

# **Managed Long-Term Services and Supports**



## **President's Committee for People with Intellectual Disabilities**

**2012 Report to the President**

## EXECUTIVE SUMMARY

Major transformations are occurring across the country in the financing and delivery of long-term services and supports for individuals with disabilities. Long-term services and supports include assistance with activities of daily living, such as getting dressed, taking medication, preparing meals, and managing money. They include a broad range of services and supports across settings, including personal assistance services, family support, home and community-based services (HCBS), intermediate care facilities for individuals with developmental disabilities (ICFs/DD), and nursing homes. These services and supports have traditionally been provided on a fee-for-service basis. However, states are increasingly interested in developing Managed Long-Term Services and Supports (MLTSS) programs, which apply principles of managed care.

While most individuals without disabilities in Medicaid receive services in managed care systems, very few individuals with disabilities and seniors who need long-term services and supports are in managed care. In MLTSS programs, states contract with managed care entities to coordinate the financing and delivery of services and supports. States are interested in designing MLTSS programs that better coordinate and integrate these services with acute care in hopes of improving quality and achieving savings.

Over the next two years alone, the number of states with MLTSS programs is projected to grow from 16 to 26. At least 11 new states are planning to include individuals with intellectual and developmental disabilities (ID/DD) in MLTSS programs. Only a handful of states have experience overseeing MLTSS programs for individuals with ID/DD. Research on outcomes is extremely limited and findings are mixed. Many states pursuing MLTSS are planning to contract with outside health plans that have little experience serving individuals with ID/DD.

Disability stakeholder engagement in the design, implementation, and oversight of MLTSS programs is essential to ensure consumer protections and shape direction.

Managed care provides powerful tools (such as contract language and quality measures) that state advocates can use to accelerate systems change towards desired outcomes. Some advocates see opportunities to make improvements in such areas as prevention and wellness, options for self-direction, and rebalancing. There is also potential to reinvest savings to help address unmet needs and waiting lists.

There are two main purposes of this report. The first section of the report provides background on MLTSS to assist with informing the ID/DD community. Managed care is complex. It is critical to have a basic understanding of the changes occurring and ways to influence outcomes. This section addresses the following questions:

- What are “Managed Long-Term Services and Supports”?
- What experiences do states have with MLTSS?
- Why are more states interested in MLTSS?
- What are potential benefits and concerns?
- How can advocates shape direction of MLTSS programs?

The second section of the report makes federal recommendations. The central mission of the President’s Committee for People with Intellectual Disabilities is to make recommendations to the President of the United States and the Secretary of the Department of Health and Human Services.

The following recommendations are made:

### **Disability Stakeholder Engagement**

- 1) The Administration for Community Living (ACL) should have access to funds to provide training and technical assistance on MLTSS for self-advocates with ID/DD and family members.
- 2) The ACL should work with the Centers for Medicare and Medicaid Services (CMS) to provide resources to coalitions of consumer organizations to

strengthen their capacity to engage in development and implementation of MLTSS programs.

- 3) CMS should collaborate with the ACL on guidance and oversight to ensure meaningful and ongoing stakeholder engagement of consumer organizations.

### **Choice and Self-Determination**

- 4) CMS should not allow states to carve out any institutional services and settings (including nursing facilities and ICFs/DD) from MLTSS.
- 5) CMS and states should promote person-centered planning and options for self-directed supports in MLTSS.
- 6) CMS should encourage states and health plans to reinvest savings from MLTSS programs to address unmet needs and waiting lists.
- 7) CMS and states should ensure that individuals with ID/DD and their families have accessible information and assistance from independent navigators to help them understand their enrollment choices and rights.
- 8) The Department of Education, in collaboration with the Department of Health and Human Services and Social Security Administration, should assist students with disabilities and their families through the transition process as students move from high school to adult life in understanding and navigating HCBS and MLTSS.

### **Consumer Protections and Rights**

- 9) CMS should not approve MLTSS programs without strong and transparent assessment of state and plan capacity and readiness to adequately serve individuals with ID/DD and their families.
- 10) CMS should require states to have independent systems in place to assist consumers with complaints, advocate on their behalf, and monitor MLTSS programs for systemic problems (often referred to as ombuds programs).\*

\*After PCPID members voted on the abovementioned recommendation, CMS started the initial work in this area.

- 11) The ACL should work with federal and state partners to promote supported decision making, self-determination, and self-advocacy, as well as avoiding inappropriate use of guardianship in MLTSS programs.

### **Quality Measurement, Data Collection and Research**

- 12) CMS should work with the ACL and key stakeholders to issue guidance on a core set of HCBS quality and reporting measures that are appropriate to the specific needs of people with ID/DD and focus on quality-of-life outcomes.
- 13) CMS should only approve MLTSS proposals that include quality measures and reporting (as indicators) that ensure access to competent, stable, and well-trained direct support professional workforce.
- 14) CMS should work with the ACL and key stakeholders to develop measures to fill gaps in HCBS quality measurement, for both the unique needs of specific populations such as individuals with ID/DD as well the measures that apply to all populations.
- 15) The ACL should convene federal partners, researchers, states, health plans, and others to promote external evaluations and research on MLTSS.

## I. BACKGROUND

Rapid transformations are occurring within states towards systems of Managed Long- Term Services and Supports (MLTSS). This movement is extremely complex and has significant implications for individuals with intellectual and developmental disabilities (ID/DD) and their families. The President’s Committee for People with Intellectual Disabilities believes it is critical for the ID/DD community to be fully informed and engaged at both the state and federal levels.

Therefore, this report consists of two main sections. The first section is primarily aimed at self-advocates, family members, and professionals at the state level, since that is where the majority of action on MLTSS will occur. It is intended to provide a basic overview to better inform the ID/DD community. It addresses the following questions:

- What are “Managed Long-Term Services and Supports”?
- What experiences do states have with MLTSS?
- Why are more states interested in MLTSS?
- What are potential benefits and concerns?
- How can advocates shape direction of MLTSS programs?

The second section of the report makes recommendations at the federal level to the President of the United States and Secretary of the Department of Health and Human Services.

*The topic of Managed Long Term Services and Supports (MLTSS) is extremely complex. The President’s Committee for People with Intellectual Disabilities has strived to make this report as understandable as possible. To assist with understanding, there is a glossary of managed care terms and list of frequently used acronyms in the appendix. Concepts are also explained in the text. The use of acronyms was kept to a minimum. In addition, a shorter version of this report was prepared using easier to understand language to make the report more accessible.*

## **What Are “Managed Long-Term Services and Supports”?**

Long-term services and supports include assistance with activities of daily living, such as getting dressed, taking medication, preparing meals, and managing money. They include a broad range of services and supports across settings, including personal assistance services, family support, home and community-based services (HCBS), intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), and nursing homes. Managed Long-Term Services and Supports (MLTSS) is a term that refers to financing and delivering long-term services and supports based on principles of managed care. Traditionally, states have provided Medicaid to individuals with disabilities through a fee-for-service system. Under this type of system, individuals who qualify for Medicaid can receive services and supports from any Medicaid health care or service provider. The fee-for-service system can lead to poor communication and coordination between providers, which can result in reduced quality of care and unnecessary costs.

Similar to private health insurance, over the past several decades more states have moved towards managed care approaches in Medicaid. There are different types of managed care models, but they all have similar goals of improving the coordination of services and controlling costs. Some models of Medicaid managed care build on the fee-for-service model. For example, some states have provided enhanced payments to primary care providers or case managers to better coordinate health care and services. However, the focus of this report is primarily on what is commonly referred to as “risk-based” managed care.

Under risk-based managed care, a state typically contracts with outside Managed Care Organizations (MCOs). MCOs agree to provide all services in a contract in exchange for a fixed monthly payment from the state. This payment process is referred to as capitation (MCOs receive a “capitated” rate for each individual they serve). Individuals in managed care typically have a care manager and team that coordinate all their care and services. Individuals must obtain approval before receiving services. MCOs also limit services and choice of providers to those that are in the plan’s “network” of providers.

Since MCOs receive a fixed payment, there are financial incentives to improve coordination of care and services, focus on prevention and wellness, and reduce unnecessary services –such as avoidable emergency room visits and hospitalizations. At a basic level, if the actual costs of providing services are lower than the “capitated” payment received from the state, then MCOs can make a profit. However, if costs are higher, then MCOs are “at risk” of a loss. States also frequently build in other financial incentives for MCOs to meet desired quality benchmarks and performance goals.

The use of Medicaid managed care has grown rapidly over the past 15 years. Of the approximately 60 million low-income individuals who receive health care and related services from Medicaid, over two-thirds are now enrolled in some form of managed care (MACPAC, 2011). While most states have required enrollment of children, pregnant women, and adults without disabilities in Medicaid managed care, only about 10% of enrollees in risk-based Medicaid managed care are individuals with disabilities. There are a variety of reasons for this, including resistance from disability service providers, health plans being unfamiliar with the complex needs of individuals with disabilities, and uncertainties about adequate rate settings and associated risks for health plans (Gifford, Smith, Snipes, & Paradise, 2011).

Recently, states have shown renewed interest in managed care for individuals with disabilities and seniors. Some managed care programs have been designed solely around acute care (physician services, outpatient medical care, hospital services, etc.). However, since many seniors and individuals with disabilities also need long-term services and supports, many states are interested in designing MLTSS programs for these populations. Some MLTSS models keep payments for acute care and long-term services and supports separate, while often putting in place mechanisms to improve coordination between the systems. Other MLTSS models provide a single risk-based payment to health plans in order to better integrate acute and long-term services and supports.



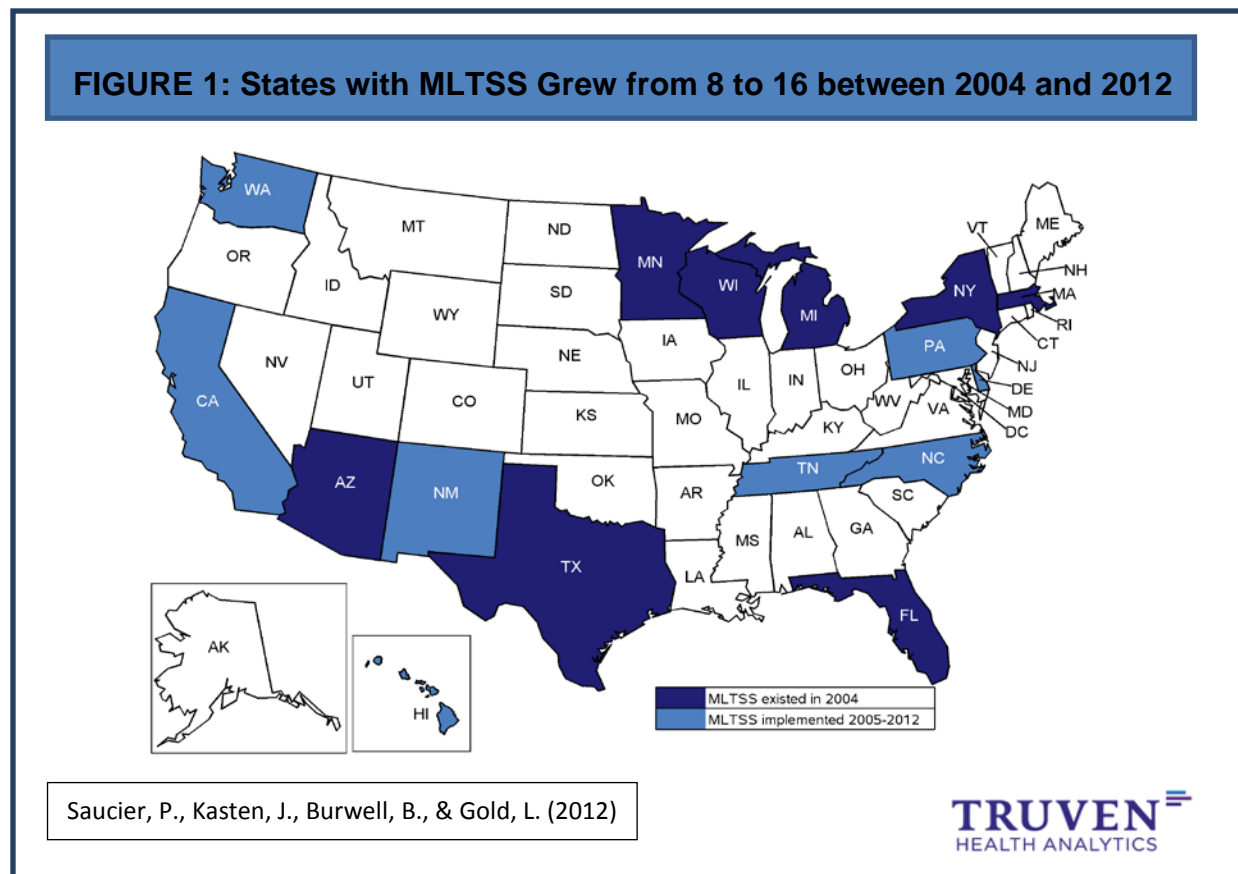
## **What Experiences Do States Have with MLTSS?**

While there is a long history of experimentation, the experience of states with MLTSS programs is very limited. Most experience comes from small-scale programs serving individuals in certain geographic locations or subpopulations of individuals with disabilities. Early models of MLTSS date back as far as the 1980s with the Program for All Inclusive Care for the Elderly (PACE) demonstrations and the Arizona Long-Term Care System (ALTCS) (O’Keeffe et al., 2010).

