



# **Managed Long-Term Services and Supports: Engaging in the Stakeholder Process**

*July 24, 2012*



# Agenda

- Housekeeping/Introductions
- Setting the stage: Where are we now? Where are we headed?
- Getting engaged in the process
- Long-Term Services and Supports in a Managed Care Environment: Advocacy Toolkit
- Questions/Comments



# Presenters

- Mary Lou Breslin, Senior Policy Advisor, Disability Rights Education and Defense Fund
- Georgia Burke, Directing Attorney, National Senior Citizens Law Center
- Silvia Yee, Senior Staff Attorney, Disability Rights Education and Defense Fund



# What is Managed Long-term Services and Supports (MLTSS)?

- Payer – typically the State Medicaid Agency – contracts with a managed care organization (MCO) to coordinate and provide LTSS
- May cover home and community-based services (HCBS) as well as institutional care
- May serve different populations: older adults, people with physical disabilities, and/or people with developmental/intellectual disabilities, or behavioral health needs.



# Where are we headed?

- Interest in MLTSS is growing rapidly
- Duals' Financial Alignment Initiative: 26 states have submitted proposals to the Centers for Medicare & Medicaid Services (CMS)
- Other states are moving toward MLTSS through the 1115 Demonstration waiver process



# Getting engaged in the process

- Both the Duals' Financial Alignment Initiative and 1115 Demonstration Waivers now require “ongoing and meaningful” stakeholder engagement throughout proposal development and the implementation processes
- Stakeholders include beneficiaries and their families, beneficiary advocates, consumer organizations, providers, plans and more
- It is critical to get engaged in the process in order to ensure the consumers' (and their families') needs are met and rights are protected



# **Long-Term Services and Supports in a Managed Care Environment: Advocacy Toolkit**



The National Senior Citizens Law Center is a nonprofit organization whose mission is to protect the rights of low-income older adults. Through advocacy, litigation, and the education and counseling of local advocates, we seek to ensure the health and economic security of those with limited income and resources, and access to the courts for all.





Disability Rights Education & Defense Fund

The Disability Rights Education and Defense Fund is a leading national law and policy center that advances the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development.

Our vision is a just world where all people, with and without disabilities, live full and independent lives free of discrimination.

<http://www.dredf.org>



# Topics for Discussion

- Stakeholder involvement
- Appeals and grievances
- Civil rights
- State and federal oversight and monitoring
- Quality measures
- Financing



# What is Meaningful Systemic Stakeholder Involvement?

- Consumer and advocacy groups must participate in developing managed care systems
  - State advisory board
  - MCO-level standing advisory committee
- Consumer involvement extends into monitoring after implementation of integration demonstrations



# Ellen

- Ellen is a 42 year old wheelchair/walker user
- She has Medicare and Medicaid
- She has diabetes, a thyroid condition, effects of a stroke, and depression
- She lived in a nursing home for 7 years until 2010 because she was having difficulty performing basic activities with her hands
- She returned to her own home through Money Follows the Person Program
- Challenges include mental health issues, transportation, changes in needed home assistance and adaptations



# Meaningful Systemic Stakeholder Involvement (continued)

- What are potential roles for stakeholders?
  - Promote beneficiary awareness/expectation for HCBS
  - Advocate for balance between medical and LTSS
  - Translate concerns into specific policy recommendations, actions, and goals
  - Consistency of involvement after implementation



# Meaningful Systemic Stakeholder Involvement (continued)

- Does the state have a stakeholder advisory board that includes:
  - Medicaid-eligible beneficiaries (e.g., Ellen)
  - Individuals with a range of LTSS needs
  - Their representatives and advocates



# Meaningful Systemic Stakeholder Involvement (continued)

- What is the role of the state advisory board?
  - Does the board advise on all aspects of:
    - Planning?
    - Implementation?
    - Operation of managed care program?
- Does the advisory board continue through implementation?



