.

Contracts include the services for which the managed care plan is responsible, and other provisions that the state seeks to enforce through the agreement. The array of services included within the contract will determine what type of managed care plan is in use. Certain requirements will vary depending on what type of managed care plan the state utilizes.¹⁴ All contracts require federal approval from the CMS. States can include Medicaid state plan services in their contracts and can also include LTSS, such as those covered under HCBS waiver programs. Contracts and many of the managed care Medicaid authorities require renewal at established intervals. Depending on state contracting and procurement requirements, re-procurements may also be needed.

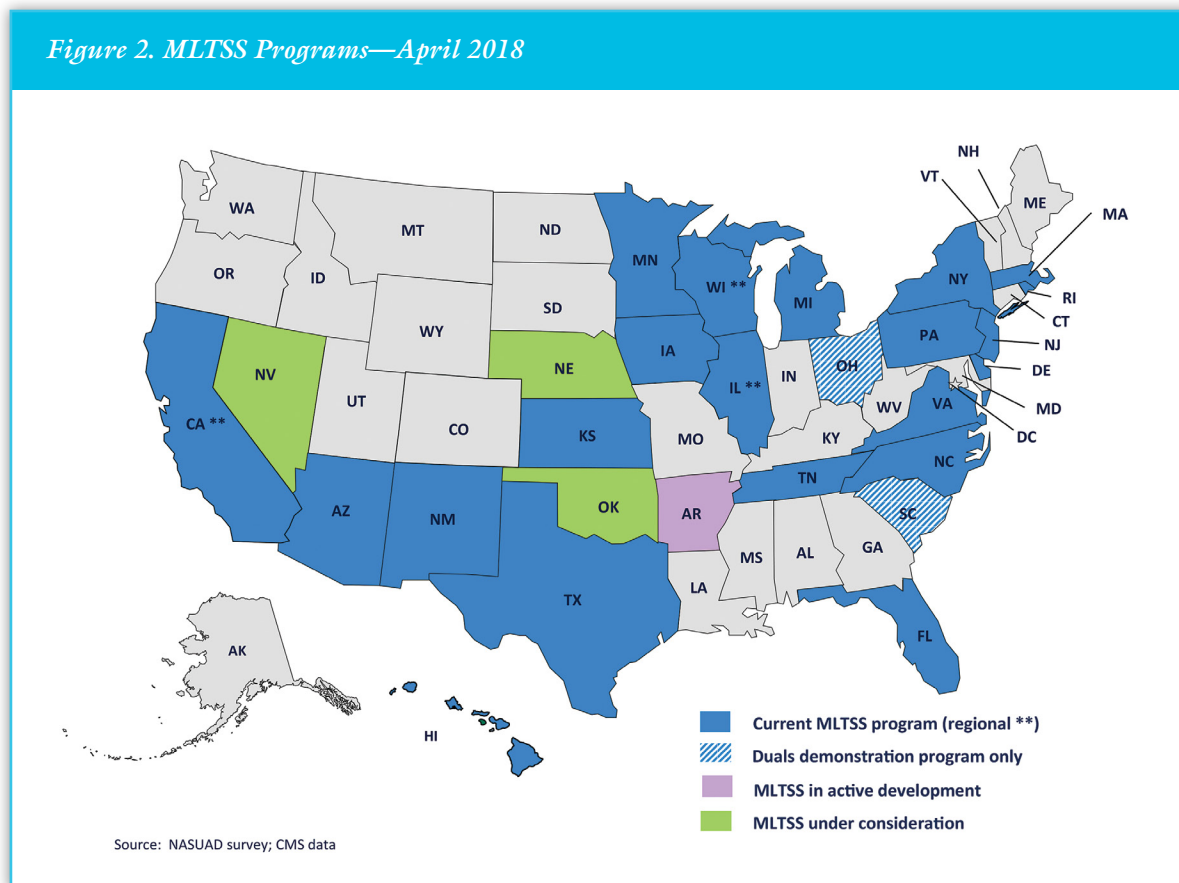
The Evolution of MLTSS

The number of states with MLTSS delivery systems continues to grow across the country. In 2010, there were only eight statewide programs, with the rest serving only part of a state (Figure 1).

Figure 1. MLTSS Programs—2010



A rapid increase in the scope and number of MLTSS programs occurred between 2013 and 2016, due in part to CMS' Financial Alignment Demonstrations for dual eligible beneficiaries, and due in part to statewide expansions of previously regional programs. As of January 2018, there are 23 programs—most of which are statewide (Figure 2).



MLTSS is viewed by a number of states as a structure that can affect positive change in efforts to rebalance the long-term services delivery system from an institutional orientation to home and community-based services, to align payments and incentives for positive outcomes and to assist individuals in gaining and maintaining services that support employment and community integration. Most MLTSS programs have focused on enrolling older adults and people with physical disabilities into MCOs for both their acute care and LTSS services. If people with I/DD are enrolled, it is most often for their acute care services only.

There are several factors that make including LTSS services for people with I/DD into MLTSS programs more complex, including the length of time individuals may require services, the existence of wait lists of people who are eligible for I/DD services, and the need to design a service array that promotes and supports community integration. In addition, the provider community for individuals with I/DD is quite different than those for clinical services or for LTSS for other populations. Unlike services for older adults, there are very few private pay recipients of I/DD services, which makes I/DD providers heavily dependent on public resources. Many of the providers started from local advocacy groups, and as a result are often small organizations serving fewer than fifty people. Since

services for people with I/DD are designed to engage the person fully in their community, there may be different providers for residential versus employment and day services. Moreover, their level of business acumen — ability to set prices, negotiate contracts, and meet stringent accountability outcomes demanded by MCOs — varies greatly across the country.

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Introducing MMC as an approach for delivery of LTSS to people with I/DD is still an emerging frontier, and requires the education, collaboration, and engagement of managed care plans, service providers, participants, families and caregivers, state systems, advocates, and other stakeholders in order to ensure that the MLTSS program can adequately meet the needs of these consumers. Managed care is not the only means available to states to achieve these goals, so careful analysis is necessary to ensure that managed care is the proper approach.

Despite these complexities, however, a growing number of states have begun including people with I/DD in their MLTSS frameworks. Some states have done so through incorporating LTSS for people with I/DD into fully capitated contracts with health plans at the same time as other LTSS populations. Other states have begun a slower process of carving in people with I/DD into pre-existing health plan managed care frameworks over time. For example, **Iowa** opted to include managed LTSS for people with I/DD as part of the overall implementation of IA Health Link. IA Health Link brought together physical, behavioral, and LTSS under one managed care program. **Texas**, on the other hand, initially chose to implement their STAR+PLUS managed care program with an I/DD LTSS carve-out.