PACE is a model that provides integrated Medicaid and Medicare services to older individuals (55 and older). It uses an interdisciplinary team approach, centered on adult day care, to support seniors in the community who otherwise would likely end up in nursing homes. Arizona has the longest history of implementing statewide Medicaid managed care. Arizona was the last state in the country to take up Medicaid. When Arizona adopted Medicaid in the early 1980s, the state used a Medicaid demonstration waiver to design their entire program around principles of risk-based managed care. In 1988-89, the Arizona Long Term Care System (ALTCS) was phased in to extend managed care to long-term services and supports statewide, including services for individuals with ID/DD.

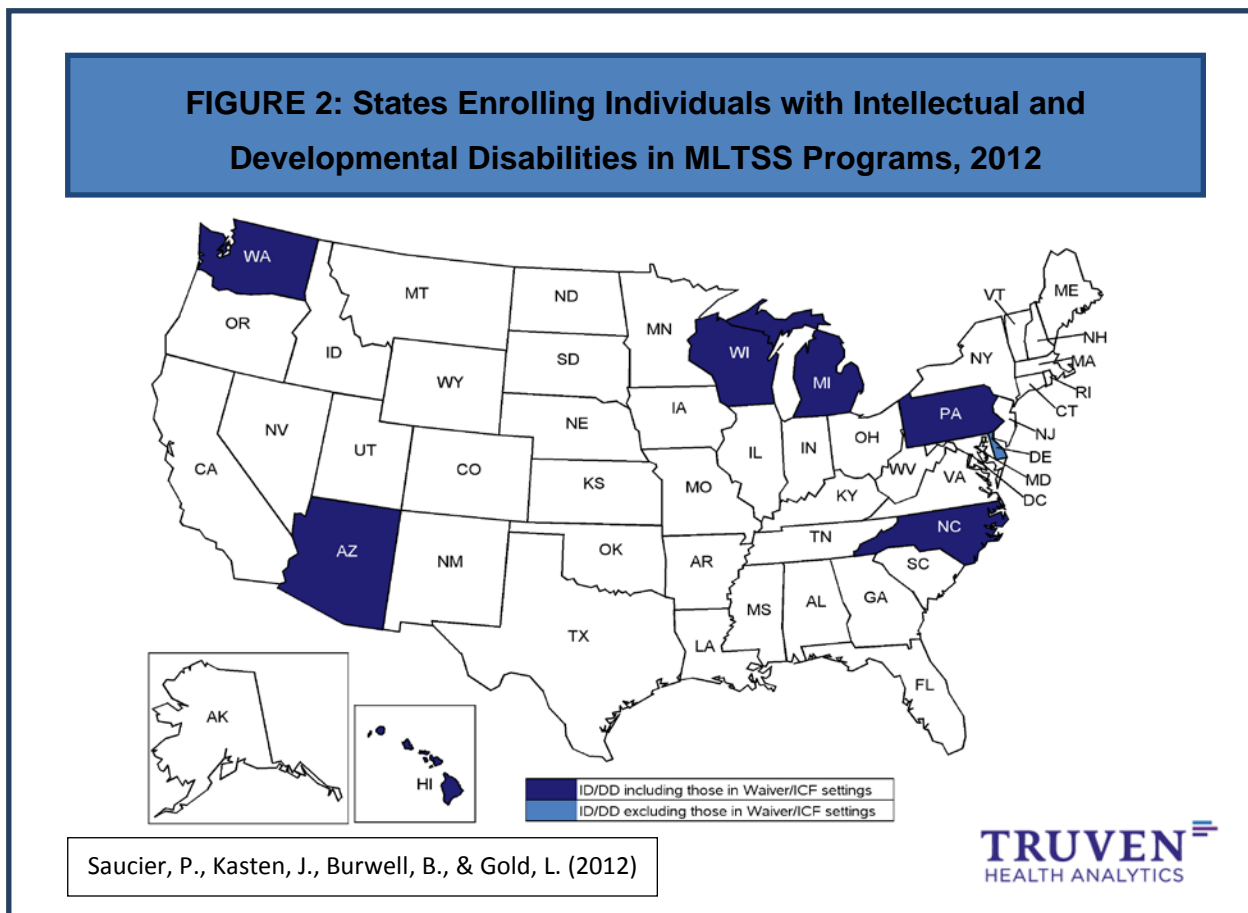
During the 1990s, other states began applying risk-based managed care strategies that included long-term services and supports, either within Medicaid alone or through initiatives to better integrate care for individuals receiving both Medicaid and Medicare. In 1997, Congress passed legislation that provided states greater authority to require mandatory enrollment in Medicaid managed care. States increasingly developed managed care systems for children and pregnant women in Medicaid. States expressed great interest in extending managed care to individuals with disabilities, including individuals with ID/DD (Smith & Ashbaugh, 1995). While programs did not materialize in all states that expressed interest, a steady stream of states ventured into MLTSS. Federal initiatives were also launched that led to small-scale state endeavors to better integrate Medicare and Medicaid.

Between 2004 and 2012, the number of states with MLTSS programs increased from 8 to 16; and the number of individuals in MLTSS programs grew from 105,000 to 389,000 (see Figure 1). While the numbers have increased over the past decade, it is important to place them in perspective. Despite growth, only about 6% of total Medicaid long-term services and supports are provided in MLTSS programs today.



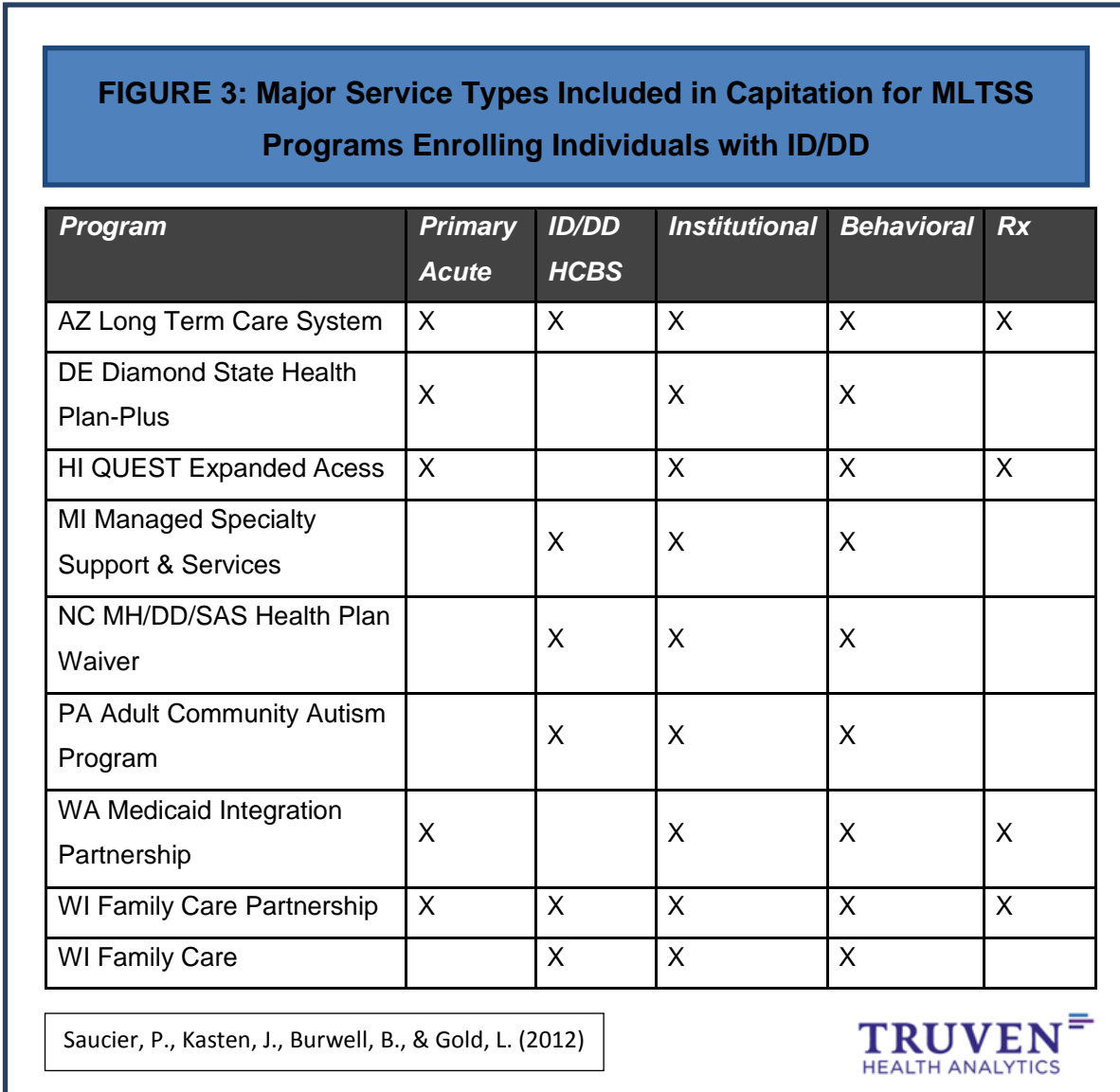
A recent study prepared for the Centers for Medicare and Medicaid Services (CMS) illustrates the tremendous diversity across existing MLTSS programs (Saucier, Kasten, Burwell, & Gold, 2012). There are a total of 19 different programs in 16 states. Several states have large MLTSS programs, some operating statewide. However, other programs are very small –such as the Pennsylvania Adult Community Autism Program, which only serves about 100 individuals. Older individuals and adults with physical disabilities are the most common populations that have been targeted for MLTSS programs.

Eight of the 16 states mandate enrollment; 7 have voluntary enrollment; and one state uses passive enrollment (meaning they automatically enroll individuals into the managed care program but they have an opportunity to dis-enroll or “opt out”). States have used a variety of contractors, including for-profit health plans, non-profit health plans, and public or county/regional-based entities. However, for-profit health plans make up about half of the market. The four top market leaders are: United Healthcare, Amerigroup, Centene, and Molina Healthcare.



