

# Coordinating Long-Term Services and Supports for Individuals Enrolled in Medicaid

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## INTRODUCTION

### Content Highlight

Managed care organizations (MCOs) are valuable partners to states as they seek to improve the delivery of services for populations in need of LTSS. Through a well-designed managed care approach, MCOs are able to enhance the delivery of coordinated, high-quality services and supports that help individuals stay in their homes and communities.

Medicaid plays an essential role in the delivery of long-term services and supports (LTSS) for those who have physical health and functional needs that result from cognitive disorders, mental health and/or substance use disorders (also collectively referred to in this paper as behavioral health conditions), or physical, intellectual or developmental disabilities. Broadly, LTSS includes services and supports that have the primary purpose of supporting individuals to live or work in the setting of their choice, which may include at the home, a worksite, nursing facility, or other residential or institutional setting.<sup>1</sup>

The delivery of LTSS has changed substantially over the years, from mostly institutional-based services to individuals receiving services in their own homes or in other community-based settings. This reflects the preference of most individuals to receive services at home or in their communities,<sup>2,3</sup> as well as a sustained commitment on the part of state and federal policymakers to provide individuals with increased choice in where services are delivered. This shift also reflects the impact of federal mandates such as the Americans

with Disabilities Act (1990), which established community integration as a civil right for individuals with disabilities. The impact of these changes was seen in federal fiscal year (FFY) 2013 when, for the first time, the proportion of public dollars spent on services delivered in the home and community exceeded that spent on services delivered in institutional settings.<sup>4</sup>

Despite this shift, policy and resource constraints continue to limit the ability of individuals with LTSS needs to access the array of services they need for optimal independence and integration into their communities. In recent years, many states have turned to managed care to design, build, and coordinate networks that deliver quality LTSS in ways that help Medicaid beneficiaries remain in their homes, increase their independence, live self-determined lives, and engage meaningfully in their communities.

Managed care organizations (MCOs) are valuable partners to states as they seek to improve the delivery of services for populations in need of LTSS. MCOs are well-positioned to address the challenges and barriers to LTSS that many Medicaid beneficiaries encounter in the fee-for-service (FFS) system. Through a well-designed managed care approach, MCOs are able to enhance the delivery of coordinated, high-quality services and supports that help individuals stay in their homes and communities. The shift to managed care can result in greater satisfaction for the populations using services, create opportunities for providers to function in the most coordinated manner, and achieve states' goals to serve Medicaid beneficiaries with high-quality care and services while operating under considerable budgetary constraints.

This paper will discuss the ways in which a comprehensive, integrated managed care approach can enhance and better coordinate the LTSS that Medicaid members receive while also achieving better outcomes for members, their families, and the Medicaid program.

## OVERVIEW OF POPULATIONS THAT COMMONLY USE LTSS

There are several populations who commonly require LTSS: older adults, adults with physical disabilities, individuals with intellectual disabilities and/or developmental disabilities (ID/DD), individuals with complex behavioral health conditions, and children with medical complexity.



### Older Adults

Older adults who receive Medicaid-funded LTSS are usually low income, age 65 and older, and have physical and/or cognitive functional needs. Demand for LTSS will increase as the Baby Boomer generation ages and will diversify as adults with intellectual or developmental disabilities grow older.<sup>5</sup> Additionally, the increasing number of older adults with Alzheimer’s disease and related dementias may eventually require services and supports (e.g., help with cooking or bathing) to address their cognitive needs and help them live safely in their homes and communities and delay or avoid nursing home admission.



### Adults with Physical Disabilities

Working-age adults (aged 21 to 64) may need LTSS if they have a disability resulting from illness or accident, acquired either as an adult or as a child. This can include spinal cord injury, traumatic brain injury, and other conditions that impact an individual’s ability to work or perform activities of daily living (e.g., bathing, dressing, running errands). According to the American Community Survey, approximately 2 percent of adults (age 21 to 64) have a visual disability, 2.2 percent have a hearing disability, and 5.5 percent have an ambulatory disability.<sup>6</sup> More than one-quarter (28 percent) of all working-age adults with a disability are living below the poverty line.<sup>7</sup>



### Individuals with Intellectual Disabilities and/or Developmental Disabilities (ID/DD)

Intellectual disabilities are generally characterized by significant limitations in both intellectual functioning – such as learning, reasoning, and problem solving – and in adaptive behavior, which includes social and practical skills. By definition, intellectual disabilities originate before the age of 18.<sup>8</sup> “Developmental disability” is an umbrella term that is more broadly defined to include intellectual disabilities as well as other cognitive and/or physical disabilities that manifest during the developmental phase, which is commonly considered to be before the age of 22, and are expected to be life-long.<sup>9</sup> Some developmental disabilities can be primarily physical such as muscular dystrophy; others may include both physical and intellectual disabilities such as Down syndrome.<sup>10</sup>



### Individuals with Complex Behavioral Health Conditions

Complex behavioral health conditions can include serious mental illness (SMI) (e.g., schizophrenia, bipolar disorder, or major depressive disorder<sup>11</sup>) or other conditions, with or without co-occurring substance use disorders that, individually or in combination, have an impact on one or more functional abilities. In 2014, an estimated 9.8 million adults (age 18 and older) had a mental health condition that significantly impaired function.<sup>12</sup> Functional limitations associated with complex behavioral health conditions, or psychiatric disabilities, can impede an individual’s ability to live independently at home and engage in the community. Additionally, individuals with complex behavioral health conditions often face challenges transitioning out of institutional settings due to a lack of supports and services to help them live independently at home.



### Children with Medical Complexity

Children with medical complexity, also considered “medically fragile,” generally have “intense medical needs that result from multisystem disease states, technology dependence, or complex medication regimens.”<sup>13</sup> Their diagnoses vary, though they typically have functional needs that require multiple medical and non-medical services including LTSS. Examples include children with congenital or acquired multisystem disease, severe neurologic conditions with marked functional impairment, or cancer and ongoing disability in multiple areas.<sup>14</sup> Many of these children are dependent on technologies such as ventilators, renal dialysis, or enteral feeding tubes.

## FUNDING OF LONG-TERM SERVICES AND SUPPORTS

### Content Highlight

Medicaid-funded LTSS comprises nearly one-third of all Medicaid spending. As the delivery of LTSS has steadily shifted from institutional settings to home and community-based services (HCBS), so too has Medicaid spending.

Public and private spending for LTSS in the United States was \$310 billion in 2013, with Medicaid covering about half of the total.<sup>15</sup> While the focus of this paper is on paid or “formal” LTSS, most LTSS are provided by family or “informal” caregivers and other natural supports. The value of informal caregiving is estimated at approximately \$522 billion annually.<sup>16</sup>

Medicaid-funded LTSS comprises nearly one-third of all Medicaid spending.<sup>17,18</sup> As the delivery of LTSS has steadily shifted from institutional settings to home and community-based services (HCBS), so too has Medicaid spending. In 2013, for the first time, the proportion of public dollars spent in HCBS settings exceeded that spent in institutional settings.<sup>19</sup>

### Spending by Population (FFY 2013)

- **Older Adults and Adults with Physical Disabilities:** Total spending on LTSS for older adults and adults with physical disabilities was \$88.8 billion, with \$53.2 billion of that spent in nursing facilities.<sup>20</sup> HCBS comprised 40 percent of total LTSS expenditures for these populations nationally.<sup>21</sup>
- **Individuals with ID/DD:** Total spending on LTSS for individuals with ID/DD was \$42.9 billion, with \$11.9 billion of that spent in intermediate care facilities for individuals with intellectual disabilities (ICF/IID).<sup>22</sup> Medicaid-funded HCBS comprised 72 percent of total expenditures for individuals with ID/DD nationally.<sup>23</sup>
- **Individuals with Complex Behavioral Health Conditions:** Total spending for Medicaid-funded LTSS for individuals with behavioral health needs<sup>24</sup> specifically was \$9.2 billion, with \$5.8 billion of that spent in mental health facilities.<sup>25</sup> HCBS comprised 36 percent of total expenditures for these populations nationally.<sup>26</sup>
- **Children with Medical Complexity:** LTSS spending for children with medical complexity is challenging to estimate. Medicaid data available do not clearly distinguish spending for these children as a standalone population. Some states have established 1915(c) waivers specifically for children considered medically fragile or technology dependent; there are 17 waivers in 16 states currently in place nationally, with an associated \$204.3 million in spending.<sup>27</sup>

Recent data indicate **managed care spending** for LTSS (also referred to as managed LTSS, coordinated LTSS, or MLTSS) totaled \$20.5 billion, accounting for 15 percent of total Medicaid LTSS expenditures. While modest in proportion to total spending, this amount has nearly quadrupled since FFY 2008. MLTSS spending has grown as states seeking to leverage managed care arrangements to improve service delivery and outcomes moved from regional to statewide MLTSS and others adopted managed care strategies to integrate services across Medicare and Medicaid for dually eligible individuals.<sup>28</sup>

Approximately 17 percent of Medicaid spending for older adults and adults with physical disabilities can be attributed to MLTSS as compared to roughly 6 percent of Medicaid spending for the ID/DD population.<sup>29</sup> Several states cover services for individuals with mental health and substance use disorders within managed care but MLTSS spending for this population is not currently available.