There are promising practices learned from states’ experiences in implementing and operating MLTSS that, combined with additional steps, can increase the opportunity for MLTSS to further improve supports and service for people with I/DD. This paper will explore uses and positive practices for MLTSS and supports for people with I/DD.

History of Managed Care for I/DD Services

Although MLTSS has historically been less common for people with I/DD, there are states with longstanding programs such as North Carolina and Michigan which approach LTSS differently than most states, in that they operate long-standing, statewide/or county-based, capitated programs that include only behavioral health and I/DD services. Since 1989, Arizona has used a unique arrangement in which the state DD agency operates as its managed care organization in the delivery of MLTSS. However, because of the uniqueness of Arizona's Arizona Health Care Cost Containment System (AHCCCS), their arrangement is unlikely to be replicable in other states.

More recently states such as Iowa and Kansas have moved to using MLTSS as a tool by which LTSS are provided to people with I/DD. These states moved LTSS for people with I/DD into fully integrated managed care, whereby a single health plan oversees and coordinates all services for this population, including LTSS, medical, and behavioral health. By shifting LTSS from FFS to managed care financing arrangements, states are seeking to reduce fragmentation of care, promote access and community inclusion, and provide high-quality, person-centered, and cost-effective services.¹⁵ Tennessee has taken a slightly different approach by allowing its MCOs to deliver LTSS services for people with I/DD (along with their acute and behavioral health services) but under a non-risk arrangement. Because the benefit structure is so different from the state's FFS 1915(c) waivers, the state has not been able to develop actuarially sound rates.

As states become more familiar with and experienced in managed care, the trend of moving LTSS for people with I/DD to managed care is likely to continue. Several states are engaged in various stages of planning for the implementation of MLTSS for people with I/DD while several other states are in the process of considering the move to MLTSS for the future of service provision for people with I/DD.

Successful Strategies for MLTSS for People with I/DD

Every managed care program has a lifecycle. The timeframes for each of the steps in the lifecycle may vary depending on state requirements, federal approval timelines, political pressures and other variables, but the steps of the lifecycle are consistent. Some stages may happen simultaneously, but each is key to ensure a strongly designed and implemented program. In addition, at each stage of the managed care lifecycle, the state must deliberately incorporate specific actions and/or elements to reinforce the focus on the goals of the MLTSS program. This process is especially important for programs aimed at individuals with I/DD, as the goals/objectives of the program may deviate from other products in the state. Consequently, adequate planning time is paramount across the lifecycle of the managed care program.

Figure 3. Stages of Managed Care Program Lifecycle



Adequate Planning Time

The most effective MLTSS system transformations are the result of a thoughtful and deliberative planning process that permits enough time for states to develop a clear vision of what they wish to accomplish in a move to MLTSS for people with I/DD. It is essential to allow adequate time in advance of implementing new, expanded or refined MLTSS program to allow for thoughtful planning and design, incorporation of stakeholder input, and implementation of safeguards to ensure a smooth transition to MLTSS. CMS recommends a two-year planning process at a minimum.¹⁶ Adequate planning time also allows for education of people who could be enrolled into MLTSS and their families, so that when the time comes, they are able to make informed decisions. Finding the right balance between time for planning new programs and pressures to implement systems reform is often a challenge for states.

“**Tennessee** spent more than two years planning prior to implementation of their MLTSS program for people with I/DD, called Employment and Community First CHOICES (ECF).”

Tennessee spent more than two years planning prior to implementation of their MLTSS program for people with I/DD, called Employment and Community First CHOICES (ECF).¹⁷ During that time, intensive planning meetings were held with individuals with disabilities and their families, the state Council on Developmental Disabilities, the Arc Tennessee, the state Protection and Advocacy organization, other advocacy groups, HCBS providers, health plans, the state developmental disability agency, and TennCare—Tennessee’s state Medicaid agency. Health plans actively participated with each other and the other Tennessee stakeholders in the planning process. Workgroups were developed around the core components of the future MLTSS delivery system and months of work with health plans sitting side by side at the table along with community advocates, the Council on Developmental Disabilities, DD providers, and DD state agency staff ensued.

Adequate planning timeframes also allow for individuals with disabilities and their families, I/DD service providers and advocates to offer robust input into any systems change efforts regarding the I/DD service delivery system. Engaging stakeholders who are grounded in knowledge about program needs and the initial planning and design of any MLTSS delivery system greatly increases the likelihood of the support of and success for system reform. Adequate planning time also offers opportunities as appropriate for health plans to familiarize themselves with LTSS for people with I/DD and their local provider network, enabling smoother network building to ensure rich choices of providers for individuals enrolled.

States must ensure that the team of state staff involved in planning for MLTSS program development includes those with expertise in managed care, LTSS services and delivery systems as well as the needs of people likely to use them. For programs designed to support individuals with I/DD, it is essential that the state includes staff with I/DD program expertise, given the programmatic and disability-specific considerations necessary for successful program design. However, state staff operating I/DD waivers may not fully embrace a managed care delivery system, and may need time to adjust to this new paradigm. Programs which have been most successful at implementation have allowed time in the program design for managed care and LTSS staff to educate each other about their programs and operations and to ensure that all personnel possess a basic level of understanding sufficient to ensure a smooth implementation as well as adequate oversight and monitoring of the MLTSS program. This is especially important for states designing I/DD-targeted MLTSS, as there are very unique programmatic and service-delivery considerations pertinent to the I/DD service system.

Need for Continuous Stakeholder Engagement

Consumer and Family Engagement

In the late 1940s and early 1950s spontaneously across the US, families began asserting a different vision, a different lifestyle and a different future for their sons and daughters with intellectual disabilities. In those days, families began to question the accepted wisdom that they should institutionalize their child or loved one with a disability. These isolated, independent developments eventually coalesced into the first wave of the ‘parent movement’. They organized and demanded services for their sons and daughters. In 1950, a small group of parents and other concerned individuals came together to act as voices for change for people with intellectual disabilities. Because so little was known about intellectual disabilities at the time, there were virtually no programs and activities in communities to assist in the development and care of children and adults with intellectual disabilities or to support families. These parents refused to accept that institutionalization was the only option as they wanted to raise their children in their own homes. No longer would they accept the dictum: “Nothing can be done for your child.” As a result, advocacy groups sprang up all over the country. Some of these groups joined to form the National Association for Retarded Children in 1953, which subsequently became The Arc.