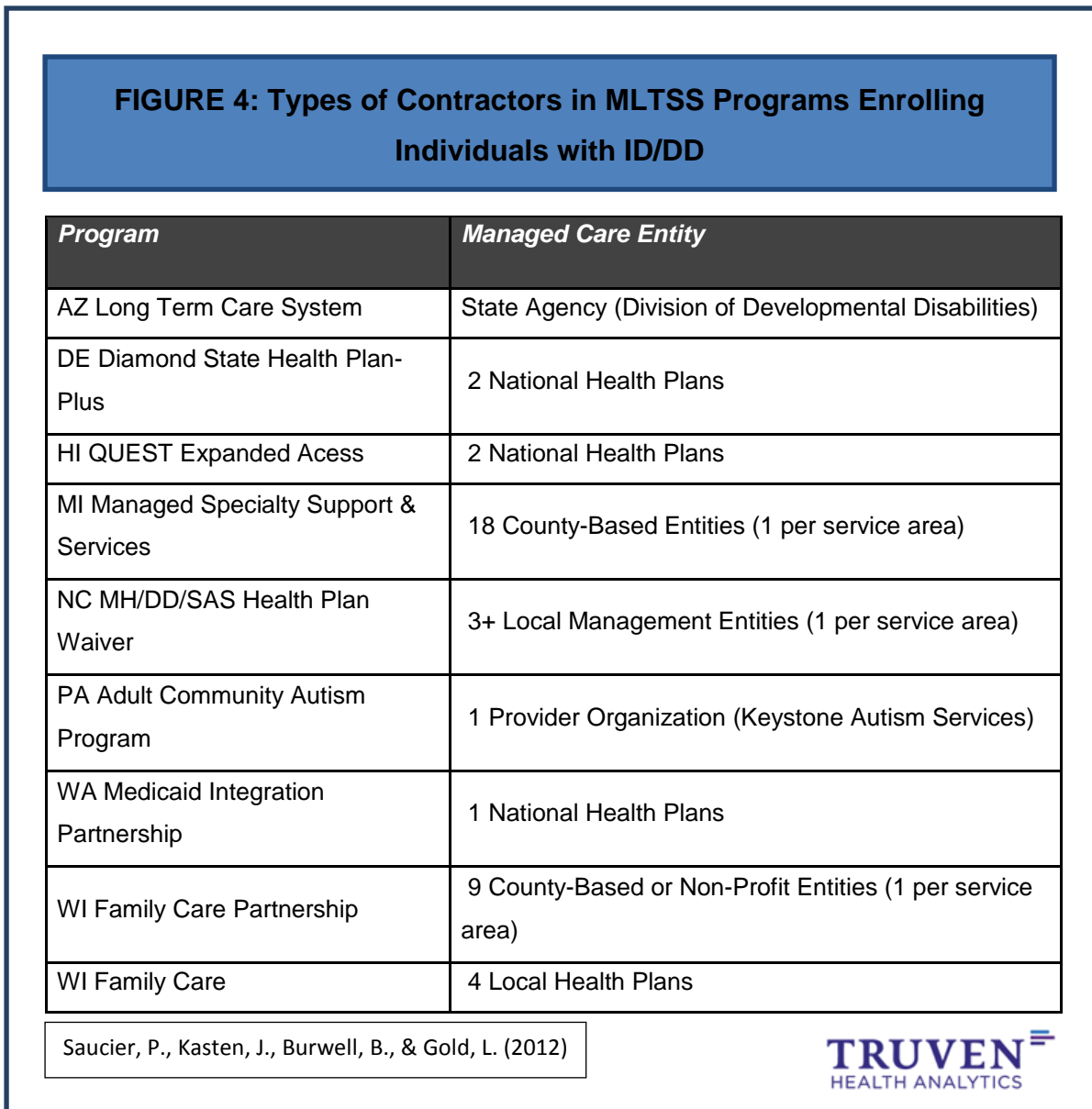
According to the environmental scan prepared for CMS, 8 states currently include individuals with ID/DD in MLTSS programs (Saucier, Kasten, Burwell, & Gold, 2012) (see Figure 2). Yet, the categories of services included vary considerably (see Figure 3). For example, Delaware, Hawaii, and Washington enroll individuals with ID/DD in managed care for acute care, but Home and Community-Based Services (HCBS) are “carved out” (meaning they are not included in the MLTSS program and are provided

separately). On the other hand, Michigan, North Carolina, Pennsylvania, and the Wisconsin Family Care Program offer HCBS waiver services in their MLTSS programs but manage acute care through separate programs.



In addition, programs vary in the types of managed care entities with which states have contracted (see Figure 4). Further illustrating the diversity of approaches states have taken, the CMS study did not list Vermont as a state that provides MLTSS. Vermont provides a unique model of MLTSS where the state serves as the managed care entity.

For the purposes of this report, Vermont is included in the discussion of MLTSS programs.



Four states stand out as having the most experience serving individuals with ID/DD in MLTSS: Arizona, Michigan, Vermont, and Wisconsin. Each state program has its own unique history, evolution, and experience. State officials and consumer advocates from three of these states (Arizona, Michigan, and Vermont) were invited to brief the

President's Committee for People with Intellectual Disabilities about their MLTSS programs. Case studies from these three states are contained in the Appendix. One striking similarity across these states is that they have pursued models of managed care that build on "public" entities versus outside health plans (Gettings, 2009).

In Arizona, the state developmental disabilities services agency serves as the managed care entity. In Vermont, the state Medicaid agency serves as the managed care entity. In Michigan and Wisconsin, the state contracts with county/regional networks based on elements of previously existing mental health, substance abuse, and ID/DD service systems. In these models there are varying levels of risk assumed directly by the entities managing care. However, the extent of risk is very different from traditional models of managed care where states contract with outside health plans. Within the current resurgence of interest in MLTSS, states are planning to predominately contract with outside health plans, mostly large for-profit health plans. There is little history of such health plans managing long-term services for the ID/DD population.

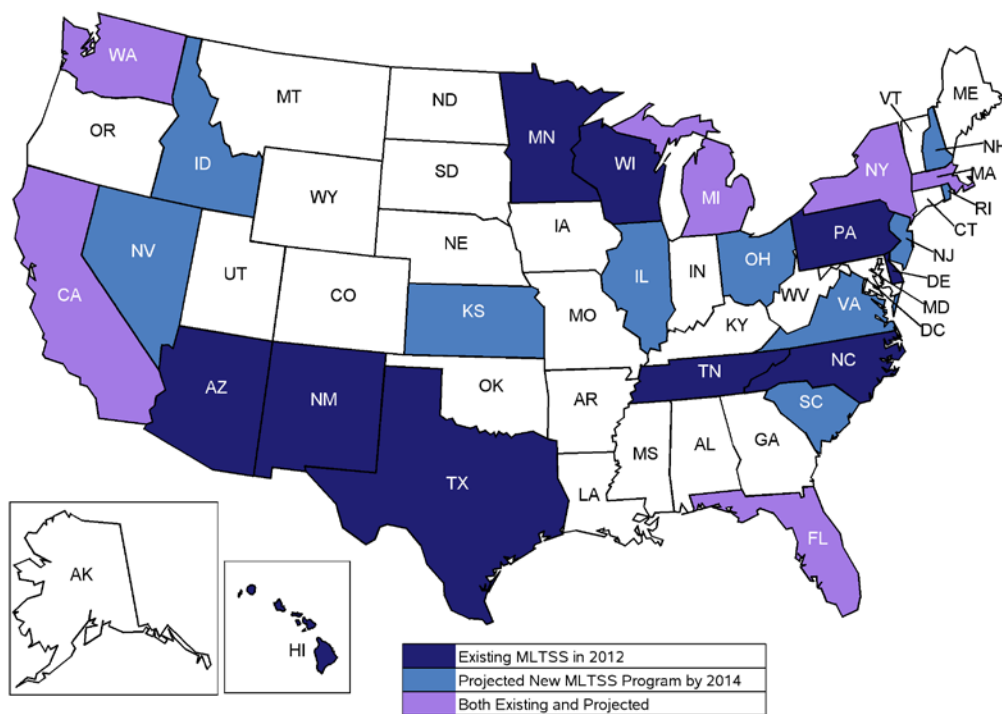
### **Why Are More States Interested in MLTSS?**

Over the next two years alone, the number of states with MLTSS programs is projected to grow significantly, from 16 to 26 (see Figure 5). In addition, at least 11 new states are planning to include individuals with ID/DD in MLTSS initiatives (California, Idaho, Illinois, Kansas, Massachusetts, Michigan, New Hampshire, New York, Ohio, Virginia, and Washington).

Two main factors are driving greater interest in the use of MLTSS: 1) state budget challenges; and 2) new opportunities and incentives in the Affordable Care Act.

States continue to face significant budget challenges due to lingering effects of the recession (Cheek et al., 2012). Major revenue sources for state general funds remain below pre-recession levels for most states. The recession has also contributed to greater pressures on Medicaid and other publicly funded services. More individuals rely on Medicaid during times of economic downturn because they lose access to their health insurance through work and have less income and assets.

**FIGURE 5: Twenty-Six States Projected to have MLTSS Programs by 2014**



Saucier, P., Kasten, J., Burwell, B., & Gold, L. (2012)

**TRUVEN**  
HEALTH ANALYTICS

Between October 2008 and June 2011, the American Recovery and Reinvestment Act provided fiscal relief to states through an enhanced federal match for Medicaid. However, this assistance has phased out while many states continue to face budget shortfalls (NGA and NASBO, 2012). States are also concerned about future pressures on the Medicaid program, including pressures related to the aging of the baby boom generation and increased needs for long-term services and supports. Since Medicaid

HCBS are optional for states, they are extremely vulnerable to cutbacks during times of economic pressures. Many states have already made short-sighted cuts in HCBS services and provider rates while waiting lists continue to grow. To avoid even deeper cuts, states are looking for ways to provide services more efficiently.

The Affordable Care Act provides many new options and financial incentives that states can adopt to improve coordination, integration and rebalancing, such as the new Balancing Incentives Program and Community First Choice Option (Caldwell, 2010). In addition to these options, the Affordable Care Act established a new Medicare-Medicaid Coordination Office. The purpose of this new office is to improve quality, reduce costs, and improve the beneficiary experience for individuals who are enrolled in both Medicaid and Medicare (commonly referred to as “dual eligible beneficiaries”). Medicaid provides health care and long-term services and supports for low-income individuals. Medicare provides health care to seniors and individuals who qualify for Social Security Disability Insurance (SSDI). Medicare does not provide long-term services and supports. There are about 9 million dual eligible beneficiaries who receive both Medicaid and Medicare.

The population of dual eligible beneficiaries is a very diverse population with complex needs for health care and long-term services and supports (Coughlin, Waidmann, Phadera, Garfield, & Lyons, 2012). There is a long history of the Medicare and Medicaid programs not working efficiently together, often resulting in poorly aligned incentives, cost shifting between the programs, and reduced quality of care. Therefore, the Medicare-Medicaid Coordination Office has launched a number of initiatives that aim to improve care coordination, integrate benefits, and enhance communication and data sharing that lead to cost-shifting between the two programs and poor quality of care for beneficiaries.

One new effort launched by the Medicare-Medicaid Coordination Office is called the Financial Alignment Initiative (commonly referred to as the “duals integration” demonstrations). In April 2011, CMS awarded design contracts to 15 states in order to



develop proposals to test demonstrations that better align the financing and delivery of services for dual eligible beneficiaries.

The initiative was expanded in July 2011, when CMS provided additional guidance to states outlining two models they could pursue: 1) capitated managed care model; and 2) managed fee-for-service model. The capitated managed care model involves a three-way agreement between CMS, the state, and health plans. Medicare and Medicaid funding will be blended to provide participating plans with a single capitated rate for all specified acute, behavioral health, and long-term services and supports. The managed fee-for-service model involves an agreement between CMS and the state. The state will be responsible for improving care coordination and ensuring access to all Medicaid and Medicare services. If states are able to achieve savings, they will be allowed to share in some of those savings.

State interest in this initiative was overwhelming. A total of 37 states, including the 15 states awarded design contracts, expressed interest to CMS in testing duals integration demonstrations. Twenty-six states (AZ, CA, CO, CT, HI, ID, IL, IA, MA, MI, MN, MO, NM, NY, NC, OH, OK, OR, RI, SC, TN, TX, VT, VA, WA, and WI) submitted proposals to CMS in early 2012, although several states have since withdrawn. The majority of states are pursuing the capitated managed care model. A handful of states are pursuing the managed fee-for-service model, and a few want to test both. The next phase in the process is a signed agreement –called a Memorandum of Understanding (MOU) – between CMS and states outlining details of their plan. Five states currently have MOUs.

State proposals for the duals integration demonstrations vary considerably, based to a large degree on existing systems and managed care structures in states (Musumeci, 2012). Some states have included all dual eligible beneficiaries, while others have targeted certain populations or geographic regions. Some states have specifically “carved out” (excluded) certain subpopulations and services from the demonstrations. Some states have proposed demonstrations that do not include individuals with ID/DD

(NASDDDS, 2012). In other states, individuals with ID/DD are partially included –for example, individuals with ID/DD may be included in the demonstration but HCBS are excluded. In at least two states, individuals with ID/DD are fully included in the demonstrations.