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## DELIVERY OF LONG-TERM SERVICES AND SUPPORTS: BARRIERS AND CHALLENGES INHERENT IN THE FEE-FOR-SERVICE SYSTEM

### Content Highlight

The FFS system presents policy and resource constraints that limit the ability of individuals with LTSS needs to access the array of services they need for optimal independence and integration into their communities. Many states have turned to managed care to design, build, and coordinate networks that deliver quality LTSS in ways that help Medicaid beneficiaries remain in their homes, increase their independence, live self-determined lives, and engage meaningfully in their communities.

Demand for publicly funded LTSS is growing in the United States, due to both demographic trends and policy shifts that are changing the way services are provided and financed. Historically, Medicaid-funded LTSS were primarily paid for on a fee-for-service (FFS) basis, even in states with large Medicaid managed care programs. The heavy reliance on FFS health and supportive services delivery systems reflects complexities in the financing and delivery of services for these high-cost populations (especially the frequent presence of “dual eligibility” for both Medicare and Medicaid coverage). States also have been reluctant to move to managed care due to the concerns of individuals, advocates and providers that traditional managed care models might introduce a “medical model” in place of the person-centered, non-medical culture of services and supports that has been the hallmark of the LTSS system, especially in community-based systems of care.

In Medicaid FFS, the delivery of HCBS through waiver programs (e.g., 1915(c) waivers) or as part of State Plan benefits (e.g., 1915(i) or 1915(k)) shares some of the same features of a managed care approach to LTSS, though in a less comprehensive manner. The Medicaid program has refined the model of service delivery for HCBS to include a person-centered approach to care planning, as written into statute and regulations.<sup>30</sup> HCBS programs offer service coordination for LTSS as a central function. Coordinators perform a comprehensive assessment to identify the individual’s needs; they then use this information to

help the individual set priorities and goals for how they want to live their life. They assist the individual or their representative to develop a person-centered care plan that is derived from input provided by the individual during the assessment and which should include representatives chosen by the individual to participate on their team. Furthermore, there is an expectation of coordination across the home and community-based LTSS provided to the individual.

However, FFS has also been associated with misaligned incentives, access issues, inefficiencies, and service fragmentation for people with disabilities, older adults, and individuals with specialized health care needs. For instance, a FFS provider may offer service coordination while at the same time offering LTSS services, presenting potential conflicts of interest in the development of the care plan and selection of who provides the services to the member. Below are some of the key barriers and challenges to delivering the most effective LTSS that are inherent in the FFS system.

**LTSS typically are delivered in their own “silo,” separate from physical and behavioral health services, which can result in a fragmented and uncoordinated system of care.**

Fragmentation is inherent in the FFS system, due to the varied programs (e.g., State Plan benefits, waivers, etc.) and funding sources with different eligibility rules, benefit structures, and provider sets. In addition, there is no single entity that coordinates care across these programs and funding sources for the eligible population.<sup>31</sup> Individuals who need LTSS often have physical and/or behavioral health conditions and struggle to obtain the full complement of services they need. The fragmented nature of the FFS system is inefficient in meeting all the care and support needs of individuals. This can result in poor health outcomes and diminished quality of care. For example:

- Individuals with ID/DD often have behavioral health needs that get overlooked by providers who may not have the necessary training to identify them or a referral system to get individuals to proper treatment.
- Older adults and younger adults with disabilities who are dually eligible for Medicare and Medicaid, as well as their families, must navigate not one, but two, convoluted delivery systems, with two different sets of rules that are sometimes misaligned, further increasing the risk of poor outcomes.
- Children with medical complexity and their families interact with many different systems and providers such as schools, maternal and child health agencies, and the medical and supportive services delivery systems. This often results in multiple entities trying to manage their care, with either duplication of or gaps in services.
- Many individuals living with chronic or disabling conditions also experience unmet social needs, from food insecurity or housing instability, to the need for assistance in obtaining and maintaining employment, to challenges of isolation and segregation, which can increase health care costs and result in poorer health outcomes and reduced quality of life.

There is a growing consensus that treating individuals' physical health, mental health, substance use disorders, and other clinical needs in silos does not yield optimal outcomes.<sup>32,33</sup> Further, the broader system in which services are provided—including health and social services, child welfare, schools, and vocational rehabilitation, among others—is also highly fragmented. This can reduce the effectiveness of medical services when the social determinants of health are not effectively addressed in a holistic manner by the system.

#### **The traditional delivery model creates barriers to accessing the full array of services and supports an individual needs to attain community living and inclusion.**

The LTSS system has evolved over time, and states' approaches to the delivery of services have generally been developed by one program or for one identified population at a time. This results in a patchwork of services and different sets of benefits across populations with the same functional need. Further, because the federal statute exhibits a fundamental institutional bias (i.e., nursing facility services are mandatory Medicaid benefits, while HCBS benefits are optional), the fragmentation of service delivery may result in missed opportunities to serve eligible individuals in the most integrated setting.

As a result of the institutional bias inherent in the delivery of Medicaid-funded LTSS, and because Medicaid HCBS waivers allow states to cap enrollment, many states have lengthy waiting lists to access HCBS. Recent data reveal that almost 350,000 individuals with ID/DD, nearly 170,000 older adults and adults with physical disabilities, and over 58,000 children are on waiting lists to access HCBS through Medicaid 1915(c) waivers.<sup>34</sup> Some individuals may remain on waiting lists for years before they can access these benefits, placing them at significant risk of institutionalization.

#### **The FFS system does not fully incentivize a person-centered model of care delivery.**

The current FFS delivery system is not person-centered in a holistic way, meaning it is not fully organized around the needs and preferences of the individual across physical health, mental health, substance use disorders, and LTSS. Most importantly, the current contracting and financial structures in FFS do not encourage providers to work in a collaborative, person-centered manner outside the HCBS system; for example, there are few if any financial incentives to coordinate benefits across physical health, behavioral health, and LTSS providers. Too often, physical health care needs are addressed in isolation of behavioral health and community-based service needs, and LTSS, which are to be planned and delivered in response to an individual's goals and preferences, are not developed in consideration of other health care needs. This fails to fully leverage the value of LTSS in improving the outcomes of physical and behavioral health care treatment and outcomes.

Further, the option of self-direction<sup>35</sup> is fundamental to a person-centered model of service delivery that respects individual choices and control. While self-direction is a part of LTSS programs in many states, individuals may not have all the tools and resources necessary to exercise self-direction under a FFS system. Self-direction empowers individuals to directly manage their LTSS services. A successful self-direction program requires supports for individuals (e.g., training, assistance with handling payroll responsibilities) to enable more individuals to participate. The FFS system may lack the flexibility or incentives to identify and offer benefits that would sufficiently address gaps in service and make self-direction more meaningful, manageable, and ultimately more person-centered for individuals and their families.

## Medicaid LTSS are not coordinated effectively with the broader system of care, including non-medical transportation and housing, employment and educational supports.