“In the 1980s, as a growing number of people with I/DD made lives for themselves outside of institutions, many worked to form ‘self-advocacy’ organizations run by and for people with I/DD themselves.”

In the 1980s, as a growing number of people with I/DD made lives for themselves outside of institutions, many worked to form “self-advocacy” organizations run by and for people with I/DD themselves. These groups played an important role in promoting de-institutionalization, supporting the development of more inclusive community-based supports, and pushing for greater autonomy and self-determination in service settings.

People with I/DD and their families are pioneers in the progression of services for people with I/DD to live in their homes and communities. It would be hard to find system change in a state that did not first have grassroots efforts from self-advocates, families, and advocates demonstrating the possibilities and pushing to have a state scale them up. Things like institutional closures, supports in the family home, person-centered planning, and driving to employment outcomes, have all started with local advocacy.

The voices of self-advocates and parents in changing the course of the future for people with I/DD is just as vital today as it was in the 1950's. They continue to be vital stakeholders with expertise, passion, experience, and love for their family member with I/DD. They are the stakeholders with the knowledge and wisdom that must be the foundation of any I/DD service model design. Self-advocates/parents/families must be at the table to ensure all MLTSS programs for people with I/DD offer person-centered supports and services that will help their loved one accomplish the important things in their lives.

In order to facilitate involvement from self-advocates and families, states must work to make the managed care planning process accessible both from the perspective of people with intellectual disabilities and others who may be unfamiliar with the jargon or technical complexity of state MLTSS systems. This may involve community forums in which state policymakers explain the specifics of MLTSS proposals in an accessible fashion, partnership with self-advocacy and parent organizations to collect input on proposals in a systematic fashion, and a willingness to work collaboratively with self-advocates and families to identify valued parts of the existing I/DD system and areas in need of improvement.

In addition to individuals and their families, stakeholders include advocates, providers, managed care plans, and other partners. While all voices are important, state Medicaid and other state agencies key to program operations must ensure that individuals with disabilities and their families have the opportunity to be involved in meaningful roles in the initial stages and ongoing implementation of managed care. In all states, individuals with I/DD, their families and advocates have been instrumental in the development of the publicly financed human service system. It follows, then, that individuals with disabilities and their families have an important and vital stake in state systems and need to be included in the design and redesign of services. CMS has raised expectations for meaningful stakeholder engagement as well, requiring evidence of a meaningful input process at design and implementation stages of program efforts. Stakeholder engagement must be a two-way process, incorporating feedback and recommendations from stakeholders into the structure of the state's MLTSS arrangement, and providing technical assistance to self-advocates, families, providers and others on the new service-provision infrastructure.

States should ensure that they have strong and transparent mechanisms for meaningful stakeholder engagement, and must ensure that their managed care partners have commitment and structures to do the same. Community Catalyst, an organization aimed at ensuring that individuals can have a voice in the local, state and national decisions that affect their health and LTSS, has produced a *Toolkit for Meaningful Consumer Engagement*,¹⁸ which may be helpful to states in shaping their own engagement strategies and requirements of MCOs. The HCBS Business Acumen Resource Center, funded by the Administration on Community Living (ACL) offers additional tools to assist states and providers in ensuring robust stakeholder engagement.¹⁹

“Community Catalyst, an organization aimed at ensuring that individuals can have a voice in the local, state, and national decisions that affect their health and LTSS, has produced a *Toolkit for Meaningful Consumer Engagement*, which may be helpful to states in shaping their own engagement strategies and requirements of MCOs.”

Several states have taken affirmative steps to ensure stakeholder involvement. **Tennessee** involved stakeholders in the design and implementation of the Employment and Community First CHOICES MLTSS program for people with I/DD early in the process. The state Medicaid agency and DD agency facilitated stakeholder meetings prior to the final development of the “Concept Paper”²⁰ which formed the basis for the state’s 1115 waiver amendment. The “Concept Paper” was developed based on extensive input received from stakeholders through in-person meetings with advocacy and provider groups, statewide community meetings with Tennesseans with I/DD receiving or waiting for services, their family members, providers and advocates, an online survey, and other written comments.

North Carolina as part of their “NC Medicaid Transformation” efforts designed opportunities for robust and continuous stakeholder engagement during the development of the amended 1115 waiver including hosting listening sessions across the state, and solicited written and verbal public input on key policy issues. Moving forward, stakeholder input will be solicited and considered by public comment on this proposed program design, concept paper public review and comment, supplementing the open invitation for written comment with targeted outreach to stakeholders representing people with I/DD and their families and advocates, as well as rural and urban providers on policy and strategic topics and implementation issues.²¹

States should also consider setting a managed care implementation timetable that leaves adequate time for stakeholder engagement and review of the successes and challenges of implementation. This may mean phasing in implementation by population or by region. **Wisconsin**, as part of the state’s FamilyCare MLTSS framework, gradually phased in MLTSS in different parts of the state over nearly two decades, allowing stakeholders ample time to ensure that the state’s MLTSS framework was adequately serving the population receiving support and giving health plans time to build local capacity in network development, case management and other core competencies in each county phased into FamilyCare.²²

MCO Best Practice:

“Sunflower Health Plan of Kansas, a subsidiary of Centene Corporation, partnered with the state and other stakeholders early in the process of developing the state program. Sunflower hired a dedicated LTSS manager with extensive experience in I/DD in Kansas. This person participated in the development of the MLTSS program for people with I/DD and was integral to the development of Sunflower’s approach to service provision.”

Other managed care plans frequently hire staff with local experience in the service system and/or state-specific I/DD programs/policies to inform the development of a program. The MCO finds that this helps build trust among stakeholder groups and a well-grounded, culturally competent approach to service delivery. MCOs also often contract with subject matter experts in I/DD, self-direction and other critical aspects of a successful LTSS program.

State Councils on Developmental Disabilities

State Councils on Developmental Disabilities (Councils) are federally funded, self-governing organizations charged with identifying the most pressing needs of people with developmental disabilities in their state. Councils are committed to advancing public policy and systems change that will support individuals to gain more control over their lives.