The duals integration demonstrations, particularly states pursuing the capitated managed care model, are driving systems transformation towards MLTSS. Many states pursuing the demonstrations are also simultaneously pursuing much larger mandatory Medicaid MLTSS applications (for example, New York). At least six other states are pursuing large Medicaid MLTSS programs outside of the duals integration demonstrations (Florida, Kansas, Pennsylvania, New Hampshire, New Jersey, and New Mexico) (NASUAD, 2012). Faced with lingering impacts of the recession and concerns about future pressures on Medicaid, states are combining multiple new Affordable Care Act provisions with existing authorities for Medicaid managed care.

### **What Are Potential Benefits and Concerns?**

The outcomes of MLTSS will be predominately driven by the design of programs at the state level. Managed care is a different way to finance and deliver health care and long-term services and supports. It is inherently neither “good” nor “bad” for individuals with ID/DD. How MLTSS programs are designed and implemented will vary greatly across states –just as the current, predominately fee-for-service state developmental disabilities systems vary. There are many potential benefits and legitimate concerns (see Figure 6).

**FIGURE 6: Potential Benefits and Concerns in MLTSS**

<p><b>Potential Benefits:</b></p> <ul style="list-style-type: none"><li>• Improved Coordination</li><li>• Reductions in Health Disparities</li><li>• Benefits in Prevention, Wellness, and Training of Health Providers</li><li>• Rebalancing</li><li>• Greater Options for Self-Direction</li><li>• Reduce Waiting Lists and Unmet Needs</li><li>• Reinvestment of Savings in Added Benefits</li></ul>	<p><b>Concerns:</b></p> <ul style="list-style-type: none"><li>• Reduced Access</li><li>• Limits in Consumer Choice</li><li>• Medicalization of Long-Term Services and Supports</li><li>• Knowledge and Expertise of Health Plans in Disability</li><li>• State Capacity and Infrastructure to Oversee Programs</li><li>• Complexities in Rate Setting</li></ul>
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While this report focuses on long-term services and supports, movement towards MLTSS is most often occurring in combination with efforts to better integrate acute care, behavioral health, and long-term services and supports. Individuals with disabilities experience significant health disparities and access barriers in the current Medicaid fee-for service system (Drum, McClain, Horner-Johnson, & Taitano, 2011; Krahn, Hammond, & Turner, 2006; Office of the Surgeon General 2002, 2005). Individuals with ID/DD are less likely to receive preventive care such as routine screenings for breast, cervical, and prostate cancer. They are less likely to receive routine influenza and other immunizations. They face significant barriers to receiving routine dental care. Individuals with ID/DD are at risk for overuse of psychotropic medications and adverse effects from drug interactions. They often do not have access to community-based behavioral supports. Individuals with ID/DD face high rates of obesity and low rates of physical activity. Many individuals with disabilities do not have access to evidence-based programs to self-manage chronic conditions, promote healthy lifestyles, and prevent the development of secondary conditions.

Individuals with disabilities frequently experience physical and programmatic access barriers to health care. While the Affordable Care Act is making strides in this area, many health care facilities and equipment (such as weight and examination tables) remain physically inaccessible (National Council on Disability, 2009). Training of health professionals in the area of disability is woefully inadequate, contributing to reduced quality of care and frequent communication barriers between patients with disabilities and health professionals. Youth with disabilities face significant barriers in health care transitions from pediatric to adult systems of health care and services (Gleason, Palmer, Bhagat, & Reiss, 2009). For example, many youth with ID/DD continue to see their pediatrician well into adulthood due to lack of adequately trained adult providers. Moreover, direct support professionals are often not recognized as important members of interdisciplinary teams to help coordinate acute care with long-term services and supports.

Compared with the traditional fee-for-service system, movement towards managed care can provide excellent tools to improve coordination, quality, and access to acute care for individuals with ID/DD. However, there are also legitimate concerns among advocates about limiting access to care. There are concerns about sudden disruptions of care and services. Managed care will limit choice of providers to those in approved networks. Some individuals with ID/DD and their families have established trusted relationships with health care providers over many years. They could lose access to the only local provider with adequate training and competence serving individuals with ID/DD. There are particular concerns about access to specialists to meet unique complex medical needs and circumstances of some individuals with ID/DD. In addition, there are concerns of denials and reductions in necessary services, which could occur due to motives of health plans to maximize profits and/or inadequate payments to health plans from states seeking to fill immediate budget shortfalls.

There are legitimate reasons for caution. The fact is that research on the outcomes of Medicaid managed care for individuals with disabilities, particularly individuals with ID/DD, is scarce and inconclusive. Recent analyses of the literature have indicated

mixed findings on access and quality (Connolly & Paradise, 2012). Moreover, it is virtually impossible to draw any general, overarching conclusions from the research due to the tremendous diversity across states in program design, populations served, and quality measures.

While many states are driven by immediate budget pressures, research on cost savings is also inconclusive. Compared with other populations, the potential for short-term costs savings in the ID/DD population is likely less. Medicaid fee-for-service rates are so low in many states that there is very little room for savings by merely squeezing provider payments (Connolly & Paradise, 2012). If savings are to be achieved they will likely come from long-term improvements in care coordination, promoting health and wellness, and avoiding unnecessary hospitalizations and institutional placements (Lewin Group, 2004). The potential for savings from preventing unnecessary hospitalizations may be less for the ID/DD population in comparison with other populations, such as older individuals (Konetzka, Karon, & Potter, 2012). However, research exploring preventable hospitalizations has often not considered major reasons for emergency room and hospitalizations for individuals with ID/DD –such as behavioral issues, seizures, and infections. There are clear opportunities to better understand this area and improve care for individuals with ID/DD. To maximize long-range outcomes, additional investments in the system, addressing unmet needs for long-term services and supports, and targeting efforts to certain subpopulations of individuals with ID/DD may be needed (Brown & Mann, 2012).

Among states that have pursued MLTSS, there has been evidence of rebalancing (providing more services in the community versus institutions) (Summer, 2012). This can produce long-term, systemic cost savings and the ability to serve additional beneficiaries (Kaye, 2012). Contracting with outside MCOs has reduced long-standing political barriers in some states. Yet, the potential for savings in the ID/DD residential service system through rebalancing may be limited. Overall, about two-thirds of total Medicaid long-term services and support spending for individuals with ID/DD is already provided in the community versus only about a third for older adults and individuals with

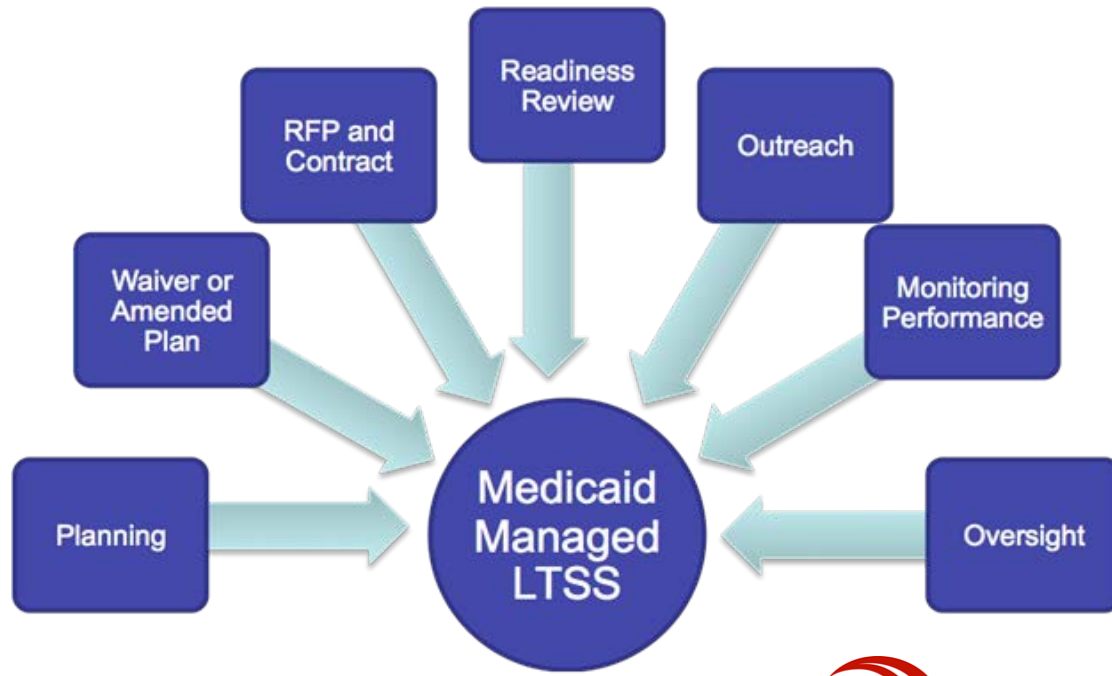
physical disabilities (Eiken, Sredl, Burwell, & Gold, 2011). Moreover, unmet service needs for individuals with ID/DD and their families are extremely high. Many states with MLTSS programs that include individuals with ID/DD have been able to not only rebalance but also significantly reduce or eliminate waiting lists and more equitably serve individuals with ID/DD, particularly those living at home with family.

Some advocates have referred to managed care as a “power tool.” It can be a powerful tool to construct systems that achieve more desirable goals and outcomes for individuals with ID/DD, but if used incorrectly can be damaging. Despite decades of progress, significant disparities remain across states in terms of rebalancing, person-centered planning, options for self-direction, and supports for community-based employment (Braddock et al., 2011). Disparities exist in supports for families, unmet needs and waiting lists, and availability of an adequate direct support professional workforce. Some of these disparities are deeply entrenched. Many disability advocates view MLTSS as an opportunity to accelerate system change towards more desirable goals and outcomes.

### **How Can Advocates Shape Direction of MLTSS Programs?**

Without early involvement and buy-in from individuals with disabilities and their families, MLTSS programs will not be successful or sustainable (Lind, Gore, Barnette, & Somers, 2010). It is not only critical for advocates to be at the table in the early stages when programs are being planned, but to maintain ongoing involvement as programs are implemented. There are many roles self-advocates, families, disability organizations and networks can play. Community Catalyst, a consumer advocacy organization, has developed a framework that highlights the many avenues in which disability advocates can shape MLTSS programs (Dembner, 2012) (see Figure 7).

**FIGURE 7: Avenues for Consumer Engagement to Shape MLTSS**



Dembner, A. (2012).



During the initial planning phase, states have taken a variety of approaches to gain stakeholder input –such as advisory committees, focus groups, meetings, and outreach to specific communities. It is critical to agree upon clear goals for MLTSS programs. For example, some states that have developed MLTSS programs for individuals with ID/DD clearly identified their goals to rebalance, support families, and reduce or eliminate waiting lists. Early opportunities exist for input into the overall design of the program, such as:

- Goals of the MLTSS program
- Scope, timeline, and phase-in of the program
- Targeted populations, services, and extent to which acute care, behavioral health, and long-term services and supports are fully integrated
- Voluntary versus mandatory enrollment

- Managed care model and type of MCOs that will be contracted

States can use different Medicaid authorities to pursue MLTSS programs (O’Keefe et al., 2010). Many states have used 1115 demonstration waivers, which provide the greatest amount of flexibility. Some states have combined 1915(c) HCBS waivers with a 1915(b) waiver for managed care. Regardless of which authority is used, states must submit applications to CMS for approval, which often provides opportunities for formal comments at the state and federal levels. In addition, prior to approving a state application, CMS must conduct a state readiness assessment to determine whether the state has the capacity to administer and oversee programs (National Council on Disability, 2012b). This provides another key pathway for stakeholder input into details of the MLTSS program, particularly to enhance consumer protections. State applications and readiness reviews should contain detailed information in areas such as:

- Assessment procedures
- Enrollment processes and consumer protections
- Care coordination
- Provider network adequacy and capacity
- State staffing and capacity for oversight

Another critical avenue for disability stakeholder input is during the contracting phase with MCOs. Requests for proposals and contracts with MCOs express in even greater detail standards and accountability. Strong contract language is one of the most powerful tools states and advocates can use to ensure consumer protections, enhance quality, and achieve desirable outcomes. The contracting phase also involves determination of payment rates and in some cases, penalties or incentives for meeting performance benchmarks. During the contracting phase, stakeholder input is important in such areas as:

- Adequate payment rates, penalties, and incentives for MCOs



- Requirements of MCOs (such as use of person-centered planning, options for self-direction, ADA compliance for medical facilities, training of health professionals in disability, and meaningful inclusion of consumer advisory boards in program development, implementation, and oversight)
- Continuity of care protections (allowing individuals to continue receiving care or services from current providers)
- Appeals and grievances procedures
- Quality measures and performance improvement

In addition to contracting with MCOs for services, states have frequently contracted with networks serving seniors and people with disabilities to provide various services and oversight of MLTSS programs (such as Area Agencies on Aging, Aging and Disability Resource Centers, and Centers for Independent Living). Consumer organizations can play key roles in such areas as: consumer outreach; independent enrollment navigation to assist individuals with disabilities in understanding their rights and choices; consumer feedback and quality assessment; and independent ombuds programs to protect rights and monitor programs. Continual monitoring and oversight is essential to identifying and correcting problems early, as well as examining performance over time and making adjustments.