Housing, employment, educational, and non-medical transportation supports are essential to sustaining community integration and making it possible for individuals with LTSS needs to meet their goals and achieve a high quality of life. Individuals of all ages with LTSS needs—including individuals with ID/DD, children with medical complexity, adults with physical disabilities, older adults who have cognitive needs and face the physical challenges of aging, and individuals with complex behavioral health needs seeking supports in recovery—will need lifelong support to fully engage in their community.



- **Housing supports**, including supportive housing services and access to affordable and accessible housing, are integral to full participation in the community and optimal health and well-being. As guided by statute, Medicaid does not cover the costs of room and board, with limited exceptions.<sup>36</sup> However, appropriate housing supports enable individuals to remain in the community or to transition from institutional settings back into the community. Connecting an individual with housing services and supports can make it possible for individuals to use more cost effective settings of care in the community instead of more costly institutional settings.



- **Employment supports** such as job training, assistance with finding and maintaining a job, and identification and coordination of assistive technologies to support work productivity are examples of the types of services needed to lead a productive and healthier life for some LTSS populations. Previously, the Vocational Rehabilitation Act of 1973 (VRA) established vocational training programs for people with disabilities. The Workforce Investment Opportunity Act of 2015 (WIOA) superseded the VRA and included stronger employment supports, especially for youth with disabilities, that focus on achieving integrated, competitive employment. While Medicaid does not pay for services available under WIOA, Medicaid services can be important additional resources for individuals who may require assistance in accessing these benefits or require supports to prepare them for competitive employment.



- **Educational supports** are critical to helping individuals achieve their goals. The Individuals with Disabilities Education Act (IDEA) ensures that individuals with disabilities have access to a free, public education with the necessary accommodations. Just as with employment supports, individuals may need assistance in accessing available services and ensuring that the school system is being responsive to their needs.



- **Non-medical transportation** is essential to facilitating community access for some individuals with LTSS needs. This includes going to school or work, and engaging in church, volunteer, or other community activities. While non-emergency medical transportation is a mandatory Medicaid State Plan benefit, non-medical transportation may only be available through HCBS waivers and, even then, is not universally provided across all waiver programs. Often the implementation of a service plan may fall short if the supports cannot be accessed due to transportation barriers. Non-medical transportation is an essential element to ensuring the individual can achieve their goals, remain connected to the community, and minimize social isolation.

In many states, Medicaid HCBS and other services are available to work in tandem with or to wrap-around the services provided by other community organizations in these crucial areas. However, the lack of coordination, insufficient availability, and the siloed nature of these services in the FFS system create challenges for individuals with LTSS needs to access community living opportunities and live independently. Too often, no single entity holds responsibility for assuring that services are coordinated across programs to increase health outcomes and quality of life for individuals.

## MANAGED CARE CAN IMPROVE THE EXPERIENCE OF INDIVIDUALS USING LTSS

### Content Highlight

States are seeking better ways to deliver Medicaid services to support community living while meeting high quality standards and achieving efficiencies. MLTSS presents the opportunity to deliver value to Medicaid beneficiaries, providers, and the state, by providing a comprehensive approach that addresses the challenges presented in the FFS system and enhances the delivery of LTSS and the experience of individuals who rely on those services and supports.

States are seeking better ways to deliver Medicaid services to support community living while meeting high quality standards and achieving efficiencies. MLTSS presents the opportunity to deliver value to Medicaid beneficiaries, providers, and the state, by providing a comprehensive approach that addresses the challenges presented in the FFS system and enhances the delivery of LTSS and the experience of individuals who rely on those services and supports. Far from bringing a medical model to LTSS, MCOs have developed the capacity to build on a person-centered approach to LTSS to promote a holistic and creative approach to individual choice, community integration, and improved health outcomes. MCOs have embraced the strengths-based approach to service planning and delivery, reflecting an individual's goals and preferences as well as needs in the care plan, and reaching beyond just LTSS to incorporate physical health, mental health, substance use disorders, and social supports in their approach to care.

Currently, 39 states operate comprehensive risk-based managed care programs through MCOs.<sup>37</sup> Historically, individuals with LTSS needs and/or their LTSS benefits were often “carved out” of state Medicaid managed care programs. Today, many states are reconsidering this policy decision and are establishing MLTSS programs where MCOs receive capitated monthly payments to deliver defined LTSS benefits to individuals while meeting quality standards. As of 2015, 22 states

provide at least some LTSS under managed care contracts for one or more populations eligible for these benefits; another five states plan to implement MLTSS programs in the next two to three years.<sup>38</sup> Four states reported that most home- and community-based LTSS are delivered by MCOs.<sup>39</sup>

### Integrate LTSS with the Broader Array of Physical and Behavioral Health Services

Many health plans have built a model of care management that adopts a holistic approach, linking the full array of health and supportive services. This approach reflects an understanding that individuals with LTSS needs often have multiple co-occurring chronic conditions (e.g., physical health needs, mental health conditions, and substance use disorders) and that individuals with multiple health needs are at higher risk of poor outcomes, including hospital and nursing facility admissions. For example, a recent survey found that nearly three-quarters of individuals with ID/DD have two or more chronic conditions; roughly 40 percent report four or more chronic conditions.<sup>40</sup> Addressing the needs of an individual in a comprehensive manner can reduce utilization of high cost institutional settings, reduce costs of care, improve quality of care, enhance health outcomes, and promote community engagement among individuals.

Functional needs are highly associated with increases in physical health costs.<sup>41</sup> When functional needs are not met, individuals may end up in the emergency room or admitted to a hospital. For example, falls are responsible for approximately 85 percent of all injury-related hospitalizations among individuals age 65 and over,<sup>42</sup>

**Addressing the needs of an individual in a comprehensive manner can reduce utilization of high cost institutional settings, reduce costs of care, improve quality of care, enhance health outcomes, and promote community engagement among individuals.**



## Working with Members and Their Caregivers to Maintain Community Living

“Emma” was on the verge of admission to a nursing home. Her granddaughter, a single parent, worked nearby and attempted to visit and care for her as often as possible. Despite her granddaughter’s assistance, Emma sustained frequent falls and suffered a broken arm. Concerned about her grandmother’s health and increasing frailty, she reached out to Emma’s home care agency for help.

A field case manager with the Amerigroup health plan in New Jersey received the agency’s referral and served as the primary point of contact with the health plan. The case manager reviewed Emma’s medical history, provider documents, and spoke with Emma and her granddaughter to understand Emma’s medical needs. The case manager learned Emma had been spending most of her time in bed, had a history of complications from diabetes—including ulcers and nerve damage—and was starting to experience periods of confusion, which limited her ability to care for herself. Emma was receiving personal care assistance and was regularly traveling to routine doctors’ appointments but was having trouble with daily activities. The family felt strongly that they wanted Emma to maintain the comfort and independence of home.

Based on the evaluation and the family’s wishes, the health plan team increased Emma’s hours of personal care assistance to the maximum amount allowable, worked with the home care agency to make certain changes that would take effect immediately and to ensure Emma had all the supplies she needed, and followed up with Emma’s doctor. They also offered any ongoing assistance that Emma and her granddaughter might need—including scheduling any appointments or services. By listening to the granddaughter’s concerns and evaluating Emma’s health history and current social supports, the case managers were able to work together to provide Emma with a care plan that best addressed her health needs and personal preferences—living in her own home and avoiding transfer to a nursing home.

Source: Program information from the Amerigroup health plan in New Jersey.  
Note: Names are fictitious to protect the identity of the member.

and contribute to more than 40 percent of nursing facility admissions. There is also a documented association between poor medication adherence and risk of falling.<sup>43</sup> MCOs have a holistic understanding of an individual’s medical conditions, use of medications, and current physical and cognitive function, allowing them to develop a comprehensive service plan with the member that focuses on safety, addresses medical needs, and mitigates risks including falls. This begins with a comprehensive face-to-face assessment as part of a person-centered service planning process. The service coordinator is able to be in the home, monitor firsthand an individual’s physical and cognitive capacity, get to know informal caregivers, and learn directly from an individual his or her goals, needs and service preferences. The result is a service plan that addresses the individual’s needs and preferences with respect to physical health, mental health, substance use disorders, and LTSS. New federal Medicaid regulations have raised the bar on conflict free assessments and person-centered service planning for HCBS, and MCOs are well-positioned to meet those expectations.<sup>44</sup>

In the example of an older adult with multiple medications or poor medication adherence, complex medical conditions, and a risk of falls, the MLTSS service coordinator is able to offer an array of resources to support all of the member’s health care needs—not just their LTSS needs. The LTSS service coordinator also reaches out to the member’s physical health and/or behavioral health case managers to ensure all of the member’s needs are addressed. For example, a service coordinator might recommend home modifications, engage a pharmacist to review the medications being prescribed to eliminate negative drug inter-

actions, and order physical therapy to increase strength to prevent a fall. The value of MLTSS is in its capacity to respond to an individual’s multifaceted needs in a comprehensive way that crosses the traditional “silos” of physical health, behavioral health, and LTSS.