Councils focus on empowering individuals through activities that teach self-advocacy skills and support self-determination. Councils are not limited to representing only people getting state and federal funding. They can represent the “All” in their communities. State I/DD agencies are dependent on and benefit from the voice that they bring to policy development and assessment of services being provided. Since the Councils’ missions are to identify ways a state can promote self-determination, community integration and inclusion, they are key allies to help a state build and sustain services that can deliver on those outcomes. Councils are often the first in the state to test out and “pilot” ideas. Person-centered planning processes and tools have long been supported through DD Council projects and funding and are now core to state practices and reflected in CMS HCBS programs. Their role as a stakeholder during any I/DD system design or redesign is one of great importance and value.

The **Tennessee** Council on Developmental Disabilities was among the stakeholders present during family meetings, public forums, and program design and implementation workgroups for the ECF program. Working side by side with people with disabilities and families, state agencies, and providers, they played an integral role in ensuring person-centered services and supports. In addition, the Tennessee Council on Developmental Disabilities sponsored a year-long intensive initiative involving the MCOs, state Medicaid agency, ECF providers, and the state DD agency called “Becoming a Person-Centered Organization.” The initiative was designed to ensure the plans involved in operating the MLTSS program were grounded in understanding person-centered supports and services for people with I/DD. The three MCOs in Tennessee, **Amerigroup Tennessee**, **BlueCare Tennessee**, and **United HealthCare** participated in more intensive work that involved a review of policies and practices to assist and identifying systemic barriers to providing person-centered services.

“...the Tennessee Council on Developmental Disabilities sponsored a year-long intensive initiative involving the MCOs, state Medicaid agency, ECF providers, and the state DD agency called ‘Becoming a Person-Centered Organization.’”

Lifecycle Step I: Goal Identification

The vision for LTSS system reform usually begins with a similar purpose—to provide people with disabilities additional options for accessing and receiving services in their homes and communities. Each state then tailors that goal against the specific concerns of the state and its stakeholder community. Prior to any program design decisions, states must identify the issue they are hoping to solve and their overarching goals, both short- and long-term.

The design of MLTSS should include both the goals for the overall system, but also focus on the individual services and supports, based on each person’s needs and interests. The principles of person-centered planning, self-determination, self-direction, increased community living, and the choice of employment options must be included into the overarching goals of any MLTSS model program operations.

For I/DD systems, the goals for MLTSS may differ from those of other populations. State I/DD systems have been largely community-based (rather than institutionally focused) since 1995, so managed care is not viewed as a path to rebalancing for individuals with I/DD.

In **Michigan**, for example, the state includes a specific *Employment Works Policy* within its managed care contracts.²³

Instead, states may look to managed care for budget predictability and stability, improved methods of payment to incentivize positive outcomes, increased access to preventive and acute care health services, enhanced coordination across service providers, and an enriched quality oversight mechanism. State I/DD agencies may wish to use managed care as a tool to further policy objectives such as increased independence, community integration and employment opportunities for people with I/DD. In any event, the articulation of the goals from the outset will be essential in determining the most appropriate strategies to meet those objectives.

The goals developed during this phase will be incorporated widely within all subsequent documents related to the program development. In **Michigan**, for example, the state includes a specific *Employment Works Policy* within its managed care contracts.²³ This policy sets the state's goals and performance expectations on all parties that, "Each eligible working age individual over 14 years old ... and ongoing to the age of their chosen retirement ... will be supported to pursue his or her own unique path to work and a career. All individuals will be afforded the opportunity to pursue competitive, integrated work (p. 275)." Ensuring that the employment goals are reinforced throughout the process, the governing documents and the quality oversight practices will ensure that the principles are integrated into the basic fiber of the program's practices. Similarly, **Tennessee's** Employment and Community First CHOICES was designed specifically to meet the goals of promoting and supporting integrated, competitive employment and independent living as the first and preferred option for all individuals with intellectual and developmental disabilities. The entire MLTSS program was constructed to meet the goals of the state including service definitions that were developed specifically to ensure that the goals of employment and community integration were likely to be reached.²⁴

Lifecycle Step II: Data Analysis, Program Design and Authority Selection

Data Analysis

Once the broad goals of the MLTSS program have been identified, states must undertake several important steps to fully understand the issues and current context. This should include a careful data-based analysis of the populations to be served, services to be offered, historical costs and utilization patterns, and identified challenges with current service delivery system. Using data on historical and projected service utilization, provider billing and engagement patterns and other data points will provide important information to consider in any program design undertaking.

This data analysis is essential to understanding the potential costs of program changes, as it will inform prospective fiscal analysis for state budgeting purposes and will serve as the basis for rate setting and capitation. Decisions on capitation structure informed by data will increase the likelihood that the capitation will reflect the priorities for systems change as identified in the overarching goals. This data analysis will importantly also provide a baseline for the state to measure the impact of the intervention of managed care, and will assist in identifying essential quality metrics critical to measuring progress toward goals. Furthermore, this data analysis will also provide information for network development requirements or system capacity building needs.

Some state DD agencies face challenges in the area of data collection and analysis often due to antiquated information technology (IT) systems. Specific IT-related issues include the inability to access all data for sources of care for I/DD individuals that states serve, including Medicaid State Plan claims and encounters, Medicare claims, and even a consolidated picture of the HCBS services they provide as a result of multiple legacy systems. Some I/DD systems have had separate financial and quality reporting systems that are labor intensive to maintain and are very susceptible to human error. As a result, this step in the development of an I/DD MLTSS program is particularly important.

Data analysis must be an ongoing activity, and must be matriculated into daily operational and program activities, with the data sources shifting from state systems to managed care submissions as the program evolves.

Program Design and Authority Selection

Broad program goals and solid understanding of state data will provide the bedrock for program design for the managed care program. In this stage, the state must define/refine the key program aspects. This refinement must identify the following:

- Populations to be served—Medicaid eligibility groups, broad target or disability groups, and the ages of individuals;
- Services to be offered—state plan services and/or HCBS to be included in the capitated arrangement;
- Geographic area—statewide or county(ies) covered;
- Enrollment Approach (voluntary or involuntary); and
- Inclusion of self-direction, if applicable.

Refining these decisions will assist the state in determining:

- Which Medicaid authority will best help them meet their programmatic objectives;
- Which type of managed care plan and procurement strategy is needed to implement;
- The approach for request for proposals (RFPs) and contract content; and
- The quality metrics and performance improvement strategy.

