

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



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

**2012 Report to the President  
Accessible Summary**

# ACCESSIBLE SUMMARY

## Introduction

This is an accessible short summary of the full President's Committee for People with Intellectual Disabilities 2012 Report to the President on Managed Long-Term Services and Supports. It uses easier to understand language and explains the main points and recommendations.

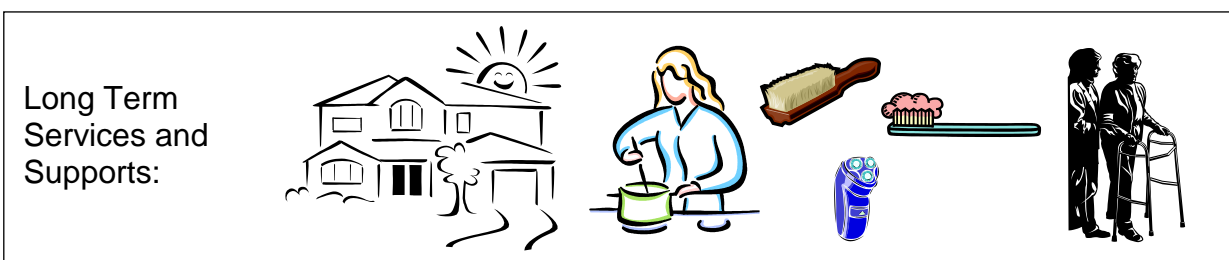
Across the country, states are starting to change how they pay for and provide long-term services and supports. This report provides background information on this change and recommendations to federal agencies on how to best serve people with intellectual and developmental disabilities in this change.

## Background

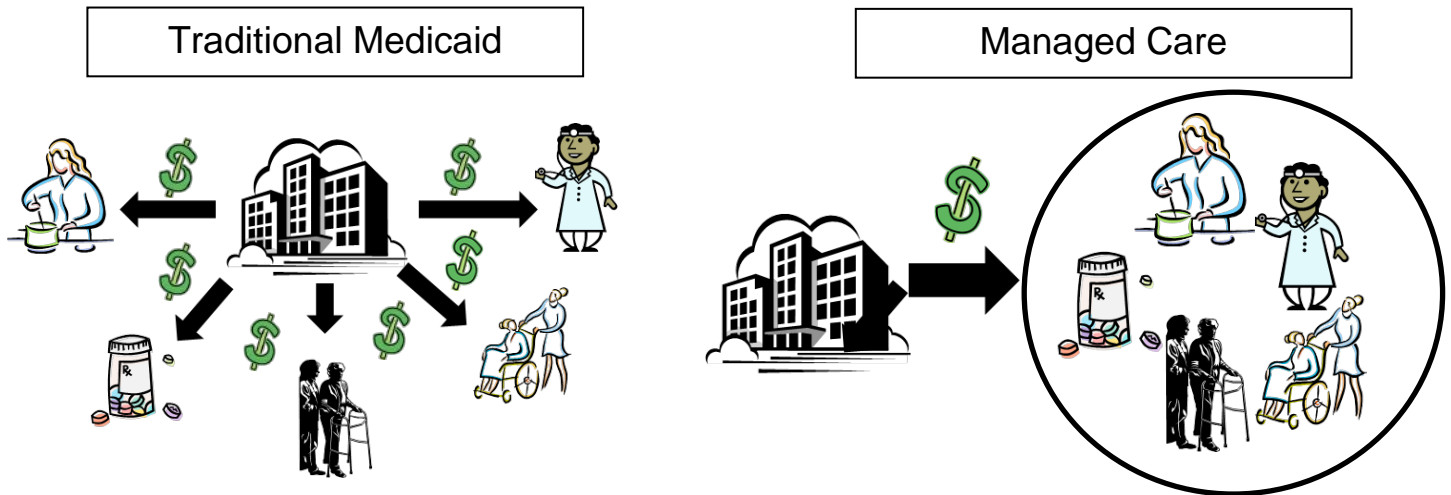
*What are "Managed Long-Term Services and Supports"?*

*Managed Long-Term Services and Supports* refers to a change in how states will pay for and provide the long-term services and supports that people with disabilities use in their daily lives.

*Long-term services and supports* are the services and supports that people need for daily life. They are sometimes called *waiver services*. This includes personal care attendants, home care assistance, and group homes. Long-term services and supports help people with daily tasks, like getting dressed, bathing, cleaning the house, or taking medications. Long-term services and supports is often shortened to LTSS.