MLTSS also offers a particularly effective framework for supporting children with medical complexity and their families. The needs of these children evolve substantially as they grow and transition to different stages of development. Initially, service coordination focuses on the needs of parents of an infant who is medically fragile to ensure they are well-prepared to address the needs of their child, which will be predominantly medical at this time. As the child grows and develops, however, service

coordination addresses the changing set of broader social support needs in addition to any ongoing or new physical and/or behavioral health needs. Having service coordinators who are able to follow the child throughout their development from infant to adolescent and transition into adulthood is highly valuable but not always possible depending on how a state structures eligibility criteria for LTSS services in the FFS system. MCOs can best support medically fragile children as they grow—creating an environment that encourages children and families to articulate their own preferences for care and working with children and families to integrate LTSS to the fullest extent within their home, school, and social environments.

As a member's needs evolve and expand, MCOs adapt as well—providing flexible support at every turn. For example, a young adult with cerebral palsy enrolled in the Amerigroup health plan in Kansas was attending college out of state on a scholarship. After about a year and a half, the payroll agent that initially agreed to pay for the member's personal care attendants while she was out of state decided to stop offering the services. The health plan's LTSS program director and targeted case manager worked closely with the member and her family to identify another payroll agent willing to do so and put in place the resources the member needed to remain in school. In order to get the new arrangement in place and maintain the member's independence, the health plan stepped in to cover the additional costs associated with out-of-state services and supports. Working as a cohesive team, the health plan helped the member and her family navigate the complicated health care system and brought her the services and supports she needed to help her achieve her life's goals.<sup>45</sup>

### Enhance Community Integration for Individuals with LTSS Needs

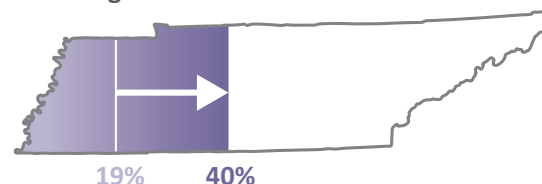
By accessing and coordinating all benefits through a single entry point, the MCO is well-positioned to reduce fragmentation and inappropriate utilization of institutional settings of care. For example, prior to the implementation of MLTSS in Tennessee, a large percent of the population needing LTSS was served in institutional settings. Between 2010 and 2013, the Amerigroup health plan in Tennessee was successful in increasing access to HCBS—increasing the percent of members receiving services in the community from 19 percent to 40 percent while reducing the percent of members in nursing facilities from 81 percent to 60 percent.<sup>46</sup>

This success can be directly attributed to the health plan's focus on diversion and transition. Health plan members who are receiving services in the community are carefully monitored for changes in their health care needs that could lead to a hospitalization or admission to a nursing facility. The MCOs' service coordinators work with the primary care provider and HCBS providers to ensure the individual's needs are met and conditions are monitored; they are able to bring more resources to bear, when needed, to avoid an institutional transfer. For those who are admitted to the hospital, the plan works closely with the hospital, primary care provider, and family to discharge the individual home with services, rather than to a skilled nursing facility. In addition, the health plans assesses every individual in an institutional setting as a candidate for transition to the community. There are transition experts on staff who partner with service coordinators across the state and engage the individual, the family and other natural supports, and providers to start early in planning for transition to the community.<sup>47</sup>

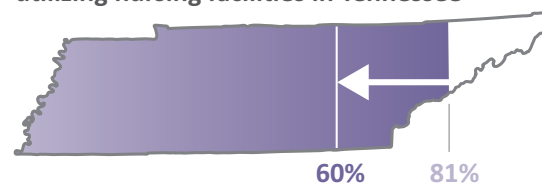
Many states are engaging an MLTSS strategy to accelerate transformation of the delivery system to deemphasize institutional care and center the delivery system on the home and community. Under FFS systems, individuals who have LTSS needs may have to access services in institutional settings or go without needed care when HCBS waiver slots are filled. MCOs have the flexibility to effectively expand access to HCBS outside of the waiver slot structure. Depending on the state Medicaid program, MLTSS can offer "waiver-like" or enhanced services to individuals who may not have access to waivers, resulting in increased access to HCBS that would not otherwise be available under FFS.

**Between 2010 and 2013, the Amerigroup health plan reduced fragmentation and inappropriate utilization of institutional settings in Tennessee.**

**21 percentage-point increase in members receiving services from HCBS in Tennessee**



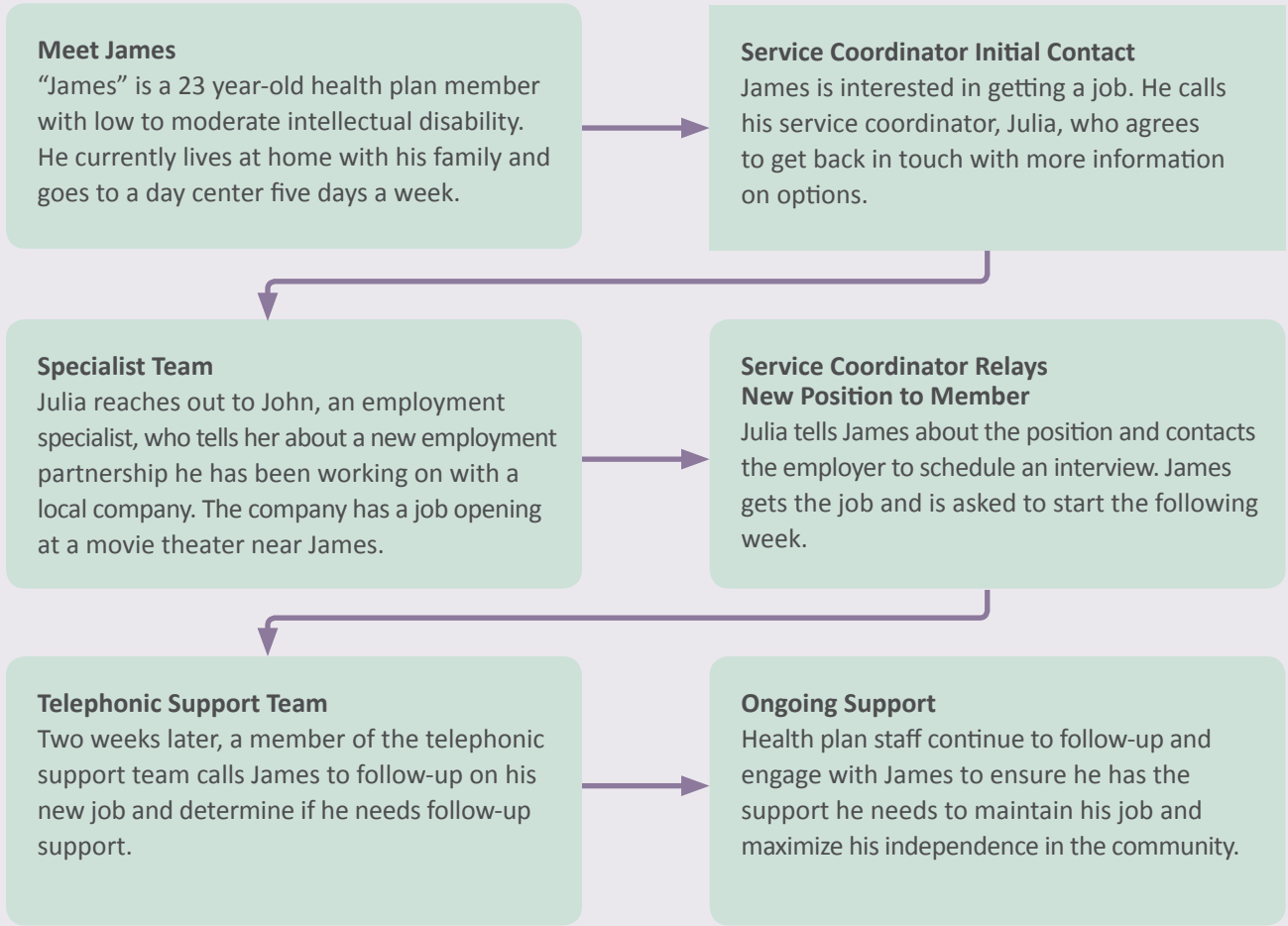
**21 percentage-point decrease in members utilizing nursing facilities in Tennessee**