From the outset of the design discussions, states must deliberately shape quality metrics, to ensure that expectations are clear and are infused in the program design, transparent to all interested stakeholders, including individuals with disabilities and their families, advocates, prospective managed care partners, and providers. For people with I/DD desired outcomes, length of time in services, and demographics of people living with their families are all important contributing factors to I/DD program design. Virtually all state I/DD programs conduct the National Core Indicators (NCI) consumer survey to identify strengths and areas for improvement in their I/DD system. When moving to a managed care delivery system, states may want to consider using NCI measures as part of their MCO quality measurement and improvement program.²⁵ **Kansas**, for example, requires their MCOs to use NCI data in their quality improvement strategies.

“Virtually all state I/DD programs conduct the National Core Indicators (NCI) consumer survey to identify strengths and areas for improvement in their I/DD system. When moving to a managed care delivery system, states may want to consider using NCI measures as part of their MCO quality measurement and improvement program.”

Lifecycle Step III: State Infrastructure Planning and Alignment

The movement to managed care requires a careful review of state level infrastructure, partnerships and human resources to ensure that the state structures will support the program design and will promote, not hinder, progress toward the identified goals.

In addition to ensuring that payment and data systems and other structural facets of the state system are prepared for the change to managed care, states must ensure that there are adequate state staff with the requisite experience and skills to review such data and information to measure the performance of the managed care plans against the established benchmarks. These state resources will be essential to ensure strong performance of each of the plans in the execution of program goals, and to provide an overarching assessment how the statewide system is faring.

The role of the state I/DD operating agency may shift, but will not lessen with the move to managed care. While the managed care plans may undertake certain functions previously performed by state staff, the state must exercise vigilance in oversight and plan management to ensure that the program is implemented as designed and that progress is made toward established goals. Performance measurement must be frequent to ensure timely corrective interventions if elements are amiss or to quickly replicate strong practices statewide if successful efforts are identified. Significant components of effective oversight include explicit contract language about plans' responsibilities, early attention on the part of states to determining how performance will be measured, and ongoing feedback from consumers and providers to help monitor program operations. State staff with expertise in program goals such as person-centered planning and meaningful community engagement and employment, must play a key role in overseeing health plan performance in this area, and should have regular communication with managed care plans to ensure their performance aligns with goals and program requirements. Developing non-congregate housing approaches for individuals with I/DD is a growing area of emphasis for both states and health plans. For individuals with I/DD, this will also include specific oversight of critical incident identification, reporting and response.

“Significant components of effective oversight include explicit contract language about plans’ responsibilities, early attention on the part of states to determining how performance will be measured, and ongoing feedback from consumers and providers to help monitor program operations.”

Opportunities for people with I/DD to live and be a part of their community life are made possible by multiple state programs. Movement to managed care may require new relationships or new roles among existing state partners and health plans. Coordination among these public systems are critical to successful MLTSS outcomes. Detailed discussions and documentation, through Memoranda of Understanding (MOU) or similar tools, must articulate the specific roles and responsibilities state agencies (including vocational rehabilitation and education), counties or local partners will have in the redesigned service system.

In order to support the priorities of competitive employment for people in **Tennessee’s** Employment and Community First CHOICES, the state VR agency and the state Medicaid agency signed a MOU. The MOU was intended to ensure that each agency provides employment services to common people in coordination with each other to ensure efficient use of resources and effective delivery of services. Moreover, the need to partner in new and unique ways also includes opportunities for MCOs to pool collective knowledge and resources together in order to support the implementation of an MLTSS system.

MCO Best Practice:

“Driven by their desire to build a quality, qualified, dynamic provider network in Tennessee, **BlueCare Tennessee** and **Amerigroup Tennessee** LTSS staff collaborated to develop and provide training regarding the ECF program across the state to organizations interested in applying to become part of the MLTSS provider network.”

Support for People with Disabilities

The 2016 federal Medicaid managed care regulations established a standard for states to “develop and implement a beneficiary support system to provide support before and after managed care enrollment...[including] making choice counseling available to all beneficiaries...[providing training to] plans and network providers on the type and availability of community-based resources and supports, [providing] assistance to all beneficiaries in understanding managed care, [and providing] assistance for enrollees who receive of desire to receive LTSS.”²⁶ The rule also establishes the expectation that the system provide these supports “in multiple ways including phone, internet, in-person, and via auxiliary aids and services when requested.”

Many people with I/DD, particularly those without strong family support, require significant assistance in understanding the complexities of MLTSS enrollment, benefits and service navigation. Choice counseling—assistance in understanding managed care and the differences among available health plan options—and ombudsman programs must take this into account. In addition, people with I/DD typically possess different service needs than the majority of people historically enrolled in MLTSS. States may wish to develop separate or specialized consumer support programs for people with I/DD, ensuring that the population will have access to and understand the different service-experience.

Lifecycle Step IV: Procurement, Contract, and Rate Development

In order to get proposals from prospective managed care partners, states typically issue a Request for Proposals (RFP).²⁷ These procurement documents are fundamental to setting the initial expectations for the programs, establishing qualifications and competencies core to the performance of the work and making clear the priorities of the state. These documents are often accompanied by data and information to provide prospective vendors with information sufficient to determine whether they can effectively perform the work and meet established expectations. Developing program requirements specifically for people with I/DD that address person-centered case management, level-of-care assessments, LTSS network adequacy, participant-directed service options, quality measures, workforce development expectations, and employment is essential.

Prospective vendors submit their proposals in response to the contents in the RFP. Emphasis in RFPs on person-centered approaches to support, supporting families, ensuring community integration (including compliance with the CMS HCBS regulations), and employment capacity and experience is critical for states wishing to gain an understanding of prospective managed care capabilities, philosophy, and track record regarding positive outcomes for individuals with I/DD.

The inclusion of such provisions within the procurement document is important to establish early expectations and to heighten the likelihood that the state will receive proposals from plans with expertise, capacity and experience necessary to successfully implement the program. Importantly, this gives prospective managed care partners an opportunity to forge partnerships if they do not directly possess the requisite expertise.

Payment Considerations

States take various approaches to designing their MLTSS payment structures—the structure of rates and of incentive payments and penalties—which can influence the financial incentives being set for MCOs. In most managed care programs, states pay managed care plans a single capitated, actuarially sound rate for each person to whom the health plan delivers an established array of services. Typically, in capitated arrangements, the managed care plans have the ability to negotiate rates with providers of services. There can be variations and states considering managed care need to consider the extent to which managed care plans may negotiate rates with service providers. Many states are now requiring managed care plans to make provider payments under value-based payment arrangements.²⁸ Regardless, states should review rate methodologies to ascertain if provider rates will achieve and sustain the network requirements (e.g. sufficiency of employment providers) to meet the goals of the program. States utilizing managed care plans operating through a capitated payment system should utilize rate methodologies that are fair, equitable, and transparent.²⁹

States can make certain contractual stipulations to increase success in priority service areas. Many states structure their capitation rates to promote program goals such as employment and community integration. Rates should be designed to facilitate and not hinder the delivery of community-based LTSS supports. Ensuring adequate payment rates and realistic, longer range targets for any savings expectations is important.