# Meaningful Systemic Stakeholder Involvement (continued)

- What qualifications should stakeholders have?
  - Do participants possess relevant personal experience or have connections with advocacy organizations with the expertise to assist them to:
    - Understand relevant state and federal laws?
    - Understand contracts and guidance that spell out CMS, state and MCO requirements?
    - Identify and recommend solutions to systemic problems w/in the MCOs?





# Meaningful Systemic Stakeholder Involvement (continued)

- How must MCOs involve stakeholders?
  - Does the MCO have a standing consumer advisory committee of
    - Seniors?
    - Younger people with disabilities such as Ellen?
    - Family of members enrolled in plans?
    - People with a range of disabilities?
    - People with a range of LTSS needs?



# Meaningful Systemic Stakeholder Involvement (continued)

- Does the MCO advisory committee:
  - Have access to MCO policies and practices?
  - Advise on policies and practices affecting the experience of care?
  - Have access to grievance and quality measures information?
  - Recommend changes to policies and practices to governing board?



# Meaningful Systemic Stakeholder Involvement (continued)

- Does the MCO:
  - Organize quarterly meetings for members?
  - Document all grievances and present written responses to board?
  - Notify the board and interested parties of meeting dates?
  - Assist w/ transportation for members?
  - Providing phone access to meetings, if needed?
  - Providing other accommodations such as American Sign Language (ASL) interpreters?
  - Would Ellen be welcomed and would she be assisted to attend?



# Appeals

## Challenge

- Protect existing rights to appeal when an individual disagrees with a care decision.
- Make the appeals system both robust and easy to navigate.

## Response

- Clear notices
- Prompt access to outside decision-maker
- Continuation of services during an appeal
- Conflict-free assistance.



# Appeals (continued)

- Does the design of the appeals system dilute any Medicaid rights?
  - Aid paid pending?
  - Immediate access to a fair hearing?
- Are appeals notices adequate?
  - What triggers the notice?
  - What information is in the notice?
- Are appeals notices understandable?
  - Plain writing?
  - Alternate formats?
  - Translated?



## Appeals (continued)

- Are decision-makers trained to evaluate LTSS needs?
  - Do they take into account non-medical goals?
- Is an ombudsman available to assist individuals pursuing an appeal?
- What is the mechanism for grievances?
- Does the state collect appeals and grievance data?
  - Are results made public?



# Appeals and Ellen

- Ellen is 42, a wheelchair/walker user. She has diabetes, a thyroid condition, effects of a stroke, and depression.
- Ellen's managed care plan just sent her a notice saying they will be reducing her personal care hours from 200 to 180. She has been experiencing a decline in the mobility and strength and thinks she actually needs more hours, not less. She is scared for her safety without the help and fearful she will end up back in a nursing home. The more anxious she becomes, the less she feels able to fight the change.



## Appeals and Ellen (continued)

- Ellen also is unhappy with the home health nurse who visits. The nurse often quizzes Ellen's personal care attendant about Ellen outside of Ellen's hearing. Ellen also worries that the nurse may be telling the care worker information about Ellen's health that Ellen does not want shared. Ellen has told the nurse that she wants to be included in any such conversation and that she wants to control the extent of her attendant's involvement in her care team. But the problem continues.





# Topics

- Civil Rights
- State and Federal Oversight and Monitoring
  - Where substantive rights and due process intersect
  - How to make rights on paper real when receiving services in one's home, a provider's office, when appealing a decision



# Civil Rights – Disability Background

- Individual providers and MCOs are subject to Title III of the Americans with Disabilities Act (ADA)
- States and local government agencies are subject to Title II of the ADA
- The Affordable Care Act (ACA) restates that health programs or activities that receive federal financial assistance are subject to federal anti-discrimination laws, including Title 504 of the Rehabilitation Act of 1973



# Civil Rights

- **Challenge:** To preserve the use of relevant civil rights laws as a source of beneficiary rights, and access to courts as another forum for individual complaint and systemic protection purposes
- **Response:** Ensure that beneficiaries are notified of their civil rights, and that all stakeholders, including providers, MCOs, and personnel involved with complaints or appeals, are trained on civil rights laws and how to meet their legal obligations



# Civil Rights – Notice

- Will the state and plans effectively notify all beneficiaries of their right to request:
  - effective communications
  - accessible provider offices
  - reasonable accommodations and policy modifications
- Will enrollment in MCOs curtail or affect the right to bring individual civil rights or class action lawsuits?