Facilitating true community inclusion for individuals needing LTSS requires coordinating with community supports that may not be directly covered by Medicaid. In particular, individuals with LTSS needs often require access to housing, employment or educational services, and non-medical transportation to enhance community participation and live independently. Although Medicaid does not reimburse for most of these services, a successful service delivery system must be able to coordinate across all these resources. And, under a capitated managed care arrangement, MCOs have the flexibility to go beyond certain FFS limitations in order to assure the most effective approach to achieving each individual’s person-centered plan goals.

The person-centered planning process for individuals with LTSS needs can identify for whom employment is a goal. Through coordination with businesses, supported employment, and vocational and/or educational programs operated by other state and nonprofit agencies, the service coordinator can begin to pull together necessary resources to help the individual in meeting that goal. MCOs can help members take advantage of services and supports in the community, such as vocational rehabilitation services, and make sure that Medicaid services, including employment supports, are available on a timely basis to avoid any disruption in health care or employment. For example, service coordinators with the Amerigroup health plan in Kansas work directly with state agency staff and other partners to facilitate member transportation to and attendance at meetings with vocational rehabilitation, which heighten job opportunities and support members’ transition to employment.<sup>48</sup> Furthermore,

### Working to Facilitate Employment Opportunities in the Community for Members with LTSS Needs



Note: Names are fictitious for the purposes of this illustrative example.

MCOs engage in partnerships with Medicaid Buy-in programs,<sup>49</sup> which can offer eligible individuals the ability to retain Medicaid coverage while they work. MCOs providing comprehensive MLTSS can enhance children's success in meeting their goals while also creating a more coordinated, efficient service system in the community. One critical area where MCOs can support children and their families is the coordination of appropriate school-based services available through the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973, or the Americans with Disabilities Act (ADA).<sup>50</sup> Through MLTSS, MCOs can coordinate with the school system to help children with medical complexity receive necessary services and supports at school that are integrated into their overall medical support plans, as well as their individual education plans (IEPs). MCOs are also practiced in engaging family and other supports in these efforts and can engage them early in a child's school experience. Further, MCOs help transition young adults to community-integrated options like integrated competitive employment.

### Helping a Member Transition to the Community and Get the Care He Needs

A 22-year-old member of the Amerigroup health plan in Kansas, who was diagnosed with Huntington's disease and a cancerous tumor, voluntarily remained at the jail post-release, having been left homeless after his mother passed away. The health plan knew more could be done to help this member live in the community with appropriate resources. His health plan care coordinator guided him through the eligibility process for waiver services and facilitated access to the various long-term services and supports he needed. Through a coordinated effort, the health plan team was able to move him to the community and into a stable home while ensuring he receives integrated care and support to help him live as independently as possible.

Source: Program information from the Amerigroup health plan in Kansas.

Managed care plans also promote integrated community living opportunities by coordinating and connecting individuals to housing resources. This is a critical area where MCOs add value to the Medicaid program and enhance the delivery of LTSS. As an example, adults with physical disabilities are more likely to reside with unrelated individuals and they are also 4.5 times more likely than others of a similar age without disability to live in public or subsidized housing.<sup>51</sup> Housing arrangements may be tenuous and there is significant need for assistance in identifying accessible and affordable housing options. Because room and board is not a covered benefit under Medicaid, there may be little help with navigating housing services for Medicaid beneficiaries in FFS arrangements. Service coordinators within MCOs are well suited to monitor a member's housing status and provide support to identify viable housing options when needed, since housing instability can increase the risk for institutionalization. Leveraging the experience and expertise of MCOs when it comes to coordinating and accessing community resources will become increasingly important as federal grant programs that have been instrumental in supporting state efforts in this area expire over the next couple of years, if they are not reauthorized (e.g., Money Follows the Person and the Balancing Incentive Program).

### Achieve Better Outcomes for Members

One of the most important contributions of MCOs is their ability to bring the best and most promising practices to MLTSS programs.

- MCOs are implementing technologies that can support the member and caregivers within the home as part of the care plan such as medication reminders, personal emergency response systems, real-time information on service delivery, and other technologies that can support remote monitoring. Several MCOs are piloting innovative web-based solutions for in-home provider documentation, real-time sharing of information, and a solution to connect members with direct support workers with skills that match the member's individual needs.
- MCOs can deliver new and innovative solutions to improve HCBS and help individuals with LTSS needs live independently and fully participate in their communities. For example, after a leg amputation below the knee due to vascular disease, a health plan member needed help with her transition home from the skilled nursing facility. The health plan care coordinator, in addition to assisting the member with her personal care and medical service took an innovative approach to helping the member live in the community. The care coordinator arranged for a home modification grant and labor from Habitat for Humanity to make the member's home safe and wheelchair-accessible.



**Within MLTSS, MCOs have the flexibility to provide services that may not be part of the state plan covered benefits, but that will have a direct benefit for the member.**

- MCOs implement best and promising practices in cultural and linguistic competence. MCOs operating MLTSS programs are adopting practices that lead to person-centered planning and practices, positive behavioral supports, and dedication to home and community-based service delivery. When an MCO better understands and communicates with a member about his/her preferences and needs, the result can be enhanced member engagement, improved adherence, and higher member satisfaction.

Within MLTSS, MCOs have the flexibility to provide services that may not be part of the state plan covered benefits, but that will have a direct benefit for the member. For example, the service coordinator works with a member who has been admitted to a hospital to facilitate transition back into the community with HCBS and other benefits, such as deposits on utilities, essential furniture or kitchen equipment, or grab bars in the bathrooms for accessibility. This enhanced coordination of services and supports can help ensure that the member returns home successfully and avoids transfer from the hospital to a skilled nursing facility or readmission to the hospital. In addition, most MCOs offer nursing facility transition services, in close collaboration with HCBS service providers, which may help facilitate the individual returning to the community sooner—expanding on the capacity of Money Follows the Person by providing enhanced benefits that are not reimbursable under Medicaid and maintaining these options once the time-limited federal grant program expires.<sup>52</sup>

Informal, or unpaid, caregivers—typically family members—are critical assets in supporting and advocating for individuals with LTSS needs. Family caregivers offer natural supports that ultimately save state program dollars, yet they need support in order to maintain their family environment and caregiving role. For example, 71 percent of the ID/DD population lives with a family caregiver and 25 percent of family caregivers are age 65 or older.<sup>53</sup> These data emphasize the growing importance of supporting parent and sibling caregivers.<sup>54</sup> MCOs are well-positioned to address the needs of the primary caregiver and family members, in addition to the individual.

- Significant predictors of institutionalization among older adults, particularly those with cognitive impairment, are the amount of time a caregiver spends taking care of the individual and the caregiver’s own self-reported health status.<sup>55</sup> Spouse caregivers often have their own health care issues, and adult child caregivers of older adults must balance not only caring for their parent(s) but also often raising their own children and attending to their professional work responsibilities. One out of every nine individuals over age 65, and one out of every three individuals age 85 and older, has Alzheimer’s disease or related dementia (ADRD).<sup>56</sup> Caring for an individual with ADRD requires a unique set of supports, and a caregiver’s needs must be considered. MCOs support training to help a loved one understand the course of dementia so they are more emotionally prepared for their caring role. MCOs can also provide necessary respite even above the limits available through the State Plan to support the caregiver continuing in that role.
- When babies are born with serious medical conditions, there is tremendous need for immediate support and coordination for both the child and parents. The baby is extremely vulnerable during the early period of life, and the parents are usually unprepared emotionally and unaware of the myriad requirements to establish their home environment. Service coordinators are trained to engage from “day one,” while the family is still in the hospital, to support, educate, and assist the parents and other caregivers in understanding the baby’s needs; arrange and coordinate the supports and services for after discharge; and follow up to ensure the baby, family, and caregivers are adequately supported. This creates the environment necessary for the parents to gain confidence in caring for their child and helping the child thrive.