“Financial tools are key to shifting the systemic bias within an LTSS system, and the state should bring these tools to bear within a managed care environment.”

Additional tools available to states include:

- *Incentives for plan performance.* “Incentive arrangements” means any payment mechanism under which a health plan may receive additional funds over and above the capitation rates it was paid for meeting targets specified in the contract.³⁰ By federal regulation, these additional funds can be worth no more than five percent of the total contract amount. States also use withholds—an amount held back from the health plan’s monthly capitation payment; these amounts can be ‘earned back’ if the plan meets specified performance targets. Withholds in MLTSS programs generally range from one to five percent. Finally, states can also impose financial penalties on MCOs for not fulfilling requirements in the contract, which may include requirements that relate to the quality of and access to services.
- *Cost-effective alternatives.* States may allow managed care plans to provide cost-effective alternatives (also called ‘in lieu of’) to services included in the capitation rate. Per federal regulations, these must be defined in advance and included in the MCO contract.

“**Kansas’s** contracts with MCOs include a rigorous pay-for-performance program that requires plans to achieve certain quality benchmarks. Five percent of an MCO’s monthly capitation payment is withheld and may be returned if the MCO not only meets the state benchmark, but also improves its own performance by five percent each year.”

Contract Provisions

In general, for individuals with I/DD, managed care contracts may need to include specific contractual obligations regarding the manner and method of service delivery, the provider network/paneling requirements, payment strategies (especially if some providers are held static during the implementation phases), quality monitoring and oversight. These elements may aim to incentivize supporting families, furthering opportunities for community engagement and raising expectations for integrated, competitive employment at or above the minimum wage.

Provider Network Composition and Competency. A diverse and robust network of providers who are culturally and linguistically competent, accessible for people with disabilities, trained in providing person-centered services, and experienced in providing LTSS is essential. Historically, LTSS service provision has depended on the development of innovative service models, often pioneered by small providers lacking the business sophistication of the larger organizations better equipped to sell their services on favorable terms to managed care entities. There has been fear that managed care plans are unfamiliar with the providers delivering services to individuals with I/DD; however, managed care plans serving individuals with I/DD are making great efforts to understand a state’s specific provider construct and ensure the broadest network possible.

In the absence of an environment that allows for or incentivizes negotiations for reasonable terms between managed care entities and innovative service providers, key service-related values frameworks built into state LTSS frameworks through considerable investment of time, energy and advocacy may stall or fall apart entirely. It is essential that states work to preserve the existence of a broad array of service provider options within MLTSS frameworks. To facilitate this, states can look to a variety of potential options, including continuity of care contract provisions, robust outreach and education efforts with small providers (i.e. simulated billing sessions, town halls, conference presentations, direct engagement, etc.) and standardization of billing and data collection procedures, to reduce the administrative burden faced by service-provision agencies.

Contract provisions, either directly or through reference, to external state regulations and policies, should set standards regarding credentialing, provider qualifications, training requirements for employment staff and expectations regarding the development of a competent workforce.

“In developing and maintaining its network of ECF CHOICES providers, **Tennessee** developed ‘preferred contracting standards’ in order to bring providers into the network that were most aligned with the values of people with I/DD and their families, TennCare, and the state DD agency regarding quality, supporting families, supporting independence, community integration, and employment.”

Some of the preferred contracting standards that TennCare implemented included:

- Demonstrated leadership in employment service delivery and community integration;
- Success transitioning people with I/DD into more independent living arrangements such as supported living;
- Provider has Letter of Agreement with the state vocational rehabilitation agency; and
- Provider has participated in process of moving to a person-centered organization.

After discussions with the state, the MCOs jointly credentialed a shared “implementation” network of providers, and used in-depth face-to-face credentialing visits to identify those providers who aligned with the preferred contracting standards.

States should also consider requiring MCOs to have I/DD LTSS specialists on staff tasked with managing interactions with service providers and taking a “whole systems” approach towards accomplishing employment related LTSS systems change. **Tennessee** required MCOs to have I/DD LTSS specialists in program priority areas as a strategy to address the MLTSS program goals. Each MCO in Tennessee was required by contract to employ a person in each of the following positions:

- Employment Services Director;
- Behavior Supports Director; and
- Housing Supports Director.³¹

With MLTSS program goals of competitive, integrated employment for people with I/DD and community integration, the expertise of these specialists will be invaluable to the MCOs.

Collaboration. Contract provisions should underscore the importance of collaboration with stakeholders and utilizing the individuals’ informal support system (e.g., family caregivers). For example, **North Carolina’s** contract includes the following provision: “The MCO shall develop stakeholder group(s) of recipients, families, advocates, and providers around Innovations waiver services...”

“**Arizona** includes contract provisions in its MCO contract which reference key principles including member-centered support coordination (case management), consistency of services, available and accessible services, most integrated settings, collaboration with stakeholders, and ensuring support of the member’s informal support system (e.g., family caregivers).”

Consumer Rights and Protections. There are specific requirements within managed care regulations for individual rights, protections and grievances and appeals. In addition to these protections, managed care entities are covered entities and must comply with the Americans with Disabilities Act (ADA) and other federal statutes.

Health plans are offering innovative approaches to ensure that people with I/DD enrolled in MLTSS are supported to understand and exercise their rights. To support MLTSS providers Vaya Health of **North Carolina** collaborated with the National Alliance of Direct Support Professionals (NADSP) to offer Supporting Informed Decision Making: A Train-the-Trainer Curriculum. Direct support professionals completing this training will be better equipped to understand why supporting people with disabilities to make their own choices is important. Further, DSPs gain an awareness of how attitudes and values toward choice can enhance or suppress the decision-making capacity of those they serve.³²

Performance Measurement and Data Management. Contract provisions should ensure that the managed care plan collect and submit to the state data to document outcome oriented indicators and provide actionable descriptive data. For example, indicators regarding employment could be: successful job placements; the type of employment (individual-based or group), with the goal being individual competitive integrated employment (including the application of supported employment and/or customized employment strategies); wages earned; hours worked; and other indicators of employment and employment-related activities, such as informed choice and satisfaction with employment supports.