## Civil Rights – Accessibility and Integration

- Is the MCO obligated to survey all its provider networks for physical and programmatic accessibility (e.g., accessible bathrooms, height-adjustable exam tables, ASL interpreters, alternative print formats, flexible appointment times)?
- Will front-line office staff and beneficiaries have access to information about available providers who are accessible?
- Will MCOs be trained in beneficiaries' rights to receive health care services in the most integrated setting in accordance with the *Olmstead* decision, participate in the state's *Olmstead* plan, and agree to establish measurable goals around helping seniors and people with disabilities maintain homes and lives in their communities?



# Civil Rights – Implementation

- Will the state and MCO commit to proactive plans to identify and consistently meet the linguistic, cultural, and accessibility needs of plan members who have characteristics linked to health disparities, such as Limited English Proficient populations, Deaf persons, Lesbian Gay Bisexual Transgendered (LGBT) persons?
- Do the plans include:
  - benchmark goals?
  - data collection and monitoring obligations?
  - training for MCO employees and all contracting providers, including LTSS providers?



# Civil Rights – Systemic Needs

- Does the state or MCO prioritize hiring and retaining LTSS providers that can meet racial/ethnic, disability, or other underserved population needs and preferences?
- Will all state administrative and internal plan staff who handle complaints and appeal processes receive ongoing training on the right to reasonable accommodations and policy modifications, both in health care service delivery and in complaint/appeal processes?



# Victor

- When Victor was 60, his legs were amputated after an infection
- He entered a nursing home, and his limited savings and disability qualified him for Medicaid and Medicare
- Victor always wanted to return to the community, and after 3 years, the Medicaid Money Follows the Person Program helped Victor find affordable housing, furnishings, and community providers
- He currently lives in a senior-living apartment complex and enjoys overall good health, the freedom to set his own schedule, and social interactions with his church community
- Victor receives a few hours of chore and meal assistance each day, and exercises daily to maintain his upper body strength and capacity to transfer independently
- Now 64, Victor uses a power wheelchair, takes heart medication, and is beginning to lose some vision





# Civil Rights: Victor

- Victor continues to receive health information, letters from the state and from his plan, and LTSS-related notices in standard print which he can barely read due to his worsening vision. His attendant is not reimbursed for reading to him, and even if he were, Victor wishes to maintain his independence and the confidentiality of his personal health information.
  - Notified of his civil right to request alternate formats?
  - Informed of his right to bring a complaint if his request is refused? Provided with accommodations during the appeal process? Is data kept on the complaint as a civil rights issue?
  - Could Victor and other beneficiaries who cannot get alternate formats bring a class action ADA or Section 504 lawsuit?



# State and Federal Oversight and Monitoring

- **Challenge:** Interrelated federal, state, and local agency responsibility (e.g., county) for distinct services areas makes it difficult to have clear lines of responsibility for oversight, monitoring and ensuring implementation
- **Response:** Avoid unnecessary overlap, achieve efficiency, foster high levels of cooperation, and maintain existing expertise



# State and Federal Oversight and Monitoring (continued)

- Does the state identify and define the role of every state or local agency or department that has been, or will be, involved in the delivery of LTSS?
  - Transitions and time periods
  - Plan to maintain developed LTSS relations and expertise – restructure and rehire
  - Single lead responsibility



## **State and Federal Oversight and Monitoring (continued)**

- Does oversight include activities to quickly identify and resolve immediate and developing issues, as well as data measures designed to monitor MCO performance and beneficiary satisfaction over the long term?