Through MLTSS, the member’s caregivers and the service coordinator work together to ensure the person-centered service plan meets the needs of the member as well as the family members. Several health plans are operating a pilot program that facilitates information sharing between a member’s unpaid caregiver and the health plan care manager; knowing more about the unpaid care a member receives can help build support for the member and their caregiver and tailor the other services and supports that the health plan provides.

The service coordinator can also evaluate caregiver strengths and needs for support, offering information, education, training, communications and problem solving, where appropriate. For example, the Amerigroup health plan in Kansas supports caregivers

by offering additional respite care, overnight respite care, and additional personal assistance services for members who qualify,<sup>57</sup> extending the existing level of coverage for these LTSS services beyond that which is covered in their monthly capitation payment from the state. Many health plans are conducting assessments of the informal caregiver's ability to continue providing care and barriers that may exist to their capacity to do so.

In addition, formal (paid) caregivers, such as personal care assistants, may also benefit from additional training and other supports that the service coordinator can identify and arrange to ensure the delivery of high quality care.

### **Provide an Accountable Structure for the Delivery of High-Value LTSS**

Managed care contracts between the state and the MCO create an effective structure of accountability for quality improvement and achieving a state's policy goals. Stakeholder engagement is a critical first step in developing a structure for the delivery of MLTSS that is accountable to members. MCOs must partner with states to engage stakeholders during the planning and implementation phases of MLTSS. In addition, plans should and are often required to establish a Member Advisory Council to provide advice and feedback regarding member experience once the program "goes live." In doing so, they can help to alleviate the concerns stakeholders may express as part of the planning and implementation of MLTSS. In fact, many MCOs set up these advisory councils prior to going live, in order to inform policy decisions and ensure person-centered processes.

One of the most tested approaches to value-based purchasing in Medicaid is the capitation payment (e.g., a single payment per member per month) established by the state for MCOs that covers all contractually required services and benefits for an individual. In establishing a capitation rate, states can choose to pool dollars across silos of the delivery system (e.g., HCBS, institutional settings, physical health, mental health and substance use disorder services, etc.), which encourages flexibility in how the MCO supports a service package that meets individuals' needs and preferences. By aligning incentives financially, the state engages the plan as a partner in achieving important policy goals. Further, by establishing prospectively paid capitated rates, states may be able to achieve better budget predictability.

Establishing clear performance expectations in the contract, linking financial incentives to performance, and requiring public reporting are just some of the ways in which states leverage managed care arrangements to improve accountability in the Medicaid program. The state's program goals can be contractually defined in the managed care relationship in ways that far exceed what states have been able to structure in the FFS LTSS delivery system. This is particularly important in ensuring the effective coordination of LTSS across the broader delivery system.

Quality measure development in LTSS (and specifically in HCBS<sup>58</sup>) is still evolving nationally. As CMS and states continue to develop standard measures of quality in LTSS, MCOs provide states with an infrastructure to systematically pursue quality improvements. All states require MCOs to develop comprehensive quality strategies, measure performance, and develop performance improvement projects (e.g., increase the use of adult day services).<sup>59,60</sup> This creates another opportunity to ensure that service providers are accountable to the state's quality and policy goals, and allows states to leverage MCO capacity to improve provider oversight while reducing state administrative burden.

MCOs can enhance an MLTSS system by evaluating key LTSS-specific measures, such as: rate of transitions from institutional to community-based care; avoidance of placement in an institutional setting; ratio of placement in an institutional setting to HCBS placement; readmission to a nursing facility within 60 days of discharge; mortality; emergency room use; meaningful employment; timely resolution of incidents; and measures of case management effectiveness including person-centered planning measures. In addition, many health plans regularly track and analyze other quality data, including grievances and appeals data, critical incidents, provider and member satisfaction surveys, and utilization data. Plans are also increasingly tracking measures related to quality of life.

MCOs also facilitate innovation and accountability in provider network development and reimbursement. Flexibility in approaches to reimbursement can encourage provider engagement in MLTSS to improve access to critical providers. MCOs are well-practiced in establishing incentive programs that reward providers for quality improvement and increased access for Medicaid enrollees in their traditional domain of physical health coverage. There are growing examples of similar value-based purchasing for managed behavioral health care. The partnerships developed between states and MCOs can create a similar framework for value-based purchasing in LTSS, which is still in its nascent stages. Plans that have experience in states that have already implemented MLTSS can shorten the learning curve around value-based purchasing in a new state.

## DESIGN PRINCIPLES FOR A SUCCESSFUL MLTSS PROGRAM

### Content Highlight

MCOs are well-positioned to support states and their Medicaid beneficiaries in achieving the vision of a high-quality and efficient LTSS delivery system.

The overarching goals of a Medicaid MLTSS program are to best meet the everyday support needs and preferences of individuals and their families and to partner with states in building sustainable, community-based service systems that meet specific state needs. A successful managed care program integrates and increases access to high quality services and supports within a more efficient, streamlined delivery system. The success of MLTSS depends on complete service integration and a commitment to person-centered solutions. Further, from the state perspective, a successful MLTSS program produces better outcomes for members while also producing value from an administrative perspective, including budget predictability. As more

states move in the direction of fully integrated managed care for all services and supports for individuals needing LTSS, the following recommendations can guide their efforts.

### Create Flexibility in Program Design to Meet Individual Needs and Preferences

As described in an earlier section, individuals who commonly rely on LTSS (e.g., older adults, adults with physical disabilities, individuals with ID/DD, individuals with complex behavioral health needs, and children with medical complexity) all have diverse aspirations, needs, and preferences that extend beyond the covered services for which they qualify. It is an MCO's responsibility to meet members where they are, understand their goals for their lives, and work with them to figure out how to achieve those goals with the array of available resources. This kind of person-centered approach to service delivery requires creativity as well as a deep knowledge of the community in which the member lives and the full array of services that are available. When the MCO contract contains a range of benefits that address the needs of the individual in a person-centered and holistic way, there is much greater potential to achieve improved member outcomes and value.

### Engage the Broad Range of Stakeholders

Programs and providers serving individuals with LTSS needs are typically and necessarily local. The success of any managed care program hinges on the development of strong and trust-based relationships with advocates, providers, and other stakeholders in the communities where managed care will be implemented. MCOs delivering MLTSS develop and build on stakeholder relationships as well as enhance training, education, and supports to providers and other stakeholders.

States that are implementing MLTSS programs require MCOs to build statewide stakeholder engagement. It is essential that stakeholders be engaged early and often during program development, implementation, and beyond. In New Jersey, the state developed a steering committee comprised of state agency staff, health plans, providers, and consumer advocates that met on a quarterly basis during the planning period.<sup>61</sup> Subcommittees were formed to focus on the details of the program, meeting on a monthly basis and bringing solutions to the larger committee for consideration and action. The result of this coordinated effort was that all parties were "on the same page" when the program became operational.<sup>62</sup>

From an operational perspective, states can work with MCOs to develop uniform processes for MLTSS providers. This pre-work can ease the transition of MLTSS providers from FFS to managed care by facilitating credentialing, the use of MLTSS service codes on claims, and claims submissions. The state can also establish a strong consumer support system through a specialized Ombudsman or similar structure, develop a sound grievance and appeals process with appropriate reporting of complaints and their resolution, and ensure that individuals have an ongoing role in assessment and system oversight.

It will be incumbent upon any MCO serving individuals with LTSS needs to learn the local landscape and the current challenges from individuals living in the community and using the services, as well as from the local providers who, in many cases, have served these individuals for numerous years. The goal is to understand the community's needs and strengths and tailor the MLTSS program to address them while leveraging both local and state resources.