Such information should be made publicly available, and disaggregated on a statewide, regional and provider level, with appropriate protections for privacy put in place to enable both targeted and statewide performance improvement initiatives. **Kansas** outlines specific MCO requirements addressing integrated employment outcomes to be achieved through services for people with serious and persistent mental illness, intellectual disabilities, physical disabilities and traumatic brain injuries. Provisions require MCOs to document and report on the number and percent of KanCare members with disabilities to have gained integrated employment.³³

Support Planning and Coordination. Strong practices in contracts often ensure that support coordinators are experienced (and have expertise) in working with people with disabilities. Requirements for caseloads of support coordinators should be reasonable and allow for personal interaction with people and their families. Person-centered planning is a requirement for HCBS and includes active participation by the person receiving services and/or their representative in the service planning and delivery process.

Lifecycle Step V: Detailed Policy and Procedure Development

The managed care system should be designed to maximize the ability of individuals with I/DD receiving support to achieve their personal goals and desired outcomes. The approved Medicaid authority and the contract with the MCE will establish the goals and requirements of the program, as well as the responsibilities of each of the parties. However, the details explaining the specific operational expectations will be contained within the state's policies and procedures manuals and other governing policies included by reference in the authorizing documents. The Medicaid agency must take care to include, directly or by reference, the rules, manuals, policies, and procedures and rules of the state agencies involved with the provision of services to individuals with disabilities (e.g., I/DD, mental health, vocational rehabilitation) to ensure key requirements, best practices and expertise built over the years with stakeholders remain part of MCE requirements.

In **Tennessee**, for example, a benefit group available in the ECF program is designed specifically to support children and adults who remain living with their families. Called Essential Family Supports, this benefit group identifies families with a child under age 21 who has an intellectual or developmental disability. Services available in this group support families facing the unique challenges of supporting a child with intellectual or developmental disabilities. Essential Family Supports helps individuals with an I/DD and their families plan and prepare for transition to employment and integrated, independent living in adulthood.³⁴

“MCOs in Tennessee are required by contract to provide training to all Support Coordinators (case managers) working for people with I/DD to be trained in the Charting the LifeCourse framework, which promotes the idea that all people have the right to live, love, work, play, and pursue their life aspirations in the community.”³⁵

Training

To ensure a complete understanding of the detailed goals, policies and procedures, states must implement a strong training component. Initial and ongoing training is essential to successful initiatives, including, or especially, one implemented through managed care for individuals with I/DD.

Supporting I/DD providers in the transition to the new MLTSS infrastructure should be a priority for state agencies to ensure a diverse and high caliber provider network for the new MLTSS environment. In many instances, these providers have experienced only a single payer—the state—for the delivery of services, and must adapt to new business relationships and changing expectations. In 2013 CMS released a technical assistance paper, *Transitioning Long Term Services and Supports Providers into Managed Care Programs*,³⁶ which notes that:

At the most basic level, the adoption of MLTSS models means that direct service providers will be selling their services to different customers. Instead of contracting directly with states (or their regional entities), LTSS providers are now being required to negotiate contracts with the managed care entities selected by states to manage their LTSS populations. Instead of having a single contract with the state, direct service, providers may have contracts with multiple managed care entities.³⁷

Moreover, the state should ensure that the managed care entities, particularly key staff such as care coordinators, supervisors, and others, receive adequate training on the principles of the MLTSS program goals. Training should ensure a common understanding of core elements, definitions of terms, and performance expectations.

“Three health plans in North Carolina, **Vaya Health, Trillium Health Resources,** and **Cardinal Innovations Health Care,** provide top training resources to providers via DirectCourse, published by Elsevier. The online training is designed for direct support professionals serving people with disabilities.”³⁸

Lifecycle Step VI: Quality Oversight and Program Improvement

Each managed care plan must have an effective comprehensive quality management system. The contract should stipulate the state’s expectations around that system and best practice strategies emphasize measuring performance on elements that reflect the overall goals for the system (i.e., supporting families, self-direction, quality of life, employment, etc). The state should provide detailed specifications for how performance measures are to be calculated and reported to support validity and consistency across MCOs.

People with I/DD typically receive services for a far longer period of time than most other people using MLTSS and access a broader array of services than most. Since people with I/DD are accessing services that may be unfamiliar to MCO staff, it is particularly important for states to have in place a quality management system that enables the tracking of outcomes in categories unfamiliar to a more traditional, clinical mode of thinking. Especially in a managed care environment, states must have an effective means to ensure the quality of long-term services and supports.

Some common indicators required by states include establishment and operation of stakeholder advisory committees, meeting a set threshold for processing enrollment applications, establishment of call centers with sufficient staff to avoid high wait times, and other items capable of being assessed prior to the MCO acquiring a track record in implementation. States may wish to evaluate the hiring of case managers familiar with I/DD, and enrolling HCBS providers with expertise in supporting living and supported employment.

“In **Tennessee**, the Medicaid agency contracts with the state DD agency to conduct on-site reviews of MCO performance in key areas. The state also requires the MCOs to participate in the National Core Indicators quality of life survey.”

States should utilize valid and reliable measures to assess activities and outcomes by state disability systems and MCOs. For example, the National Core Indicators (NCI) is used by 46 states plus the District of Columbia to assess system performance and individual outcomes, including personal experience and employment. The instrumentation is valid, reliable and risk-adjusted to permit state-to-state comparisons. NCI evidence is used by states to benchmark performance, improve quality and assess policy outcomes. Long used to evaluate developmental disabilities services, the instrumentation has been adapted to assess older adults and persons with physical disabilities.³⁹ Data covers outcomes across key employment areas including choice of job, job setting, and wages earned, hours worked, worker satisfaction and other measures. **North Carolina** conducts face-to-face interviews with people with I/DD to gauge satisfaction with services and supports, including their case management.

Conclusion

The move to expand MLTSS for people with I/DD provides opportunities to expand HCBS, promote employment and community integration for people with I/DD and increase quality and efficiency, all of which could improve the lives of people with I/DD. In the long-term, increased efficiency, flexibility and budget predictability might aid in slowing the growth in Medicaid spending and therefore help avoid cuts. MLTSS are still relatively new to the I/DD community, so states should proceed thoughtfully and deliberately to create a MLTSS program for these population. MLTSS for people with I/DD can be successful if the program is carefully and appropriately designed. A critical component of that design is adequate engagement with stakeholders, namely people with I/DD and their families, to ensure a full understanding of the unique needs of the I/DD community. Furthermore, state policymakers should not hesitate to use different quality measures, timeframes and policies for supporting people with I/DD within MLTSS, recognizing the needs and concerns of the population.