The stakes are high in MLTSS. The risks for individuals with ID/DD and their families are real. Members of the President's Committee for People with Intellectual Disabilities have significant concerns about the movement towards MLTSS in the states. Rather than slowly implementing programs, testing pilots, and providing individuals with choice, some states are planning to mandatorily enroll populations statewide. There is little research and experience to guide best practice. Many state agencies do not have capacity and infrastructure ready to effectively oversee MLTSS programs. Many health plans interested in contracting with states do not have knowledge and experience serving individuals with ID/DD and their families.

At the same time, based on the case studies presented to the President's Committee for People with Intellectual Disabilities, members also see potential for positive system changes that could improve the lives of individuals with ID/DD and their families. Opportunities exist to improve service coordination, promote health and wellness, and enhance self-determination. There is potential for achieve efficiencies which could prevent cuts. Savings could be reinvested to better meet needs and address growing waiting lists for services and supports. However, goals for MLTSS programs must be clear. Decisions should never be driven by cost savings. Improving systems to better meet the needs and desires of individuals with ID/DD and their families must be the driving force of MLTSS.

It is essential to ensure that managed care structures and systems are designed to meet the needs of individuals with ID/DD. Some states are planning to develop MLTSS for other groups first, and then include individuals with ID/DD at a later date. MLTSS will only be successful with meaningful stakeholder engagement. The phrase "Nothing About Us Without Us," is central to the Disability Rights Movement. It is critical for individuals with disabilities and their families to be involved early. This is important even in states where individuals with ID/DD are initially "carved out" of MLTSS programs. CMS requires that when a state is proposing changes in the Medicaid program there must be meaningful opportunities for stakeholder and public input. These requirements are an important protection to ensure that the input and concerns of individuals with ID/DD and their families are considered in the design and implementation of MLTSS.

There are federal requirements for public input and comment into Medicaid proposals (e.g. 1115 Medicaid waivers and duals demonstrations). This is a core component of principles articulated by the National Council on Disability and many other disability organizations. This is a critical stage in the process. However, even before this stage, disability stakeholder engagement is essential to articulate clear goals and influence early decisions and planning. Moreover, establishing mechanisms for ongoing stakeholder input and guidance is also critical to ensure oversight and direction of programs as they are implemented.

Whether or not the great amount of state interest that has been expressed in MLTSS materializes, and the shape different programs take, will unfold over time. Yet, the history of the developmental disabilities field teaches us one thing for certain: The greatest dangers occur when the voices of individuals with ID/DD and their families are not meaningfully included.

## II. RECOMENDATIONS

The central mission of the President’s Committee for People with Intellectual Disabilities is to provide advice and assistance to the President of the United States and the Secretary of Health and Human Services on a broad range of topics that impact people with intellectual disabilities and the field of intellectual disabilities. Therefore, the recommendations discussed below focus primarily at the federal level. The design, implementation, and outcomes of MLTSS programs will be driven by actions at the state level. However, the federal government can play key roles in promoting successful outcomes in the following four key areas:

- Disability Stakeholder Engagement
- Choice and Self-Determination
- Consumer Protections and Rights
- Quality Measurement, Data Collection, and Research

The Centers for Medicare and Medicaid Services (CMS) has the largest role to play in federal oversight and guidance, but other federal partners can also play key roles. In particular, the establishment of the Administration for Community Living (ACL) provides a new structure to enhance interagency collaboration, common vision for home and community-based services, and aging and disability network involvement in MLTSS.

### **Disability Stakeholder Engagement**

Excellent resources have emerged to help provide advocates and states guidance on the design and implementation of MLTSS programs. Three resources are highlighted below:

- 1) The National Council on Disability (NCD, 2012a, 2012b) has outlined principles and a set of recommendations for successfully enrolling individuals with disabilities in managed care (available at [www.ncd.gov](http://www.ncd.gov)).
- 2) The Consortium for Citizens with Disabilities (CCD, 2012), a coalition of approximately 100 national disability organizations, has similarly developed principles and recommendations for transitioning individuals with disabilities into managed care (available at [www.c-c-d.org](http://www.c-c-d.org)).
- 3) The National Senior Citizens Law Center and the Disability Rights Education Defense Fund developed an online toolkit for consumer advocates to ensure consumer protections in MLTSS programs (available at [www.dualsdemoadvocacy.org](http://www.dualsdemoadvocacy.org)).

These resources highlight a common vision for well-designed MLTSS programs and can assist state advocates. However, the extent to which this vision is translated into practice will be influenced by many factors, including:

- Capacity of consumer advocates to effectively engage
- Processes established for meaningful stakeholder engagement
- Strong federal guidance and oversight

The capacity of advocates to effectively engage in the development of programs is currently very limited. Knowledge and expertise is primarily concentrated within states that have implemented MLTSS programs. Advocates within these states have learned how to effectively advocate within a managed care environment. However, for the vast majority of individuals with disabilities, families, and disability networks, managed care is completely new and unfamiliar territory. Advocacy within a managed care environment presents new and extremely complex terminology, tools, and points of intervention to impact outcomes.

- **RECOMMENDATION #1: The Administration for Community Living (ACL) should have access to funds to provide training and technical assistance on MLTSS for self-advocates with ID/DD and family members.**

Targeted efforts are needed to build the capacity of self-advocates with ID/DD and their families to engage in duals integration and MLTSS activities occurring in states. Approximately 18% of all dual eligible beneficiaries are individuals with ID/DD (MedPAC, 2010). Yet, there is little reference to any involvement of self-advocates with ID/DD or self-advocacy organizations in state proposals submitted to CMS for the duals integration demonstrations. Some self-advocates with ID/DD and self-advocacy organizations are involved in planning processes within states considering new MLTSS programs, but many more are not fully aware or engaged in their states.

No specific training or technical assistance efforts have been launched to assist self-advocates with ID/DD in understanding MLTSS. Materials and trainings should be developed that use pictures, simple language, and other tools to make communications more accessible and effective. Self-advocates and allies should work together to develop new trainings opportunities, outreach to self-advocates, and provide peer-to-peer support. Coordinated efforts could enhance the capacity of self-advocates to engage in the stakeholder process, understand the potential roles self-advocacy organizations could play in MLTSS, and shape the direction of MLTSS programs.

The Administration on Intellectual and Developmental Disabilities (AIDD) has provided strong federal leadership in supporting the self-advocacy movement. During 2011 and 2012, AIDD convened nine regional self-advocacy summits that brought together state teams of self-advocates and allies from every U.S. state and territory. The *Envisioning the Future: Allies in Self-Advocacy* summits promoted inclusion and collaboration between self-advocates, state developmental disabilities service agencies, and Developmental Disabilities Act partners (Caldwell, Arnold, & Rizollo, 2012). Knowledge was gained from these summits about working together while ensuring the voice of self-advocates remains primary. AIDD has also provided a limited number of small awards

to assist self-advocacy organizations in building infrastructure. With additional resources, AIDD could build upon these efforts to strengthen the capacity of self-advocates to effectively engage as stakeholders in duals integration and MLTSS.

- **RECOMMENDATION #2: The ACL should work with the Centers for Medicare and Medicaid Services (CMS) to provide resources to coalitions of consumer organizations to strengthen their capacity to engage in development and implementation of MLTSS programs.**

In addition to training and technical assistance for self-advocates with ID/DD, opportunities exist to support broad-based consumer coalitions to engage in MLTSS programs. While federal training and technical assistance initiatives have been aimed at state Medicaid agencies to enhance their capacity to pursue duals integration and MLTSS, similar initiatives have not been launched to build capacity of consumer stakeholders to meaningfully engage. Aging and disability organizations have found a common ground and benefit in working together on these issues, particularly to ensure strong consumer protections. Rather than working in isolation, coalitions have allowed consumer organizations to pool their skills and expertise, have a stronger voice, and more effectively influence the design of programs.

The Friday Morning Collaborative, supported by The SCAN Foundation, has provided a forum for national aging and disability organizations to monitor state activity on MLTSS and duals integration, provide input into federal guidance, and communicate with state affiliates and advocates. At the state level, the California Collaborative for Long-Term Services and Supports was modeled on the Friday Morning Collaborative to provide a vehicle for aging and disability organizations in California to guide efforts on duals integration. In Massachusetts, Disability Advocates Advancing Our Healthcare Rights (DAAHR) similarly formed in response to state efforts on duals integration and MLTSS. DAAHR has been extremely effective in forming a statewide coalition of aging and disability organizations, developing a working relationship with the state, and influencing the design of the Massachusetts duals integration demonstration.

Loose coalitions, and elements of potential coalitions, exist in various other states pursuing duals integration and MLTSS programs. Statewide networks of aging and disability consumer organizations, including self-advocacy organizations, could be pulled together with modest structural funding and support. Consumer coalitions could develop plans and activities based on their particular strengths and needs for technical assistance to enhance their capacity to engage within their states. A national training and technical assistance infrastructure could also be established to promote communications across states, share promising practices, and provide ongoing technical assistance from topical experts across the country.

- **RECOMMENDATION #3: CMS should collaborate with the ACL on guidance and oversight to ensure meaningful and ongoing stakeholder engagement of consumer organizations.**

Strong federal guidance and oversight is necessary for meaningful stakeholder engagement from consumer organizations. CMS has articulated high expectations for robust, meaningful stakeholder engagement in proposals from states pursuing duals integration demonstrations. Moreover, recent regulations concerning 1115 demonstration waivers (which many states are pursuing for authority to implement MLTSS programs) strongly enhance transparency and opportunities for formal public comment. While some flexibility is needed to allow states to determine the best approaches to gaining input from stakeholders, remarkable differences exist across states in the level of engagement, responsiveness, and transparency. Stronger federal guidance is needed to set clearer expectations. The ACL could assist CMS in establishing guidance and oversight to ensure meaningful involvement from aging and disability stakeholders.

### **Choice and Self-Determination**

The ID/DD field has a long history of advancing choice and self-determination for people with disabilities. Many of the most important advancements have come through



Medicaid HCBS to assist individuals in leading enviable lives. Home and community-based services, self-direction and person-centered planning have been hard-fought victories for individuals with disabilities and their families. These advances must not be lost in the migration to managed care.

- **RECOMMENDATION #4: CMS should not allow states to carve out any institutional services and settings (including nursing facilities and ICFs/DD) from MLTSS.**

Full integration of acute, behavioral health, and all long-term services and supports maximizes the potential for better coordination. MCOs have incentives to improve care coordination and control costs when they are responsible for the full array of services a beneficiary might require. The nursing home industry in some states has lobbied to be excluded from duals integration demonstrations and MLTSS programs. However, this would severely limit the ability of states to design coordinated systems and achieve goals of rebalancing. It could also exacerbate an institutional bias for individuals with high needs for services and supports. If nursing facilities and other institutional services are not included in managed care contracts, health plans would only be responsible for community-based services. Managed care plans would have few incentives to prevent individuals from going into institutions or return individuals from institutions to the community.