### Provide Administrative and Program Value to the State

A well-designed MLTSS program should offer value to individuals and their families and support a person-centered approach to service delivery. It should also produce value for the state sponsor. Some of the key areas where states can look to MCOs to deliver value include:

- Supporting Olmstead compliance goals, which enable individuals to move from institutional settings to homes or community-based settings of their choice.
- Establishing a comprehensive, person-centered approach that gives members the opportunity to self-direct their care and supports members in achieving full community inclusion.
- Accelerating the state's movement to shift LTSS funding from institutional care to home and community-based settings in a thoughtful and strategic way to ensure success.
- Eliminating unnecessary duplication of services while still providing the needed services and supports an individual prefers, enhancing coordination among services and programs, integrating community resources and supports in the coordination of covered benefits, and streamlining the assessment and person-centered service planning process.
- Establishing a data-driven assessment and evaluation process that measures both individual and program outcomes. Integrated data analyses may identify opportunities for system and program improvement as well as track important health and service outcomes by provider, consistent with other MCO-enrolled populations.
- Coordinating assistive services and other supports that might also be covered under Medicare, such as through billing processes, coordination of benefits, and program integrity efforts, to ensure members receive the best possible services and that Medicaid remains the payer of last resort.
- Realizing greater budget predictability while potentially reducing or eliminating waiting lists.
- Leveraging plan resources to enhance oversight of providers and quality improvement.
- Creating a point of accountability for quality that will facilitate state and federal efforts to implement new measures as they are developed and adopted.
- Being an innovative partner for the state in the design and implementation of a value-based purchasing framework that can shift the system as a whole toward accountability.
- Serving as a knowledgeable, flexible and adaptable business partner for the state, as the needs and preferences of the state and its Medicaid beneficiaries change over time. Experienced MCOs can be valuable partners in anticipating and preparing for externalities, as well as adapting and adjusting as issues arise (e.g., in transition related to the HCBS Settings Rule or other new federal rules).

## CONCLUSION

Managed LTSS offers an opportunity for individuals and their families to drive and participate in the delivery of their services and supports. MCOs bring value to individuals and their families by enhancing quality of services through the person-centered orientation of service planning and coordination. The integrated approach through managed LTSS emphasizes independence, individual choice, well-being, and self-direction through active engagement and ongoing coordination of services and supports.

MCOs are also valuable state partners for improving the delivery of Medicaid-funded LTSS benefits and creating more predictability in state budgets. In partnership with MCOs, a state's MLTSS program creates mechanisms for collaboration across health and supportive services, promotes access to HCBS, enhances quality of care and services, and develops payment methods that reward the coordination of the full array of services and supports an individual with LTSS needs may have (e.g., physical health, mental health and substance use disorders, LTSS, housing, education, and employment supports). MCOs are well-positioned to support states and their Medicaid beneficiaries in achieving the vision of a high-quality and efficient LTSS delivery system.



## END NOTES

- <sup>1</sup>. CMS (2016). Medicaid and Children’s Health Insurance Program (CHIP) Programs: Medicaid Managed Care, CHIP Delivered in Managed Care, and Revisions Related to Third Party Liability, Final Rule. 81 Federal Register 27498. Available at: <https://www.gpo.gov/fdsys/pkg/FR-2016-05-06/pdf/2016-09581.pdf> (Accessed May 20, 2016).
- <sup>2</sup>. A recent AARP survey found that over 85% of adults age 45 and older preferred home and community-based settings for LTSS. AARP (2010). Home and Community Preferences of the 45+ Population. Available at: <http://assets.aarp.org/rgcenter/general/home-community-services-10.pdf> (Accessed January 22, 2016).
- <sup>3</sup>. J. Ryan and B. Edwards (2015). Health policy Brief: Rebalancing Medicaid Long-Term Services and Supports. Health Affairs. 2015 September 17. Available at: [http://healthaffairs.org/healthpolicybriefs/brief\\_pdfs/healthpolicybrief\\_144.pdf](http://healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_144.pdf) (Accessed June 23, 2016).
- <sup>4</sup>. S. Eiken, K. Sredl, B. Burwell, and P. Saucier (2015). Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FFY 2013: Home and Community-Based Services were a Majority of LTSS Spending. Available at: <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf> (Accessed January 10, 2016).
- <sup>5</sup>. D. Braddock, R. Hemp, M.C. Rizzolo, E.S. Tanis, L. Haffer, and J. Wu (2015). The State of the States in Intellectual and Developmental Disabilities, 10th Edition (Boulder: Coleman Institute and Department of Psychiatry, University of Colorado).
- <sup>6</sup>. W. Erickson, C. Lee, and S. von Schrader (2016). Disability Statistics from the 2014 American Community Survey (ACS). Ithaca, NY: Cornell University Yang Tan Institute (YTI). Retrieved October 4, 2016 from [www.disabilitystatistics.org](http://www.disabilitystatistics.org). While vision and hearing are not typically included as a functional deficit used for Medicaid eligibility, they can be a mitigating factor in determining an individual’s functional status and plan of care.
- <sup>7</sup>. Ibid.
- <sup>8</sup>. American Association on Intellectual and Developmental Disabilities (AAIDD) (2013). Intellectual and Developmental Disabilities Definitions. Available at: <https://aaid.org/> (Accessed January 15, 2016).
- <sup>9</sup>. The Developmental Disabilities Assistance and Bill of Rights Act of 2000.
- <sup>10</sup>. American Association on Intellectual and Developmental Disabilities (AAIDD) (2013).
- <sup>11</sup>. Other diagnostic categories include borderline personality disorder, post-traumatic stress disorder, some anxiety disorders, obsessive compulsive disorder, and agoraphobia. These are included in the category of complex behavioral health if they manifest as sufficiently interfering with or limited functional abilities.
- <sup>12</sup>. SAMHSA (2015). Behavioral Health Barometer: United States, 2015. Available at: [http://www.samhsa.gov/data/sites/default/files/2015\\_National\\_Barometer.pdf](http://www.samhsa.gov/data/sites/default/files/2015_National_Barometer.pdf) (Accessed March 15, 2016).
- <sup>13</sup>. K.H. Burns, P.H. Casey, R.E. Lyle, T.M. Bird, J.J. Fussell, and J.M. Robbins (2011). Increasing Prevalence of Medically Complex Children in US Hospitals. *Pediatrics*; 126(4): 638-646.
- <sup>14</sup>. E. Cohen, D.Z. Kuo, R. Agrawal, J.G. Berry, S.K.M. Bhagat, T.D. Simon, and R. Srivastava (2011). Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics*; 127(3): 529-538.
- <sup>15</sup>. Kaiser Commission on Medicaid and the Uninsured (2015). Medicaid and Long-Term Services and Supports: A Primer. Note: The definition of LTSS used in this analysis is somewhat broader than is used elsewhere in this paper; total spending data include spending in nursing facilities, residential care facilities, home health, HCBS waivers, some ambulance providers, and some post-acute care (not traditionally considered LTSS). This analysis does not include Medicare spending on post-acute care. Private spending includes out-of-pocket costs and private insurance. Public spending includes Medicaid as well as the Children’s Health Insurance Program, the Department of Defense, the Department of Veterans Affairs, worksite health care, the Indian Health Service, workers’ compensation, general assistance, maternal and child health, vocational rehabilitation, other federal programs, Substance Abuse and Mental Health Services Administration, other state and local programs, and school health.
- <sup>16</sup>. A.V. Chari, J. Engberg, K. Ray, and A. Mehrotra (2015). The Opportunity Costs of Informal Elder-Care in the United States: New Estimates from the American Time Use Survey. *HSR*; 50(3): 871-882. In some cases, family members can be paid by the state for providing care for their loved one. However, this estimate reflects the amount of unpaid care that family members provide each year.
- <sup>17</sup>. Eiken, et al.
- <sup>18</sup>. The spending data for the analyses conducted by Eiken and colleagues from Truven Health Analytics are derived from CMS-64 reports, which are submitted by states to the federal government to claim the federal share of spending for their Medicaid program. These reports include some MLTSS spending, but only for states that participated in the Balancing Incentive Program (BIP). Truven researchers supplemented the CMS-64 reports with data gathered directly from states with MLTSS programs broken down into the five categories of service that historically comprise most of their managed care payments: nursing facilities, ICF/IID, 1915(c) waivers, personal care, and home health. It is important to note that not all states with MLTSS programs submitted data to Truven for their analysis. Spending data may not always be directly attributable to specific populations; however, Truven has been able to identify most services as being directed to one of three groups: older adults and/or adults with physical disabilities, individuals with intellectual/developmental disabilities, and individuals with serious mental illness or serious emotional disturbance.
- <sup>19</sup>. Eiken, et al.
- <sup>20</sup>. Eiken, et al. Note: Spending data are not available for older adults and adults with physical disabilities independently in part because many of the spending authorities across states cover both populations.
- <sup>21</sup>. Ibid.
- <sup>22</sup>. Ibid.