MLTSS offers both opportunities and challenges for people with I/DD and their families. States should design their MLTSS frameworks and rollout processes accordingly.

ENDNOTES

- ¹ David Braddock, editor, *Disability at the Dawn of the 21st Century and The State of the States* (American Association on Mental Retardation, 2002) 91.
- ² Larson, S.A., L. Hallas-Muchow, F. Aiken, B. Taylor, S. Pettingell, A Hewitt, M. Sowers, and M.L. Fay.(2016). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2013*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- ³ This title was the actual title at the time, and does not reflect more contemporary language describing individuals with intellectual and developmental disabilities.
- ⁴ Gettings, R., *Forging a Federal-State Partnership: A History of Federal Developmental Disabilities Policy*
- ⁵ *ibid*
- ⁶ Eiken, S., K. Sredl, B. Burwell, R. Woodward. *Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2015*. Truven Health Analytics, an IBM Company. April 14, 2017.
- ⁷ Eiken, S., Truven Health Analytics. *Medicaid 1915(c) Waiver Data Based on the CMS 372 Report, 2013-2014*. September 2017.
- ⁸ CMS-2249-F; CMS-2296-F
- ⁹ U.S. Department of Justice. (2016) Statement of the Department of Justice on application of the integration mandate of Title II of the Americans with Disabilities Act and *Olmstead v L.C.* to state and local governments' employment service systems for people with disabilities. Retrieved from https://www.ada.gov/olmstead/olmstead_guidance_employment.html.
- ¹⁰ Medicaid Managed Care Enrollment Report Summary Statistics. Centers for Medicare & Medicaid Services. <https://www.medicaid.gov/medicaid/managed-care/enrollment/index.html>
- ¹¹ 42 CFR 438.6 <https://www.gpo.gov/fdsys/pkg/CFR-2012-title42-vol4/pdf/CFR-2012-title42-vol4-sec438-6.pdf>
- ¹² 42 CFR 438.2 <https://www.gpo.gov/fdsys/pkg/CFR-2012-title42-vol4/pdf/CFR-2012-title42-vol4-sec438-2.pdf>
- ¹³ *Actuarially sound capitation rates* means capitation rates that (A) Have been developed in accordance with generally accepted actuarial principles and practices; (B) Are appropriate for the populations to be covered, and the services to be furnished under the contract; and (C) Have been certified, as meeting the requirements of this paragraph (c), by actuaries who meet the qualification standards established by the American Academy of Actuaries and follow the practice standards established by the Actuarial Standards Board.
- ¹⁴ MMC includes Managed Care Organizations (MCOs), Prepaid Inpatient Health Plans (PI-HPs), and Prepaid Ambulatory Health Plans (PAHPs). The type of plan is determined by service array.
- ¹⁵ State Trends and Innovations in Medicaid Long-Term Services and Supports.” Center for Health Care Strategies, December 2012. Available at: http://www.chcs.org/media/State_Trends_and_Innovations_in_Medicaid_LTSS_12_17_12_FINAL.pdf
- ¹⁶ <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/downloads/mltss-timeline.pdf>
- ¹⁷ <https://www.tn.gov/tenncare/long-term-services-supports/employment-and-community-first-choices.html>
- ¹⁸ <http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement>.
- ¹⁹ <http://www.hcbsbusinessacumen.org/toolkit.html>
- ²⁰ <https://www.tn.gov/content/dam/tn/tenncare/documents/ConceptPaper.pdf>
- ²¹ https://files.nc.gov/ncdhhs/documents/files/MedicaidManagedCare_ProposedProgramDesign_REV-FINAL_20170808.pdf
- ²² <https://www.dhs.wisconsin.gov/familycare/enrollmentdata.htm>
- ²³ MDCH/CMHSP Managed Mental Health Supports and Services Contract: FY18 Agreement Between Michigan Department of Community Health and CMHSPs for Managed Mental Health Supports and Services. Attachment C6.9.8.1 June 7, 2011. CMHSP Contract Bundle, page 275.
- ²⁴ <http://fulfillthepromise.org/Docs/Amendment27ECFCHOICES.pdf>

- ²⁵ Unlike the CAHPs® tools, MCOs are not permitted to administer the National Core Indicators survey; it remains exclusively a state-administered tool.
- ²⁶ <https://www.federalregister.gov/d/2016-09581/p-59>
- ²⁷ States may use different terms for this solicitation document, such as Request for Qualifications or Intent to Negotiate.
- ²⁸ Value-Based Payments in Medicaid Managed Care: An Overview of State Approaches. Center for Health Care Strategies, February 2016. <https://www.chcs.org/resource/value-based-payments-in-medicaid-managed-care-an-overview-of-state-approaches/>
- ²⁹ *ibid.* National Council on Disability (2013).
- ³⁰ 42 CFR 438.6 <https://www.gpo.gov/fdsys/pkg/CFR-2012-title42-vol4/pdf/CFR-2012-title42-vol4-sec438-6.pdf>
- ³¹ Amendment Number 6 Statewide Contract between The State of Tennessee d.b.a TennCare and MCO, July 1, 2017. Section 2.29.1.3.41 and 2.29.1.3.42. <https://www.tn.gov/content/dam/tn/tenncare/documents/MCOStatewideContract.pdf>
- ³² <http://vayahealth.com/community/reinvesting-in-our-communities/#workforce-development>
- ³³ KanCare Program Medicaid State Quality Strategy. (June 2013). State of Kansas Quality Improvement Strategy Attachment J. p.91.
- ³⁴ Amendment Number 6. Statewide Contract between The State of Tennessee d.b.a. TennCare and MCOs, July 1, 2017. Section A.1. Definitions.
- ³⁵ <http://www.lifecoursetools.com>
- ³⁶ Burwell, B. and Kasten, J. *Transitioning Long Term Services and Supports Providers Into Managed Care Programs*. Prepared for the Centers for Medicare & Medicaid Services by Truven Health Analytics, May 2013. <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/Transitioning-LTSS.pdf>.
- ³⁷ *ibid.*, 15.
- ³⁸ <http://vayahealth.com/community/reinvesting-in-our-communities/#workforce-development>
- ³⁹ www.nci-ad.org

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