Some President's Committee for People with Intellectual Disabilities members expressed concerns about MLTSS programs limiting access to ICFs/DD. Declines in the use of ICFs/DD have occurred in many states which have adopted MLTSS programs. Michigan, for example, no longer operates any ICFs/DD or public institutions. However, declines have steadily occurred nationally for decades in states with and without MLTSS programs due to state and federal leadership and desires of individuals with ID/DD and their families (Braddock et al., 2011). By including the full range of long-term services and supports in MLTSS programs, states can preserve a person-centered approach that promotes choice. Moreover, one of the greatest potential benefits of

MLTSS for individuals with ID/DD is to improve coordination across an array of services. If institutional services are not included, beneficiaries residing in these facilities lose the opportunity to benefit from tools to address health disparities and improve acute care health outcomes.

If all elements of the system are not incorporated in MLTSS, individuals with the most significant medical and behavioral support needs may not be well-served. Not including all Medicaid-financed long-term services and supports provided in states, could lead to MCOs moving individuals with more significant need to institutional settings, regardless of their needs or desires.

➤ **RECOMMENDATION #5: CMS and states should promote person-centered planning and options for self-directed supports in MLTSS.**

As CMS, states, and health plans establish MLTSS contracts, they must ensure that person-centered planning and options for self-direction are available to all beneficiaries. Person-centered planning is a concept that originated within the field of ID/DD. At its core, it is an approach to designing service plans based on values of individual choice and self-determination. Person-centered planning is a process intended to identify the strengths, capacities, preferences, needs, and desired outcomes of individuals. The process recognizes that individuals, their families, and others selected by the person best know what is needed. When individuals and families are at the center, services are most efficient and successful.

CMS has made great strides in clarifying expectations for person-centered planning through recent regulations concerning HCBS and the Community First Choice Option. It is particularly important that these standards are proactively carried to MLTSS programs. Many advocates are concerned that health plans interested in serving individuals with disabilities do not understand the history, meaning, and philosophy of person-centered planning. Many health plans entering the MLTSS environment come from a predominately medical-model orientation. Terms such as “patient-centered”

medical care or “interdisciplinary care teams” may sound similar to person-centered planning, but often mean wildly different things in practice. For instance, in some of the duals integration demonstration proposals states submitted, it was unclear whether development of service plans would even involve individuals receiving services, let alone be directed by them.

Options for self-direction are also important to promote in MLTSS programs. Self-direction is a broad term that refers to providing consumers more control over their services. CMS has provided different options within Medicaid to provide self-direction. One option allows individuals to hire, direct, train, and fire their own personal assistants and direct support professionals (known as employer authority). Another, more comprehensive option provides individuals with a flexible budget to purchase a range of goods and services to meet their needs (known as budget authority). Most often, individuals have chosen to use fiscal intermediaries to assist them with the financial management aspects of self-direction.

At first, there may seem to be inherent conflicts between promoting self-direction and principles of managed care. However, providing options for self-direction can mutually benefit individuals, states, and health plans. An extensive body of literature, including research from the Cash and Counseling demonstrations, has documented positive outcomes from self-direction for individuals and their families (Brown, Carlson, Dale, Foster, Phillips, & Schore, 2007). Providing options for self-direction has relatively minor cost implications and could produce savings associated with reduced administrative costs and the ability of individuals and families to allocate resources more efficiently. Finally, providing options for self-direction can assist states with gaining buy-in from individuals with disabilities and families. Of the 16 states that currently have MLTSS programs, 12 have offered options for self-direction, and four include budget authority in their models. The Wisconsin Family Care Program, for example, was designed on a framework of providing greater self-direction to individuals with ID/DD and their families.

- **RECOMMENDATION #6: CMS should encourage states and health plans to reinvest savings from MLTSS programs to address unmet needs and waiting lists.**

While research on cost savings is mixed, it is reasonable to hypothesize that if MLTSS programs are well-designed they could lead to savings through better coordination of acute and long-term services and supports. Some states have considered limiting the amount of profits that health plans can make (by putting in place mechanisms known as Medical Loss Ratios). Given the extent of unmet needs for individuals with ID/DD, states and health plans should be strongly encouraged to reinvest savings back into community-based services. Not all states maintain or report accurate waiting list data. However, according to available data, waiting lists for 1915(c) HCBS waiver programs have more than doubled over the past decade (Ng, Harrington, Musumeci, & Reaves, 2012). In 2011, there were 511,174 individuals in 38 states on waiver waiting lists. Approximately 62% (316,673) were individuals with ID/DD.

Some states have also encouraged health plans to provide additional benefits beyond those provided in Medicaid. For example, some health plans have provided additional prevention, dental, respite, wheelchair repair, and other services. Typically, plans have provided benefits that might produce savings or attract consumers who have a choice of plans. Opportunities for added benefits could provide self-advocates and families with tools to enhance systems of self-advocacy and flexible family supports, which have been difficult to fund through Medicaid. Health plans and states should also consider reinvesting savings in other sorely needed areas to promote community-living, such as housing, transportation, and the direct support workforce.

- **RECOMMENDATION #7: CMS and states should ensure that individuals with ID/DD and their families have accessible information and assistance from independent navigators to help them understand their enrollment choices and rights.**

To fully exercise choice and self-determination, individuals with ID/DD and their families must have access to understandable information and assistance to navigate complex managed care systems. Enrollment into duals integration demonstrations or MLTSS programs may be voluntary, mandatory, or have a passive (or “opt-out”) enrollment process. In most states, individuals will have a choice of health plans to select from. The transition from a traditional fee-for-service system into managed care can be extremely complicated and confusing. Yet, some states have elected to notify individuals only by mail. This is grossly inadequate for individuals with cognitive disabilities, individuals with limited reading ability, and individuals from diverse cultural backgrounds.

States must ensure that beneficiaries fully understand the transition to managed care and their enrollment options, rights, and responsibilities (Prindiville & Burke, 2011). One way states can ensure this is through independent enrollment navigators. A variety of community-based organizations could assist with filling these roles, such as local chapters of The Arc, other non-profit disability organizations, or Developmental Disabilities Act partners. One of the most important requirements is that they are conflict-free (in other words, are not providers of services or tied to managed care plans).

Assistance is also needed from community-based organizations in aggressive outreach and education efforts, particularly through organizations that can reach, and are trusted by, underserved communities. All materials must be available in a variety of accessible formats, including cognitively accessible language and language appropriate for the cultural and linguistic groups represented in the state.

- **RECOMMENDATION #8: The Department of Education, in collaboration with the Department of Health and Human Services and Social Security Administration, should assist students with disabilities and their families through the transition process as students move from high school to adult life in understanding and navigating HCBS and MLTSS.**

A long-standing issue for students with ID/DD and their families is the lack of information they receive during transition from high school about accessing and navigating the adult service and support systems. Youth with ID/DD and their families too often leave high school without connections to state agencies overseeing developmental disabilities services. They are not provided with accurate information about Medicaid as a lifeline to community living, including community-based employment services. Realistic information about their choices, options, and waiting lists for services and supports should be provided.

Having experienced a right to educational services, the lack of rights and available options from community-based services in the adult service system can come as a shock. Therefore, necessary connections are needed to self-advocacy organizations, Centers for Independent Living, non-profit disability organizations, and Developmental Disabilities Act partners. MLTSS provides one more layer of complexity for individuals with ID/DD trying to transition successfully from high school. Efforts should be launched to educate, connect, and assist youth with disabilities and their families in navigating the community-based services and supports system during the transition process.

### **Consumer Protections and Rights**

The President's Committee for People with Intellectual Disabilities and many advocates are concerned about the speed and scope with which states are pursuing MLTSS. Over the next couple years, hundreds of thousands of individuals with disabilities could be enrolled in MLTSS programs. Due primarily to budget pressures, many states are rushing to mandate statewide enrollment rather than providing consumers with choice, slowly phasing in programs, and learning from demonstrations and pilots. Many states are considering contracting with large, for-profit health plans, the majority of which have virtually no experience serving individuals with disabilities, especially individuals with ID/DD. Moreover, there are significant concerns about adequate state capacity to effectively oversee MLTSS programs. Timelines will vary based on existing state capacity and infrastructure. However, many states are already delaying initial plans as

they more fully realize the complexities and challenges involved. It takes resources, planning, and time to get it right.

- **RECOMMENDATION #9: CMS should not approve MLTSS programs without strong and transparent assessment of state and plan capacity and readiness to adequately serve individuals with ID/DD and their families.**

Strong CMS oversight is needed in the evaluation of state capacity and readiness to move forward. State proposals should not be approved without robust and meaningful consumer stakeholder engagement, strong consumer protections, and adequate state infrastructure and capacity. State capacity to oversee MLTSS programs includes having adequate staff with qualifications in core functions, such as: program management, contract monitoring, provider network adequacy, beneficiary rights and education, and rate setting (Lipson, Libersky, Machta, Flowers, & Fox-Grange, 2012). Information technology (IT) systems must also be in place to effectively monitor contracts and performance.

In addition to state readiness, it is essential to assess plan readiness. States and CMS should require health plans to demonstrate their ability to serve individuals with ID/DD through adequate networks and partnerships with the developmental disabilities network. Given the range of diverse needs within the population of individuals with developmental disabilities, health plans must be able to demonstrate robust networks of primary and specialty care that are properly trained in serving individuals with ID/DD. It is essential to put in place protections to avoid disruptions in care and services by allowing individuals to continue receiving services from current providers during the transition to MLTSS programs (commonly referred to as “continuity of care” requirements). Plans should build networks based on the needs of individuals with ID/DD, incorporating existing providers of home and community-based services and maximizing consumer choice. Health plans should also be required to form consumer-advisory boards that consist of a majority of beneficiaries with disabilities and families.

- **RECOMMENDATION #10: CMS should require states to have independent systems in place to assist consumers with complaints, advocate on their behalf, and monitor MLTSS programs for systemic problems (often referred to as ombuds programs).**

As states implement MLTSS programs there will be systemic challenges to confront and address as they mature. In order to meet these challenges and protect the rights of consumers, federal requirements are needed for states to establish independent, conflict-free ombuds programs. The term “ombuds” or “ombudsman” refers to an independent, external advocate that represents the needs and perspectives of beneficiaries. A coalition of twelve national aging and disability consumer organizations has developed a white paper outlining the following three core functions of an ombuds program (NSCLC, 2012):

- 1) *Individual Assistance:* The primary role of the ombuds programs should be to give individual members assistance in navigating the complexities of managed care. This role includes assisting consumers with understanding their rights and responsibilities, accessing benefits, and appeals at all levels of plan denial, reduction, or termination of service decisions.
- 2) *System Monitoring and Reporting:* The ombuds should provide policymakers and stakeholders an “on the ground” beneficiary perspective on how the demonstration or waiver is performing. The program can identify areas where individual problems demonstrate broader issues with system design or implementation.
- 3) *Consumer Education and Empowerment:* The ombuds must reach out to, and be a resource for beneficiaries, family caregivers and advocates. It is particularly important that the ombuds establish connections with hard to reach beneficiaries including, but not limited to, those who have limited English proficiency, are homeless, are homebound, lack literacy skills, have communication impairments, or are living in institutions.



Depending on existing state infrastructure, a variety of different entities could best fulfill ombuds functions. Given the range of diverse populations that will be served in MLTSS programs, a collaborative partnership approach makes sense. For individuals with ID/DD, the existing network of Protection and Advocacy Associations (P&As) provides a logical platform upon which to build. Self-advocacy organizations, centers for independent living, disability rights organizations, legal services, and other non-profit organizations might also fulfill ombuds functions.

Models of ombuds programs exist in states such as California, Hawaii, New York, Vermont, and Wisconsin. States have taken various approaches. For example, in Wisconsin the P&A, Disability Rights Wisconsin, operates the ombuds program for individuals under 60 participating in MLTSS programs. In Hawaii, the Hilopa Family to Family Health Information Center provides limited ombuds functions. In other states, legal services organizations and coalitions of local and state organizations have fulfilled ombuds roles.

One of the essential requirements of ombuds programs is independence. An ombuds should be located outside the state agency overseeing the MLTSS program and should not be affiliated with health plans (it should be conflict-free). It is also critical for the ombuds program to receive adequate funding. Existing structures such as P&As and legal services organizations are already stretched thin. Without adequate additional funding they will not be able to effectively fulfill added ombuds roles.