*Managed* long-term services and supports means that states are changing how they pay for and provide these services. Instead of the state paying each provider for services, the state will sign a contract with a *managed care organization*. A managed care organization is a company that provides health care and other services. The managed care organization will be responsible for providing each person on Medicaid with all of the services that he or she might need.



There are two important ideas needed to understand managed care. The first is *incentives*; the other is the *fragmentation versus coordination*.

### Important Terms

#### *Incentives*

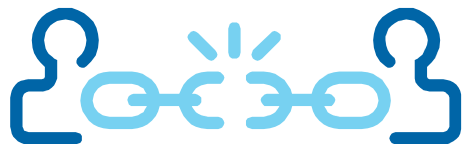
When a person or company might benefit from doing something, we say that the person or company has an *incentive* to do it. For example, if I want to hire you, I'll need to give you good reasons why you should work for my company, like higher pay. I need to give you an *incentive* to change jobs and come work for me.

There are *incentives* in health care and LTSS as well. When doctors or providers are paid for each service they provide, they have incentives to provide more service – even if they aren't the services a person needs most. The goal of managed care is to change these incentives. Managed care organizations try to use money to focus on keeping people healthy, instead of only paying for more services.



#### *Fragmentation and Coordination*

*Fragmented* means broken-up. Today, a lot of our health care services, including LTSS are *fragmented*. It's rare for doctors or providers to talk to each other or to help make a plan for the health of their patients. It's even rarer for doctors to talk to providers of LTSS. *Fragmented* medical services cause people to be confused about their medical care, prescriptions, and what they are supposed to do to stay healthy.





**Concerns:** The “managed” part of managed LTSS means that one company will provide most services. Some advocates are concerned that this could limit the options for people on Medicaid, or force some people to change doctors or service providers.



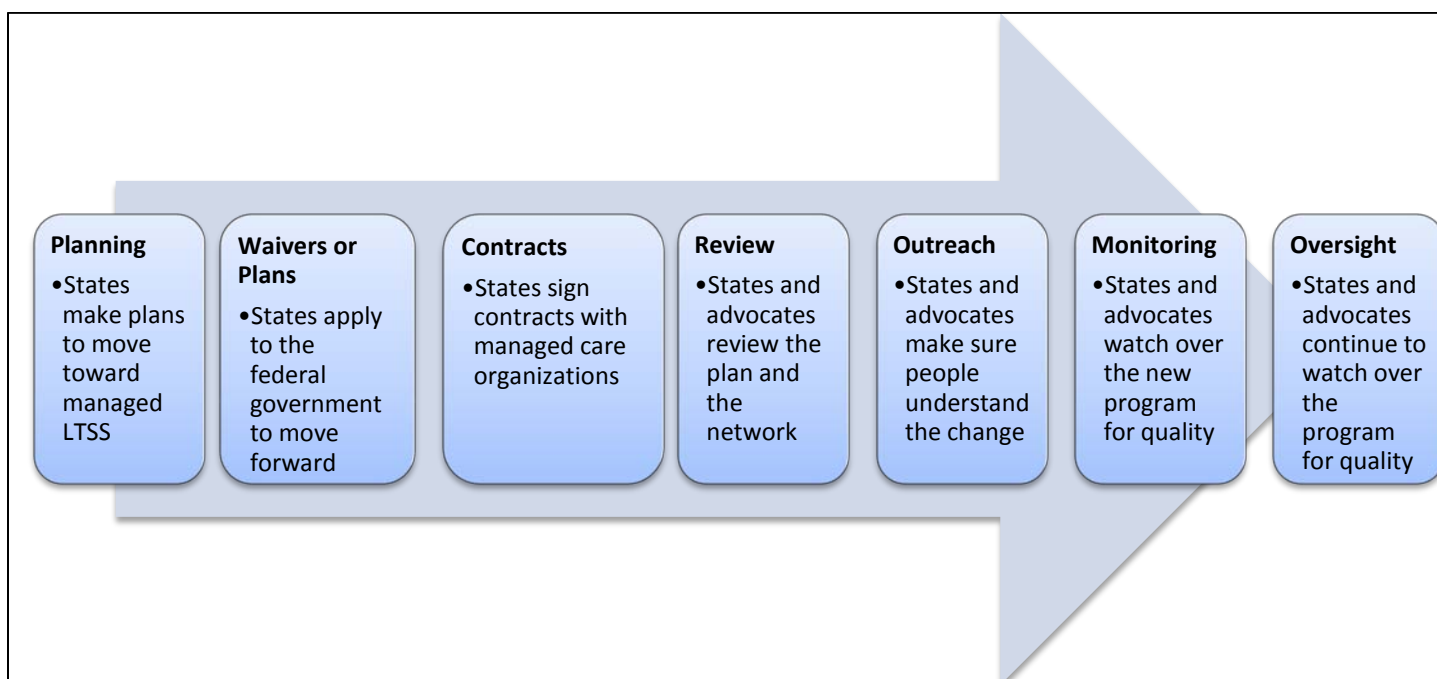
Others are concerned that managed care organizations have limited experience serving people with intellectual and/or developmental disabilities. Managed care organizations are usually health care providers who might not have experience supporting people for self-determination and independence.

