Sept. 12, 2012

Cindy Mann, Director
Center for Medicaid and Chip Services
Department of Health and Human Services
Via email

Re: MLTSS policies, in response to NAMD letter of Aug. 6

Dear Ms. Mann:

As representatives of organizations that serve consumers of Medicaid Managed Long-Term Services and Supports (MMLTSS), we write to provide another perspective on some of the recommendations made by the National Association of Medicaid Directors in a letter to you on Aug. 6.

We very much appreciate the work that CMS is doing to improve MMLTSS by providing resources on a new website, commissioning reports and preparing guidance to the states. Like you, we believe that consumers and the nation will be better served if both existing and new MMLTSS programs provide high-quality, efficient, accessible, person-centered services and supports.

We support some of NAMD’s recommendations, such as the development of a learning community for states, federal-state collaboration on development of quality measures, and maintenance of some existing flexibility in policies to allow for differences among the states. We believe that states can and should learn from each other, that federal-state collaboration is essential to make the programs work well, and that states do need to retain some flexibility to tailor programs to the particular needs of their residents.

However, we are concerned that some of the other recommendations are not in the best interests of consumers. Specifically, we are concerned about NAMD’s recommendations to:

- ease or eliminate the CMS review process for some program changes through waivers or state plan amendments
- allow state flexibility to design consumer engagement and education, including withholding “certain proprietary information and detailed financial data”
- allow states to pick and choose among national quality measures being developed for LTSS
- permit state quality data collected by CMS to be used to evaluate performance, but “not compare states to normative standards”

Consumers of MLTSS include some of the most vulnerable in our society. To protect consumers, we believe it is essential that CMS exercise strong oversight of program changes in MMLTSS, including using data to compare states publicly to each other and to national standards to encourage the pursuit of excellence and to let the public know where states fall short. We also believe that there should be strong federal standards that set a floor for all state MMLTSS programs, especially in the areas of consumer engagement and education, transparency and quality. Details of our concerns and recommendations follow.
Federal oversight of MLTSS programs

CMS oversight of MLTSS programs, particularly programs newly established but also changes that alter any significant aspect of existing programs, is crucial to protect consumers. This is particularly important as states increasingly shape MMLTSS programs with specific cost-saving goals as the prime driver, and bring in for-profit companies to run their programs. While MMLTSS programs can indeed save money by rebalancing programs toward home and community-based services, a rush toward savings or profits must not be permitted to jeopardize services that are essential to help seniors and people with disabilities live with dignity and as much independence and community participation as possible. Readiness reviews of new programs and new plans are an essential state function that should be backstopped with federal standards and federal review. An example of the need for federal standards is the absence in NAMD’s list of core readiness categories of any mention of capability and plans for consumer engagement in implementation, monitoring and evaluation.

Certainly, as NAMD suggests, new programs need the ability to improve as problems come to light. But CMS must continue to review significant changes. If needed, the states and CMS could work out new timelines for review, but that review should allow time and space for stakeholder input.

Consumer engagement and education, and plan transparency

NAMD maintains that states need flexibility in designing consumer engagement and education. We strongly believe that CMS should set standards for required levels of consumer engagement, including consumer participation in planning and evaluation of LTSS programs through state task forces and meetings with state officials, consumer involvement in implementation through representation on plan governing boards or regional consumer advisory committees, and consumer feedback through independently conducted consumer surveys designed for LTSS that ask about quality of life as well as quality of services. These standards are needed since many states have either not included consumers in planning and implementation oversight, or have included them in name only, failing to provide opportunity and supports for full and meaningful participation.

In addition, states should be required to provide full transparency about the financing of MMLTSS in language understandable by the public. The use of public dollars requires nothing less.

Measuring and monitoring quality

We applaud the federal work to develop quality standards and measures specific to LTSS, and agree with NAMD that states with experience in MMLTSS should be participants in the standard-setting and measure development processes. We also believe that other stakeholders, including consumer and provider organizations, should have a robust role in setting standards.

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and defining measures, and appreciate the opportunities that CMS has already provided to do just that.

However, we do not agree with NAMD that states should be allowed to pick and choose which measures they use. We believe there should be a core set of measures required for all states that capture the key outcomes and quality of life of consumers. Several of the organizations signing this letter have previously shared suggestions on quality measures with CMS. We also recommend that core set include baseline data to measure the adequacy (volume, compensation, stability) of the home-and-community-based personal care workforce, which provides 80 percent of the paid care to LTSS consumers and which directly affects quality of care. States may choose to add additional quality measures on top of the required core measures.

The core measures are essential because some states are hiring companies to run their MMLTSS plans that have limited track records in LTSS or with the specific populations being enrolled. Core measures are also needed to provide a tool for federal oversight that can hold states accountable for providing quality, person-centered LTSS. Contrary to NAMD, we believe that using these measures to compare states’ performance publicly to each other and to national standards will encourage the pursuit of excellence and ultimately will protect consumers.

Thank you for the opportunity to share our concerns and suggestions with you and for your commitment to this issue.

Many of the organizations below are part of a collaborative of national aging and disability organizations that work together to advance LTSS policy. Collaborative members stand ready to help you improve MMLTSS across the country. Please contact Community Catalyst Project Director Alice Dembner 617-275-2880 or adembner@communitycatalyst.org with any questions about this letter. Please contact Joe Caldwell at NCOA if you would like to engage the collaborative broadly on LTSS issues.

Sincerely,

Alice Dembner
Community Catalyst

And

ACCSES
American Association on Health and Disability
The Arc
Association of University Centers on Disabilities
Bazelon Center for Mental Health Law
California Alliance for Retired Americans
The Center for Independence of the Disabled
Colorado Cross-Disability Coalition
Congress of California Seniors
Direct Care Alliance
Disability Rights Education and Defense Fund
Easter Seals
Empire Justice Center
Families USA
Family Voices
Family Voices Colorado
The Jewish Federations of North America
Leading Age
Legal Services of Southern Piedmont
Lutheran Services in America Disability Network
National Association of Area Agencies on Aging
National Association for Home Care & Hospice
The National Consumer Voice for Quality Long-Term Care
National Council on Aging
National Council on Independent Living
National Council on Medicaid Home Care
National Disability Rights Network
National Health Law Program
National Multiple Sclerosis Society
National Respite Coalition
National Senior Citizens Law Center
PHI – Quality Care through Quality Jobs
SEIU Healthcare
Tennessee Justice Center
United Spinal Association
Virginia Poverty Law Center

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