Ombuds programs should be considered an essential part of the state infrastructure necessary to establish a successful MLTSS program. However, avenues for additional federal support should be pursued. Some states, such as Vermont, have used Medicaid funding to cover some duties of ombuds programs. Recently, the Center for Medicare and Medicaid Innovation (CMMI) within CMS announced a funding opportunity for 15 of the states pursuing duals integration demonstrations to allow them to build capacity, including using funding to establish ombuds programs. Funding for additional states is needed.

- **RECOMMENDATION #11: The ACL should work with federal and state partners to promote supported decision making, self-determination, and self-advocacy, as well as avoiding inappropriate use of guardianship in MLTSS programs.**

Finally, as more states integrate acute and long-term services and supports, there are concerns about MLTSS programs contracting with health plans that historically come from a “medical-model” orientation. Health plans with little experience serving individuals with ID/DD will not understand how to best support self-determination and decision-making. There are concerns that health plans could urge the use of guardianship out of convenience or unfamiliarity with less restrictive alternatives, such as supported decision-making models. Ombuds programs could monitor and provide a level of protection against this from occurring. However, proactive measures should also be taken. For example, states could require training for health plans and networks on enhancing self-determination and supported decision making. Quality measures should also be established to promote supported decision-making and involvement of individuals with ID/DD in self-advocacy.

### **Quality Measurement, Data Collection, and Research**

Quality measurement and monitoring activities are powerful tools for consumers and states. While strong HCBS quality systems are important in traditional fee-for-service Medicaid, quality measures take on increased significance in a MLTSS environment because they are often tied to accountability and payment for MCOs. Quality measures and reporting requirements can help:

- Ensure consumer protections, identify problems, and enhance plan performance
- Provide consumers with information to make choices about plan selection

- Align payments, incentives, and penalties to meet desired goals –such as promoting options for self-direction, rebalancing, community employment, or strengthening the direct support professional workforce

➤ **RECOMMENDATION #12: CMS should work with the ACL and key stakeholders to issue guidance on a core set of HCBS quality and reporting measures that are appropriate to specific needs of people with ID/DD and focus on overall quality-of-life outcomes.**

Currently there is very little federal guidance to states on quality measures for MLTSS programs. While CMS has required a core set of quality measures on acute care for the duals integration demonstrations, core measures for HCBS have not been required. States have taken vastly different approaches to measuring HCBS quality in MLTSS programs. Figure 8 provides examples of HCBS quality measures currently being used by states with MLTSS programs. The majority of HCBS measures states have used are process and structural measures (for example, the timeliness of receiving services). More challenging to measure, but equally important to achieving goals of HCBS, are person-centered outcomes, such as consumer experience and quality-of-life outcomes.

Given the great diversity among HCBS programs and populations of individuals with disabilities, developing guidance on a core set of measures is challenging. Yet, over the past several decades the field has moved towards a more common vision for community living. CMS has sought to achieve greater consistency through recent initiatives, guidance, and regulations. For example, a much more consistent vision of person-centered planning has emerged across different HCBS options, including new provisions in the Affordable Care Act.

**FIGURE 8: Examples of HCBS Quality Measures in Existing MLTSS Programs, 2012**

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• Timeliness of completing level of care assessments</li> <li>• Timeliness of initiating HCBS</li> <li>• Turnover among interdisciplinary team members</li> <li>• Receipt of services authorized</li> <li>• Person-centeredness of service planning</li> <li>• Institutional admissions</li> <li>• Successful community transitions</li> <li>• Participation in volunteer or paid work</li> <li>• Participation in self-directed services</li> </ul> | <ul style="list-style-type: none"> <li>• Member satisfaction</li> <li>• Member experience</li> <li>• Service plan audits</li> <li>• Observation of service planning and coordination</li> <li>• Review and audit of LTSS provider network availability</li> <li>• Comparison of LTSS provider claims paid and encounters submitted</li> <li>• Review of LTSS utilization</li> <li>• Review of critical incidents</li> <li>• In-person interviews with members</li> </ul> |
|---|--|

Saucier, P., Kasten, J., Burwell, B., & Gold, L. (2012)



Aging and disability consumer groups have found a great deal of common ground in such areas as rebalancing, self-direction, community employment, and the rights of individuals to live in the most integrated setting appropriate to their needs. While there are some differences between populations, common elements of an overall vision for HCBS exist and are seen in such national efforts as the AARP Scorecard (Reinhard, Kassner, Houser, & Mollica, 2011) and the National Core Indicators Project (NASDDDS & HSRI, 2011).

- **RECOMMENDATION #13: CMS should only approve MLTSS proposals that include quality measures and reporting (as indicators) that ensure access to competent, stable, and well-trained direct support professional workforce.**

Availability of an adequately trained and compensated direct support professional workforce is an essential component of quality. The ability to find, keep and retain qualified direct support professionals is a major challenge for individuals with disabilities, their families, and service providers. Annual turnover rates for direct support professionals serving individuals with ID/DD average around 50% (Hewitt, Lakin, & Larson, 2006). Demand for direct support professionals will increase in coming decades due to the aging of the U.S. population, including aging of individuals with ID/DD and individuals living with aging family caregivers. The developmental disabilities field has launched initiatives to enhance training of direct support professionals, such as the College of Direct Supports and the CMS' sponsored Direct Service Workforce Resource Center, and to improve recruitment and retention. However, major factors driving high turnover and low retention are low wages and benefits for direct support professionals (ANCOR, 2009).

MLTSS could provide opportunities to improve data collection and incentives to address workforce issues. CMS should require minimum, baseline data on workforce that includes wages and benefits, work hours, turnover, training, and availability of workers to meet the needs of individuals with disabilities and their families (Edelstein & Seavey, 2009). Quality measures and performance incentives for health plans could be designed around these measures to achieve outcomes, such as reduced turnover and increased availability of trained direct support professionals. In addition, as previously mentioned, if savings are achieved through MLTSS programs, states and health plans should consider reinvesting savings into infrastructure to better recruit and retain direct support professionals. States could also consider investing in infrastructure to support self-directed options for individuals with disabilities and their families to hire workers, such as fiscal intermediaries and registries of available direct support professionals.

The Administration for Community Living is well positioned to work with key stakeholders to assist CMS in developing guidance on core HCBS quality measures for MLTSS. Attention must be given to ensure that core measures are appropriate across different HCBS populations. Supplemental measures may be necessary to address

needs of specific subpopulations, such as individuals with ID/DD. Moreover, balance is needed in promoting greater consistency across states, while maintaining a level of flexibility for states to select appropriate measures based on their unique needs and desired outcomes for programs.

- **RECOMMENDATION #14: CMS should work with the ACL and key stakeholders to develop measures to fill gaps in HCBS quality measurement, for both the unique needs of specific populations such as individuals with ID/DD as well as measures that apply to all populations.**

Unfortunately, significant gaps currently exist in the availability of valid and reliable HCBS quality measures. The National Quality Forum (NQF) is the leading non-profit organization that endorses national measures. The NQF recently established a workgroup on dual eligible beneficiaries that examined 148 potential HCBS measures from various sources, including an extensive environmental scan conducted by the Agency for Healthcare Research and Quality (AHRQ) at the request of Congress (NQF, 2012). The majority of measures did not meet scientific standards and criteria for approval across populations. The NQF identified some promising measures, highlighted important quality domains and gaps, but has not yet endorsed any HCBS quality measures. The void of approved HCBS quality measures is extremely troublesome given the rapid pace at which states are venturing into MLTSS.

Work is beginning at the federal level to develop measures to meet standards for NQF endorsement. CMS, in partnership with AHRQ, is working with contractors to develop and test a new HCBS Experience Survey. The survey is intended for use across all populations of individuals with disabilities that use HCBS. Versions will be made available in English and Spanish. The survey will be field tested across the country using a combination of phone and face-to-face interviews. Careful attention was paid in designing the survey to fit with other surveys that are frequently used to measure consumer experience by managed care health plans –known as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) family of measures.

The survey measures quality of services received from direct support professionals and case managers. It also measures quality in areas of transportation, personal safety, community inclusion, and empowerment. In addition, supplemental measures are being developed on employment which could provide a useful tool for advocates to promote community employment. Following testing, the goal is to seek NQF approval, which will greatly increase the likelihood of adoption by states and plans.

As the HCBS Experience Survey is further developed, it is important for the ID/DD community to have continued input. One concern that has been raised by some advocates is lack of allowance for surrogate or proxy respondents. While consumers should always be the primary respondents, not providing alternative methods for data collection could exclude a significant number of individuals with cognitive disabilities. The ID/DD research community, including the network of University Centers for Excellence in Developmental Disabilities (UCEDDs), has extensive experience designing surveys for individuals with ID/DD and family members that maximize consumer input and could be of assistance in addressing this issue.

In addition, attention must be paid to the infrastructure and resources that will be needed to administer consumer surveys. Self-advocacy and disability organizations could play key roles in this area. In the mental health system, at least four states have developed quality measurement systems that use independent peer-to-peer consumer organizations as interviewers. Some state developmental disabilities service systems have hired and trained self-advocates with ID/DD to assist with HCBS quality systems. For example, Vermont contracts with the statewide self-advocacy organization, Green Mountain Self-Advocates, to provide consumer input related to their MLTSS program.

Development of the HCBS Experience survey is a significant step forward. However, much stronger federal investment in HCBS quality measurement is urgently needed if MLTSS programs are to succeed. The quality structures and entities that currently exist in the managed care environment predominately focus on acute care and come from a

“medical model” orientation. The ID/DD community can play a leadership role in educating and transforming these quality systems to adopt a more person-centered, non-medical approach to measuring quality and outcomes. Two promising areas to start with are the National Core Indicators and Council on Quality and Leadership.

The National Core Indicators (NCI) project is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute. The NCI are a nationally recognized set of performance and outcome indicators for developmental disabilities service systems that have been in use since 1997. The framework includes approximately 100 performance and outcome indicators organized across five broad domains:

- Individual Outcomes
- Health, Welfare, & Rights
- Staff Stability & Competency
- Family Outcomes
- System Performance

Data is collected from multiple sources. An Adult Consumer Survey is conducted face-to-face with service recipients and their families or other representatives. In addition, three different versions of Family Surveys are administered through the mail to gain the perspectives of family members and guardians on quality. Provider surveys and systems data are also used. The NCI framework is currently used by 34 states, with AIDD providing resources to expand NCI to all states by 2016. While it has been primarily used at the state level, versus a tool for use at the plan level, potential exists to explore its use in MLTSS programs.

The Council on Quality and Leadership (CQL) is a non-profit organization dedicated to the definition, promotion, measurement and improvement of personal and community quality of life for people with disabilities, people with mental illness, and older adults. A central focus of CQL’s work over the past 20 years has been development of a set of



valid and reliable measures of individual quality of life known as Personal Outcome Measures. The measures serve as a tool for evaluating personal quality of life, defined by individuals, and the degree to which organizations support individualized outcomes.

CQL has accredited several hundred community-based organizations serving persons with ID/DD and other disabilities. The Personal Outcome Measures have been primarily used as a quality improvement tool to assist organizations and service providers. However, a great deal can be learned from its approach to measuring person-centered outcomes. Potential application within a MLTSS environment should be explored.

- **RECOMMENDATION #15: The ACL should convene federal partners, researchers, states, health plans, and others to promote external evaluations and research on MLTSS.**

As previously noted, limited research exists on outcomes of MLTSS programs for individuals with disabilities and their families. As states move forward, strong investments in research and evaluation are sorely needed at both state and federal levels. Independent external evaluations are necessary at the state level to closely monitor and assist stakeholders with improvements over time. Successful development of MLTSS will require information technology (IT) improvements for data collection. CMS, states, and health plans should work together to make as much data as possible available to researchers, while protecting confidentiality and rights, in order to promote independent research on the outcomes of MLTSS. Moreover, significant opportunities exist for health plans to develop partnerships with disability researchers to explore data on health disparities and develop evidence-based interventions to promote health and wellness.