The figure below outlines the potential benefits and concerns:

Benefits	Concerns
Service coordination	Limited choice of providers
Save money	Need for state oversight
Reduce waiting lists	Lack of experience serving people with ID/DD
Care focused on staying healthy	






### Can Self-Advocates Get Involved?

Yes! Self-advocates can and should get involved. Providing LTSS in a “managed” way is new, so states and managed care organizations need to hear from self-advocates. Self-advocates can get involved at any stage in the process. The graphic below shows the timeline of activities where self-advocates can get involved as states move to managed LTSS.



## Recommendations

The recommendations will call on several federal agencies to take action. Here is a list of the federal agencies in the recommendations and what they do.

Federal Agency	Duties
<p><b>Administration for Community Living (ACL)</b></p> 	<p>ACL oversees the Administration on Intellectual and Developmental Disabilities, Office on Disability, and Administration on Aging. It works to increase access to community supports and full participation for older people and people with disabilities.</p>
<p><b>Administration on Intellectual and Developmental Disabilities (AIDD)</b></p> 	<p>AIDD is the federal agency that supports the developmental disabilities network. The network includes Developmental Disabilities Councils (DD Councils), University Centers for Excellence in Developmental Disabilities (UCEDDs), and Protection and Advocacy systems (P&amp;As).</p>
<p><b>Center for Medicare and Medicaid Services (CMS)</b></p> 	<p>CMS oversees the Medicare and Medicaid programs. They must approve any state plan to move to a “managed” model in Medicaid.</p>
<p><b>Department of Health and Human Services (HHS)</b></p> 	<p>HHS is responsible for all of the health and other service programs in the federal government, including Medicaid. ACL, AIDD, and CMS are all a part of HHS.</p>
<p><b>Department of Education (DOE)</b></p> 	<p>DOE is the federal agency responsible for all education programs and policies in the United States.</p>
<p><b>Social Security Administration (SSA)</b></p> 	<p>SSA is the federal agency in charge of Social Security, including Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).</p>

## Disability Stakeholder Engagement

### **1. The Administration for Community Living (ACL) should have funds to educate self-advocates and family members about managed LTSS.**

It is very important that self-advocates, families, and other disability advocates be involved as states move to managed LTSS. Advocates must understand the process and potential benefits and risks in order to be meaningfully involved. ACL should have the funds to provide this education, training, and assistance so that self-advocates and others can be involved.



### **2. The Administration for Community Living (ACL) and the Centers for Medicare and Medicaid Services (CMS) should help fund coalitions of self-advocacy organizations and other groups to get involved in the move toward managed LTSS in their states.**

Self-advocacy groups should be involved as states move to managed LTSS. However, most groups lack the money for such an effort. Two parts of the federal government, ACL and CMS, should work together to provide money for self-advocacy and other advocacy groups to get involved.



### **3. The Centers for Medicare and Medicaid Services (CMS) should work with the Administration on Community Living (ACL) to ensure that states include disability advocates and others affected by the change.**

CMS must approve each state's plan to move toward managed LTSS. ACL should work with CMS to only approve states that have plans to meaningfully include disability advocates and others affected by the change.

## Choice and Self-Determination

### **4. The Centers for Medicare and Medicaid Services (CMS) should not allow states to carve out any institutional services and settings (including nursing homes and ICFs/ID) from MLTSS.**



Any service that is “carved-out” of managed care means that the managed care organization would not be responsible for providing or paying for those services. Leaving out settings like nursing homes and intermediate care facilities (ICFs) would create an incentive for the managed care organization to encourage people to live in those settings, particularly people with more significant needs. (The term *incentive* is explained on page 2). All settings should be included in managed LTSS so that all people have access to the benefits of managed care and managed care organizations do not have incentives to encourage a setting that is not appropriate for the individual.

**5. The Centers for Medicare and Medicaid Services (CMS) should promote person-centered planning and self-directed supports in managed LTSS.**

Person-centered planning and self-directed supports are very important to promoting self-determination. These ideas may be new to the managed care organizations that may not have experience serving people with intellectual and developmental disabilities. CMS and states must ensure that person-centered planning and self-direction is included in managed LTSS.