23. Ibid.
24. In the Truven report by Eiken, et al., complex behavioral health comprises the population with serious mental illness or serious emotional disturbance.
25. Eiken, et al.
26. Ibid. Note: FFY 2010 is the earliest year for which spending data on rehabilitative services spending was available.
27. HMA calculation of 1915(c) waiver spending specifically identified for medically fragile children. This calculation may underestimate total waiver spending on this population in states where services for medically fragile children are combined with other populations. Data for this calculation came from a report by Truven Health Analytics available at: <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/1915-expenditures-2013.pdf> (Accessed January 25, 2016).
28. Ibid.
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30. CMS (2014). Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers. 79 Federal Register 2947. Available at: <https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>.
31. Kaiser Family Foundation (2015). Medicaid Delivery System and Payment Reform: A Guide to Key Terms and Concepts. Available at: <http://files.kff.org/attachment/issue-brief-medicaid-delivery-system-and-payment-reform-a-guide-to-key-terms-and-concepts> (Accessed February 2, 2016).
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33. World Health Organization (2003). Organization of Services for Mental Health. Geneva: World Health Organization.
34. Data come from the Kaiser Family Foundation. The most recent data are from 2014 available at: <http://kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/>. The majority of HCBS waivers serving older adults and adults with physical disabilities are combined waivers and thus the waiting list data for these two populations were combined.
35. Self-direction, or sometimes referred to as “consumer directed” Medicaid services means that participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process. Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided. For example, participants are afforded the decision-making authority to recruit, hire, train and supervise the individuals who furnish their services. CMS calls this “employer authority.” Participants may also have decision-making authority over how the Medicaid funds in a budget are spent. CMS refers to this as “budget authority.” CMS, <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/self-directed-services.html>
36. CMS (2015). CMCS Informational Bulletin: Coverage of Housing-Related Activities and Services for Individuals with Disabilities. Available at: <https://www.medicaid.gov/federal-policy-guidance/downloads/CIB-06-26-2015.pdf> (Accessed March 10, 2016). Note: Only through 1915(c) HCBS Waivers are states permitted to cover certain housing costs. For example, states are permitted to cover the costs of “transition and tenancy supports”.
37. Kaiser Family Foundation & National Association of Medicaid Directors (2015). Medicaid Reforms to Expand Coverage, Control Costs and Improve Care: Results of a 50-State Medicaid Budget Survey for State Fiscal Years 2015 and 2016. Available at: <http://files.kff.org/attachment/report-medicaid-reforms-to-expand-coverage-control-costs-and-improve-care-results-from-a-50-state-medicaid-budget-survey-for-state-fiscal-years-2015-and-2016> (Accessed February 2, 2016).
38. Ibid. A state is considered to have MLTSS if it includes at least some 1915(c), 1115 HCBS, and/or institutional long-term care services in a capitated arrangement.
39. Ibid.
40. D.A. Ervin, B. Hennen, J. Merrick, and M. Morad (2014). Healthcare for Persons with Intellectual and Developmental Disability in the Community. *Frontiers in Public Health*; 2(83): 1-8.
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45. Program information from the Amerigroup health plan in Kansas.
46. Program information from the Amerigroup health plan in Tennessee.
47. Ibid.

- <sup>48</sup>. Program information from the Amerigroup health plan in Kansas.
- <sup>49</sup>. Medicaid Buy-In programs offer certain individuals the opportunity to retain Medicaid eligibility while they work, should they earn more than the allowable limits in Medicaid.
- <sup>50</sup>. A health plan cannot duplicate services available through other avenues but can coordinate benefits and the service coordinator can engage teachers and other school-based staff to understand the needs of the member and ensure that the child's needs are being met while at school. IDEA is a federal law that governs all special education services for children in the United States. Section 504 of the Rehabilitation Act of 1973 requires that schools not discriminate against children with disabilities and provide them with reasonable accommodations. Lastly, the ADA requires all educational institutions, other than those operated by religious organizations, to meet the needs of children with psychiatric disorders. Under each of these authorities, it is illegal to deny a child access to educational benefits and schools must provide necessary accommodations to the child.
- <sup>51</sup>. S. Zeruld and C. Blakeway (2004). Long Term Support for Individuals with Disabilities, Part 1: Supporting Adults with Physical Disabilities. Aging & Disability Resource Center Technical Assistance Exchange. Available at: [www.adrc-tae.acl.gov/tiki-download\\_file.php?fileId=2823](http://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=2823) (Accessed February 3, 2016).
- <sup>52</sup>. Money Follows the Person (MFP) is a federal initiative, currently in place in 43 states and the District of Columbia, designed to support transitions from nursing facilities to the community. In order to be eligible for MFP, a Medicaid beneficiary must reside in a nursing facility for at least 90 days. Those days on which the resident was in the facility for short-term rehabilitation reimbursed by Medicare do not count toward those 90 days.
- <sup>53</sup>. American Association on Intellectual and Developmental Disabilities (AAIDD) (2013).
- <sup>54</sup>. Braddock, et al.
- <sup>55</sup>. J.E. Gaugler, R.L. Kane, R.A. Kane, T. Clay, and R. Newcomer (2003). Caregiving and Institutionalization of Cognitively Impaired Older People: Utilizing Dynamic Predictors of Change. *Gerontologist*; 43(2): 219-229.
- <sup>56</sup>. Alzheimer's Association (2015). Alzheimer's Disease Facts and Figures. Available at: [https://www.alz.org/facts/downloads/facts\\_figures\\_2015.pdf](https://www.alz.org/facts/downloads/facts_figures_2015.pdf).
- <sup>57</sup>. Program information from the Amerigroup health plan in Kansas.
- <sup>58</sup>. In recognition of the growing demand for HCBS and the lack of a quality measurement framework for HCBS, the National Quality Forum (NQF) has been engaged by the federal Department of Health and Human Services. The goals of this project are to develop a conceptual framework and perform an environmental scan to address performance measure gaps in home and community-based services to enhance the quality of community living. With the support of a diverse stakeholder advisory panel, a catalogue of existing measures and measures in varying stages of development across states and at the national level have been identified. More information about NQF's efforts can be found at: [http://www.qualityforum.org/Measuring\\_HCBS\\_Quality.aspx](http://www.qualityforum.org/Measuring_HCBS_Quality.aspx).
- <sup>59</sup>. Association of Community Affiliated Plans (2012). Fact Sheet: How can states leverage Medicaid managed care to improve health care quality. Available from the ACAP website at: <http://www.communityplans.net/ResourceCenternbsp;/FactSheets/tabid/214/Default.aspx> (Accessed April 28, 2016).
- <sup>60</sup>. B. Jackson, et al. (November 2013). Quality in Managed Long-Term Services and Supports Programs. Prepared by Truven Health Analytics for the Office of the Assistant Secretary for Planning and Finance, U.S. Department of Health and Human Services, p. 15. Available at: <https://aspe.hhs.gov/sites/default/files/pdf/76866/LTSSqual.pdf> (Accessed May 23, 2016).
- <sup>61</sup>. Program information from the Amerigroup health plan in New Jersey.
- <sup>62</sup>. Ibid.

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### **About the Anthem Public Policy Institute**

The Anthem Public Policy Institute was established to share data and insights to inform public policy and shape the health care programs of the future. The Public Policy Institute strives to be an objective and credible contributor to health care innovation and transformation through publication of policy-relevant data analysis, timely research, and insights from Anthem's innovative programs.

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