The ACL can play a leading role in bringing together multiple sectors to promote research on MLTSS. The ACL could convene states, health plans, philanthropic foundations, consumer stakeholders, and federal agencies to develop partnerships and a research agenda. The Administration on Intellectual and Developmental Disabilities,

the University Centers for Excellence in Developmental Disabilities (UCEDDs) and Councils on Developmental Disabilities could provide networks to enhance evaluations and research. Federal agencies such as the National Institute for Disability and Rehabilitation Research (NIDRR), Agency for Health Care Research and Quality (AHRQ), National Institutes for Health (NIH), and the Centers for Disease Control and Prevention (CDC) could play key roles in advancing a strong research agenda on outcomes of MLTSS.

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## CASE STUDIES OF MANAGED LONG-TERM SERVICES AND SUPPORTS PROGRAMS SERVING INDIVIDUALS WITH ID/DD

State officials and consumer advocates from Arizona, Michigan, and Vermont briefed the President's Committee for People with Intellectual Disabilities on MLTSS programs in their states. Case studies below were informed by their presentations, follow up consultation, and information from Gettings (2009), Health Management Associates (2010), and Saucier, Kasten, Burwell, & Gold (2012).

### Arizona Long-Term Care System (ALTCS)

Arizona did not begin participating in the Medicaid program until 1982. Their entire Medicaid program is operated under an 1115 Demonstration waiver, based on a statewide mandatory managed care structure known as the Arizona Health Care Cost Containment System (AHCCCS). In 1988-1989 long-term services and supports were phased in under a program known as the Arizona Long Term Care System (ALTCS). The ALTCS is divided into two populations: 1) older individuals and individuals with physical disabilities; and 2) individuals with ID/DD. For older individuals and individuals with physical disabilities, Arizona contracts with three managed care entities; tribal services are provided on a fee-for-service basis. For individuals with ID/DD, the state Medicaid agency (AHCCS) contracts with the state developmental disabilities service agency, the Department of Economic Security/Division of Developmental Disabilities (DES/DDD). DDD negotiates a managed care contract that outlines its responsibilities in providing all acute, behavioral health, and long-

*This is a self directed system, thus consumers can choose an agency to provide services or use a fiscal intermediary; our state prides itself on consumer choice. We do not have any waiting lists, however we can have network capacity issues in certain parts of our state which can be an issue anywhere. The state coordinates care between the medical and community based systems.*

*Maureen Casey (Parent Advocate from Arizona)*

term services and supports. DDD subcontracts with health plans to deliver acute care. Behavioral health services are provided through regional agencies under an interagency agreement.

Long-term services and supports for people with ID/DD are provided in a managed care model in which the DDD contracts with providers, including HCBS service providers. The DDD employs case managers, or Support Coordinators, who are accountable both to DDD and AHCCCS. Support Coordinators are responsible for coordinating all services that are implemented across systems –acute, behavioral health, and long-term services and supports. HCBS services in Arizona are an entitlement in state statute for all individuals with ID/DD at “immediate risk of institutionalization.”

Families report a robust service delivery system with a focus on consumer choice. Because the state legislature limits the ability of state employees to direct consumers to certain contracted providers, families rely on providers, other families, and advocacy organizations to make choices. Supporting individuals to enter the workforce and to live in the community with supports are major goals of the DDD system.

### **Michigan Managed Specialty Services and Supports Program (MSSSP)**

Michigan began implementing its managed care program in 1998. CMS authority for the Michigan Managed Specialty Services and Supports Program (MSSP) is granted under a concurrent 1915(b) and 1915(c) HCBS waiver. The program is statewide and mandatory. The state contracts with regional Prepaid Inpatient Health Plans (PIHPs). The foundation of the PIHP system is a network of county-based entities, Community Mental Health Services Programs, which serve individuals with mental illness, substance abuse, and ID/DD. There are currently 18 PIHPs across the state serving a single county or group of counties.

PIHPs are responsible for all behavioral health, substance abuse, case management, and LTSS services, including HCBS waiver services for individuals with ID/DD. Supports Coordinators are used to help coordinate acute, behavioral, and long-term

services and supports –not just the supports and services funded through their managed care entity. According to advocates, managed care for acute care has improved access to doctors and medical care, including specialists, for those who utilize Medicaid.

PIHPs are responsible for serving all eligible people in their service area regardless of their “level of care,” as long as the services are medically necessary. Advocates in Michigan have fought for a broad definition of medical necessity to avoid denial of needed services and supports for individuals with disabilities. Use of person-centered planning has been required by Michigan law since 1993. Home and community-based services have improved and expanded. The 1915(b) waiver provides flexible services and supports to promote community inclusion, participation, and productivity under this definition of medical necessity. There is no waiting list for 1915(c) HCBS waiver services for individuals with ID/DD. Approximately 57% of individuals with ID/DD reside with family; and supports are provided to families. Michigan no longer operates any public institutions or private ICFs/DD for individuals with ID/DD.

The state sets the direction for delivery of services and supports with strong stakeholder involvement from advocates. Advocates assisted the state with the move towards managed care to ensure minimal disruptions in care for individuals. Current providers were maintained until the person receiving services and their supporters decided, in a person-centered planning process, that they wanted another provider or to be supported differently. Michigan has an extensive advocacy network, independent of the service system, which provides individual advice, guidance, and assistance with

*We would urge that persons with ID/DD, their families and representatives be very alert and immediately get active. It is critical to get involved in the discussion, planning, and implementation of managed care. Insist on regular communication, both formal and informal. Offer to help with anything including details. Not only is that where the devil is, it is usually what determines how and where the system touches or affects individuals. Coalesce with others, including those who represent other populations likely to be affected, and providers.*

*Dohn Hoyle, Executive Director, The Arc of Michigan*

complaints and appeals. The rights of service recipients are written in statute and extensive rules govern the operation of Recipients Rights Offices. Regional entities who manage Medicaid funding for supports and services are also required to have a “Customer Service” department or office, which have been staffed by individuals who receive services and family members. This system provides assistance in navigating or negotiating the system.

The state reports regularly by region on quality and performance monitoring, such as penetration rates, how quickly individuals receive services following initial requests, and how many individuals are working at minimum wage or above and hours of work. This data is public so anyone can compare performance across regions. It also goes to the state Quality Improvement Council. Advocacy organizations sit on the Council, which sets acceptable standards to be met by PIHPs. Information on quality also goes to the Developmental Disabilities Practice Improvement Team, which similarly includes representation of local advocacy organizations.

### **Vermont Global Commitment Waiver**

Vermont was approved for an 1115 Medicaid demonstration waiver in 2005 known as the Vermont Global Commitment to Health Waiver. The state’s interest in applying for the waiver was driven by desire for flexibility. The state sought to gain greater flexibility to prioritize services, reduce administrative burdens associated with separate authorities, and capture savings for reinvestment in flexible supports. The state Medicaid agency became the managed care entity. In exchange, the state agreed to comply with federal regulations for Medicaid MCOs and to assume a level of financial risk under a negotiated global federal spending cap.

Services for individuals with ID/DD were included in the Global Commitment waiver. Prior to the Global Commitment Waiver, Vermont was already a leader in providing community-based services to individuals with ID/DD. The state had also already moved away from fee-for-service payments. The Global Commitment waiver provided the state

with additional flexibility to expand covered populations and to tailor services to certain eligibility and priority determinations.

Vermont has a unique statewide plan (known as the State System of Care Plan) that clearly details the values, vision, and method for providing developmental disabilities services. Eligible individuals may receive targeted case management, the bridge program (care coordination for children), and flexible family funding . HCBS services are funded using priorities based on a person's circumstances.

1. Health and Safety: Ongoing, direct supports and/or supervision are needed to prevent imminent risk to the individual's personal health or safety. (Priority is for adults age 18 and over.)
2. Public Safety: Ongoing, direct supports and/or supervision are needed to prevent an adult who poses a risk to public safety from endangering others. (Priority is for adults age 18 and over.)
3. Preventing Institutionalization – Nursing Facilities: Ongoing, direct supports and/or supervision are needed to prevent or end institutionalization in nursing facilities when deemed appropriate by Pre-Admission Screening and Resident Review (PASRR). (Priority is for children and adults.) Services are legally mandated.
4. Preventing Institutionalization – Psychiatric Hospitals and ICF/DD: Ongoing, direct supports and/or supervision needed to prevent or end long term stays in inpatient public or private psychiatric hospitals or end institutionalization in an ICF/DD. (Priority is for children and adults.)

5. Employment for High School Graduates: Ongoing, direct supports and/or supervision needed for a high school graduate to maintain employment upon graduation. (Priority for adults age 19 and over.)
6. Parenting: Ongoing, direct supports and/or supervision needed for a parent with developmental disabilities to provide training in parenting skills to help keep a child under the age of 18 at home. Services may not substitute for regular role and expenses of parenting; maximum amount is \$7,800 per person per year. (Priority is for adults age 18 and over.)

Vermont has no waiting lists for HCBS services for individuals with ID/DD who meet funding eligibility criteria. This has primarily occurred through flexibilities to target services to priority needs. However, it does not mean there are no unmet needs. All eligible individuals and their families receive some services and supports. Some individuals receive higher levels of services and supports if they meet a funding priority.

Vermont has also been a leader in supporting community employment. The number of individuals with ID/DD receiving community employment supports in Vermont is four times the national average.

*As other states convert to a managed care system, the key is nothing about us without us. To build a system that meets the needs of people with intellectual and developmental disabilities, they need to be involved at all levels. One way to measure the strength of a system is to look at the strength of the state's self advocacy movement.*

*Self Advocacy in Vermont is strong, and diverse. Despite being a rural state, we have 21 local groups with 600 plus active members. We are not just any organization; we have a purpose. Our purpose is to strengthen our peer connections. It is important to have a peer to peer connection because you learn how much you have in common. You get the honest truth from your peers. When information comes from others, it can be sugar coated; the environment can feel too controlling or biased. When you get involved in self advocacy, you realize you are not alone when facing tough times."*

*Max Barrows, Green Mountain Self Advocates*

## GLOSSARY AND ACRONYMS

### **Managed Care Terms:**

*Capitation or Capitated Rate:* “Capitation” means a fixed payment. Managed care organizations receive a fixed amount per person each month to cover all services in a contract. This is called their “capitated rate.”

*Carve Out:* “Carve out” means exclude. A lot of times people say individuals with ID/DD are “carved out” or home and community-based services are “carved out.” This means they are not included in the MLTSS program.

*Continuity of Care:* “Continuity of Care” means that people can continue to see their current doctor or get services from their current provider. When states do contracts with managed care organizations they can require them to allow this.

*Dual Eligible Beneficiaries:* “Dual eligibles” are individuals that receive both Medicaid and Medicare.

*Duals Integration:* “Duals integration” means trying to make Medicaid and Medicare work better together. Sometimes it means combining Medicaid and Medicare payments into one payment.

*Fee-for-Service:* “Fee-for-service” means reimbursing doctors and providers for services they provide. This is the traditional way Medicaid has worked. Individuals with Medicaid can go to any qualified doctor or provider to get services.

*Managed Care Organization:* A managed care organization (MCO) is an entity that states contract with to provide health care and/or long-term services and supports. Usually this is a health plan. Although, sometimes it can be a state agency or local/regional agency.

*Managed Long-Term Services and Supports:* Managed-Long-Term Services and Supports (MLTSS) is a term that refers to financing and delivering long-term services and supports based on principles of managed care. Typically states sign

a contract with a managed care organizations to provide all services for a fixed per person capitated rate.

*Ombuds or Ombudsman Programs:* “Ombuds” or “Ombudsman” programs are independent advocates that can assist individuals with protecting their rights in MLTSS programs.

*Passive or “Opt-Out” Enrollment:* “Passive enrollment” enrollment means that individuals are automatically enrolled in MLTSS programs. However, they have the option to disenroll, or “opt-out.”

**Frequently Used Acronyms:**

ACL	Administration for Community Living
AIDD	Administration on Intellectual and Developmental Disabilities
CMS	Centers for Medicare and Medicaid Services
HCBS	Home and Community-Based Services
ICF/DD	Intermediate Care Facility for Individuals with Developmental Disabilities
ID/DD	Intellectual and Developmental Disabilities
MLTSS	Managed Long-Term Services and Supports
MCO	Managed Care Organizations



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