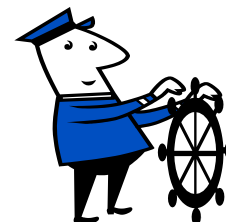
**6. The Centers for Medicare and Medicaid Services (CMS) should make sure states to use any savings from the change to managed LTSS to improve services or serve those on the waiting list.**

One of the potential benefits of moving toward managed LTSS is the possibility of saving money. CMS and states should make sure that these savings are used to improve services or serve people on the waiting list.



**7. The Centers for Medicare and Medicaid Services (CMS) and states should provide “navigators” to help people with disabilities understand their options, rights, and responsibilities under the new managed LTSS system.**

“Navigators” help people find their way. The new system of managed LTSS can be very confusing. CMS and states should provide each person on Medicaid with a “navigator” to help people understand their options, rights, and responsibilities under the new system.



**8. The Department of Education, Department of Health and Human Services, and Social Security Administration should work together to ensure that students and families know their options for LTSS when they transition from high school.**

Transitioning from high school into post-secondary school or work is a challenging time for all students and can be more challenging for students with disabilities. Often, families lack information on their options for LTSS at a time when students might be transitioning from their family home. With the move to managed care, states and schools will need to work even harder to help students and families understand their options, rights, and responsibilities.



Consumer Protection and Rights

**9. The Centers for Medicare and Medicaid Services (CMS) should ensure that states are ready to implement and oversee MLTSS programs and are contracting with health plans that can adequately serve individuals with intellectual and developmental disabilities.**



States have to be ready to implement and oversee MLTSS programs. Managed care organizations often operate a network of providers. Mostly, people on Medicaid under managed LTSS will only be able to receive services from providers in that network. Before moving forward with managed LTSS, CMS and states must ensure that the network is ready to meet the needs of people with intellectual and developmental disabilities.

**10. The Centers for Medicare and Medicaid Services (CMS) should require states to have systems or organizations dedicated to helping people on Medicaid with complaints and appeals, to advocate on their behalf, and to monitor the system as a whole.**

Managed LTSS can be confusing, particularly if something goes wrong. States should hire independent advocates, often called “Ombudsmen,” to assist and advocate for people on Medicaid if they have complaints or need to appeal a decision. These “ombuds” programs should also keep watch over the system as a whole to ensure that the rights of people on Medicaid are protected.



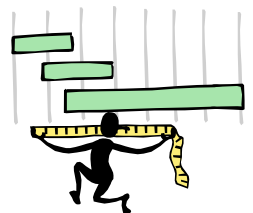
**11. The Administration for Community Living (ACL) should work with states to promote supported decision-making, self-determination, and self-advocacy – as well as avoid inappropriate guardianship – in states moving toward managed LTSS.**

Managed care organizations often have little experience working with people with intellectual and developmental disabilities. States should ensure that managed care organizations and care coordinators are encouraging supported decision-making, self-determination, and self-advocacy so that managed care organizations do not encourage guardianship where it is not appropriate.

Quality Measurement, Data Collection, and Research

**12. The Centers for Medicare and Medicaid Services (CMS) and Administration for Community Living (ACL) should work together to create consistent measures of quality specific to people with intellectual and developmental disabilities.**

Managed care organizations often have little experience working with people with intellectual and developmental disabilities. Because of this lack of experience, states should pay special attention and create measures of quality specifically for people with intellectual and developmental disabilities.



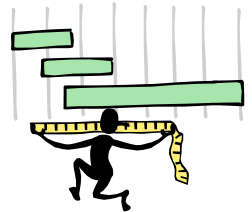
**13. The Centers for Medicare and Medicaid Services (CMS) should only allow managed LTSS to move forward if states will report on the quality of the direct support professional workforce.**

High quality direct support professionals are very important to high quality LTSS. Managed care organizations and states should be required to report data on the wages, hours, turnover, and availability of workers. This reporting should encourage managed care organizations to improve the workforce.



**14. The Centers for Medicare and Medicaid Services (CMS) and Administration for Community Living (ACL) should work together to create measures of quality for home and community-based services.**

The system of long-term services and supports across the country lacks measures of quality. Federal agencies and states should work together to create these measures. States and managed care organizations should be required to report on them.



**15. The Administration for Community Living (ACL) should bring together federal agencies, states, researchers, and health plans to promote research on managed long-term services and supports.**

Overall, there is not enough knowledge about managed long-term services and supports, particularly for people with intellectual and developmental disabilities. Federal agencies, states, researchers, and health plans should work together to do research on managed long-term services and supports and how it affects people.