# State and Federal Oversight and Monitoring (continued)

- What specific activities will the state commit to in its oversight and monitoring:
  - Secret shopper surveys of LTSS networks?
  - Audits of MCO operations and LTSS subcontracts?
  - Review and analysis of MCO encounter data on LTSS?
  - A state-run “dashboard” that can track how well MCOs provide timely access to home and community-based services (HCBS) over time and during critical care transition periods?
  - Real-time state back-up for critical individual LTSS services (e.g., personal assistants)?



# State and Federal Oversight and Monitoring: Accountability

- Is information exchange with stakeholder groups and any independent ombudsman built into state oversight and monitoring?
- Will the state provide the public with historical and ongoing data from its monitoring of MCO performance and quality in a timely and regularly updated fashion?
- Will federal information about plans providing Medicare benefits be similarly available?



# Maria

- Spanish speaker, lives alone. Little public transportation.
- At age 82, declining mobility because of hip problems. She needs help to stay at home safely and can't do a lot of things, like bathe, without assistance. Sometimes get depressed because her life has become so much more limited. Her daughter tries to organize the help Maria needs but it is difficult.
- At 84, Maria suffers a fall. Breaking her shoulder and bruising some ribs. She is in the hospital and rehab for a couple of days.
- At 85, Maria has a serious stroke resulting in very high care needs. She moves to a nursing home.
- At 88, Maria has been in the nursing home for three years. She has increasing dementia and is very frail but enjoys the people there and the activities. Her daughter makes all her decisions.



# State and Federal Oversight and Monitoring: Maria

- After Maria's stroke, she and her daughter seek information about her LTSS options. What agencies:
  - Oversee their receipt of current, conflict-free information about HCBS, assisted living and nursing home options?
  - Make updated MCO performance and quality data, and MCO monitoring of nursing home contractors, available?
  - Oversee how hospitals and medical and LTSS providers will be paid during and after hospitalization, and take the monitoring lead over coordination during the transition?
  - Oversee Maria's receipt of Spanish translation and written materials?





# LTSS/HCBS Quality Measurement

- What is it?
- Why is it important?
- What should be measured?
- Are tools available now to measure LTSS/HCBS outcomes?
- How can advocates be involved in developing meaningful measures?



# LTSS/HCBS Quality Measurement (continued)

- What is it?
  - Data and information about personal quality of life outcomes, quality assurance processes, and organizational quality improvement efforts that promote quality at the **individual, provider, and system levels.**



# LTSS/HCBS Quality Measurement (continued)

- What is it?
  - At the person level: Data is best tool to understand progress toward person centered goals and desired quality of life outcomes
    - Are mechanisms available to ensure desired services are delivered?
    - Is progress being made toward achieving goals?
    - Does the person have a feedback mechanism to report progress/problems?
  - At the provider and system level: Data outcomes drive quality improvement



# LTSS/HCBS Quality Measurement (continued)

- Why is it important?
  - Data enables state oversight of the extent to which MCOs honor commitments to person-centered, quality services to people with disabilities and seniors
  - Data encourages MCOs to focus on meeting stated needs of consumers
  - Tracking outcomes gives advocates tools to hold both plans and MCOs accountable



# LTSS/HCBS Quality Measurement (continued)

- Why is it important?
  - Data helps consumers make informed choices when they have a choice among MCOs
  - When similar outcome measures are used across programs and service settings (e.g., community versus institutions), data can be used by consumers to make choices and by advocates and policy makers to shift resources to programs and settings with better outcomes \*

\*H. Stephen Kaye, Testimony before the California Senate Human Services Committee, Personal Assistance Services, Institute for Health and Aging, University of California, San Francisco, March 27, 2012



# LTSS/HCBS Quality Measurement (continued)

- What should be measured?
  - Person centered outcome data
    - Quality, adequacy and impact of services
  - Quality of life and social participation
    - Autonomy, choice, meaningful relationships, privacy, dignity
  - Family and caregiver data
    - Adequacy of support, stress, financial impacts



# LTSS/HCBS Quality Measurement (continued)

- What should be measured?
  - Health, functioning and diagnostic data
  - Cost data
  - Incident reporting data
  - Complaint data



# LTSS/HCBS Quality Measurement (continued)

- Are tools available now to measure MLTSS outcomes?
  - HCBS are non-medical and operate in a different framework than the health system
  - Performance measure in HCBS are in the early stages of development compared w/ clinical services and settings
  - None have been validated for use nationally

(See National Quality Forum report, Measuring Healthcare Quality for the Dual Eligible Beneficiary Population, June 2012; AHRQ Environmental Scan of Medicaid Title XIX Home and Community-Based Services)





# LTSS/HCBS Quality Measurement (continued)

- Are tools available now to measure LTSS/HCBS outcomes?
  - Some instruments are already in use and have been validated for specific settings
  - Some states have used existing tools that contain relevant elements
  - National research projects on improving LTSS are a resource



# LTSS/HCBS Quality Measurement (continued)

- How can advocates be involved in developing meaningful measures?
  - People with disabilities of all ages who use LTSS and HCBS are the best resource on experiences and outcomes
  - State and plan advisory boards and stakeholder forums present structured opportunities to participate in developing quality measurement tools



# LTSS/HCBS Quality Measurement (continued)

- How can advocates be involved in developing meaningful measures? Urge states to:
  - Structure state MCO contracts with a requirement for uniform, valid, and reliable reporting and evaluation through the use of personal outcome measures
  - Broaden the definition of standardized quality measures— Data can be aggregated on items that are personally defined rather than standardized in the traditional sense



# LTSS/HCBS Quality Measurement (continued)

- How can advocates be involved in developing meaningful measures? Urge states to:
  - Maintain uniform metrics throughout the state and across all MCOs
  - Make sure that clinical, functional, and personal outcomes are integrated



# LTSS/HCBS Quality Measurement (continued)

- How can Ellen participate?
  - Valuable experience and wisdom to provide insights into the process
  - Requires evaluation of her own personal outcomes and quality of life



# Financing

- **Challenge**

- Incentivize quality care and expansion of HCBS supports.
- Devise a payment strategy that encourages rebalancing away from institutional care.
- Don't spend too much. Save money.

- **Response**

- Good risk adjustment mechanism with ratings based on functional impairment and diagnosis.
- Risks for plans in nursing home admissions, rewards for moving people into the community.
- Recognize that savings may not be immediate.
- Reinvest savings in care improvements.



## Financing (continued)

- Is rate setting based on diagnosis and functional limitations?
- Are there risk corridors or similar mechanisms?
- Does the payment structure incentivize moving individuals back into the community? How?
- Is quality rewarded? How? Are savings being achieved through quality improvements, not reductions in payment rates to providers? What mechanisms ensure this result?
- Does the rate mechanism squeeze out smaller non-for-profit community based MCOs?



# Financing and Maria

- Maria, 82, Spanish speaker, lives alone. Little public transportation. Experiencing declining mobility because of hip problems. She needs help to stay at home safely and can't do a lot of things, like bathe, without assistance. Sometimes get depressed because her life has become so much more limited.
- Will the financing structure encourage her MCO to do just enough to keep her out of an expensive nursing home or will it encourage quality care, including making sure that Maria gets access to the social interaction she needs?





# Financing and Victor

- At age 60, Victor's legs were amputated after an infection. He entered a nursing home, and his limited savings and disability qualified him for Medicaid and Medicare. Victor always wanted to return to the community. Let's assume that Victor has been living in the nursing home for three years and is now in an MCO. Leaving the nursing home will require significant up-front costs and intensive case management through the transition.
- What financing structure will encourage the MCO to help Victor re-enter the community?



Mary Lou Breslin  
[mlbreslin@dredf.org](mailto:mlbreslin@dredf.org)

Silvia Yee  
[syee@dredf.org](mailto:syee@dredf.org)

Disability Rights Education  
& Defense Fund  
[www.dredf.org](http://www.dredf.org)  
510-644-2555

Georgia Burke  
[gburke@nsclc.org](mailto:gburke@nsclc.org)

National Senior Citizens Law  
Center  
[www.nsclc.org](http://www.nsclc.org)  
510-663-1055



## Resources: **MLTSS**

- <http://dualsdemoadvocacy.org/resources/ltss> (Toolkit: *Long-Term Services and Supports: Beneficiary Protections in a Managed Care Environment*)
- <http://dualsdemoadvocacy.org/> (NSCLC resource website on dual eligible integrated care demonstrations)
- [http://www.nasuad.org/medicaid\\_reform\\_tracker1.html](http://www.nasuad.org/medicaid_reform_tracker1.html) (NASUAD State Medicaid Reform Tracker)
- [http://www.nasuad.org/documentation/nasuad\\_materials/ARP732\\_OntheVerge\\_REPORTFeb1v33.pdf](http://www.nasuad.org/documentation/nasuad_materials/ARP732_OntheVerge_REPORTFeb1v33.pdf) (AARP/NASUAD report -- *On the Verge: The Transformation of Long-Term Services and Supports*)



# Resources: **MLTSS**

- Kaiser Family Foundation resources:
  - <http://www.kff.org/medicaid/upload/8243.pdf> (Issue Brief: Examining Medicaid Managed Long-Term Service and Support Programs)
  - <http://www.kff.org/medicaid/upload/8278.pdf> (Issue Brief: People with Disabilities and Medicaid Managed Care)
  - <http://www.kff.org/medicaid/upload/8290.pdf> (Policy Brief: An Update on CMS's Capitated Financial Alignment Demonstration Model For Medicare-Medicaid Enrollees)
- [http://www.chcs.org/info-url\\_nocat5108/info-url\\_nocat\\_list.htm?attrib\\_id=16308](http://www.chcs.org/info-url_nocat5108/info-url_nocat_list.htm?attrib_id=16308) (Center for Health Care Strategies MLTSS resources)



# Resources: **MLTSS**

- CMS Medicare-Medicaid Coordination Office resources:
  - <http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/StateDemonstrationstoIntegrateCareforDualEligibleIndividuals.html> (State Demonstrations to Integrate Care for Dual Eligible Individuals)
  - <http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialModelstoSupportStatesEffortsinCareCoordination.html> (Financial Alignment Initiative)
- <http://www.integratedcareresourcecenter.net/> (CMS Integrated Care Resource Center)

## Resources: **1115**

- <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/SHO-12-001.pdf> (State Medicaid Director letter providing guidance on revised review processes for Section 1115 demonstrations)
- <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1115#wavers> (Database of CMS Medicaid waivers and demonstrations website)
- <http://cmsideas.uservoice.com/forums/141980-medicaid-gov> (CMS Idea Factory to post comments on some of the 1115s submitted by states)



## Resources: *Affordable Care Act*

- [http://www.aoa.gov/Aging\\_Statistics/Health\\_care\\_reform.aspx](http://www.aoa.gov/Aging_Statistics/Health_care_reform.aspx)  
(AoA's Health Reform web page – where webinar recordings, transcripts and slides are stored)
- <http://www.healthcare.gov/news/factsheets/2010/11/affordable-care-act-americans-disabilities.html> (Fact sheet on the Affordable Care Act for Americans with Disabilities)
- <http://www.healthcare.gov> (Department of Health and Human Services' health care reform web site)
- <http://www.thomas.gov/> (Affordable Care Act text and related information)
- <http://www.healthcare.gov/blog/2012/04/disability041812.html>  
| (Disability, Disparities and the Health Care Law)



# Next Training

- Topic (*tentative*): Accountable Care Organizations and Community-Based Organizations
  - August date TBD; watch your email in early-mid month for registration information





# Questions/Comments/Stories/ Suggestions for Future Webinar Topics?

Send them to:

[AffordableCareAct@aoa.hhs.gov](mailto:AffordableCareAct@aoa.hhs.gov)