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May 9, 2011

New York State Department of Health
Division of Managed Care
Bureau of Program Planning and Implementation
Empire State Plaza
Corning Tower, Rm. 1927
Albany, New York 12237

RECEIVED
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BUREAU OF PROGRAM
PLANNING AND IMPLEMENTATION

Dear Sir or Madam:

Enclosed, please find a letter, dated May 2, 2011, hereby submitted as public comment to the undated Public Notice of the proposal to require Mandatory Enrollment of Medicaid Eligibles in Managed Long Term Care (posted at http://www.health.state.ny.us/health_care/managed_care/appextension/mrt_waiver_materials/docs/mrt_public_notice.pdf)

I am troubled that there is very little detail posted online at http://www.health.state.ny.us/health_care/managed_care/appextension/index.htm#mrt_waiver_materials about the proposed expansion of Managed Long Term Care, as well as about the expansion of Medicaid Managed Care to include long term care services such as nursing home and personal care. As shown in the attached letter, there are myriad policy and practice issues that will have to be thought through and decisions made. The state budget law at section 41-a specifically requires:

> The commissioner, shall seek input from representatives of home and community-based long term care services providers, **recipients,** and the Medicaid managed care advisory review panel, among others, to further evaluate and promote the transition of persons in receipt of home and community-based long term care services into managed long term care plans and other care coordination models and to develop guidelines for such care coordination models. The guidelines shall be finalized and posted on the department's website no later than November 15, 2011.

The development of guidelines for these care coordination models is a primary component of the waiver request to CMS, and should be shared with the public and, specifically, with recipients, to afford the opportunity to comment. In the absence of such information, we submit the enclosed comments.

a beneficiary of
UJA Federation
of New York

Thank you.

Very truly yours,

Valerie Bogart
Director, Evelyn Frank Legal Resources Program
vbogart@selfhelp.net
Direct Dial 212.971.7693

On behalf of all signers of enclosed letter dated May 2, 2011

Encl.

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May 2, 2011

Jason Helgerson
Director, New York State Medicaid Program
Dep. Commissioner, New York State Dept. of Health
Office of Heath Insurance Programs
Corning Tower, Empire State Plaza
Albany, NY 12237

By electronic mail dhg03@health.state.ny.us

Dear Mr. Helgerson:

We write as consumer advocates to express our concern about the waiver that will mandate enrollment in Managed Long Term Care or other long-term care coordination models, as enacted in L. 2011, Ch. 51, Part H §§ 41, 41-a, 41-b et al, and ask that we be allowed to participate in any workgroup that will be convened to develop guidelines for the development of such a waiver. Several important issues that impact on recipients' continued access to services are implicated in mandating that all adults receiving home and community based services enroll in a managed long term care ["MLTC"] program. This letter identifies some of the issues, but by no means is intended to constitute the totality of input by consumers and their advocates.

1. Protection of recipient's rights, and health and safety concerns for current recipients of high-hour personal care and certified home health care.

There are currently thousands of recipients who currently receive 10 or more hours per day of personal care or certified home health [CHHA] services. These recipients remain entitled to the services they have been determined eligible for notwithstanding a change in the State's funding mechanism. Moreover, these services may only be reduced or terminated pursuant to procedures that meet due process standards of notice, aid continuing, and fair hearing rights. In addition, substantive grounds such as improvement in the medical condition must exist to warrant any reduction. *See Mayer v. Wing*, 922 F. Supp. 902 (S.D.N.Y. 1996); *Catanzano v. Dowling*, 60 F. 3d 113 (2d Cir. 1995). Mere changes in reimbursement or in the modality of providing home care would not satisfy these criteria.

The requirement in the budget law that the MLTC plans must provide "transitional care" for 30 days following enrollment of a current consumer of personal care or CHHA services would not satisfy these legal requirements if the MLTC plan is then permitted to reduce services based on

their initial assessment, without complying with the substantive and procedural requirements described above.

In order to ensure continued provision of services to these vulnerable consumers, the Department should consider both funding and oversight mechanisms. Funding systems could include an outlier payment structure, exemption of some outlier consumers from mandatory MLTC enrollment, or other mechanisms to ensure that continued provision of these services is not an "unfunded mandate" that will lead MLTC programs to cut services illegally. An oversight mechanism is needed to review decisions by MLTC plans that would substantially reduce services from the amount previously provided through personal care or CHHA. The need for such safeguards is shown by the fact that already, at least one CHHA has refused to follow guidance issued by DOH regarding patient rights, and has illegally reduced services in response to the reimbursement cuts that have already gone into effect.[1]

2. <u>Ensuring Due Process Protections without Local District Involvement</u>

Allowing MLTC plans to develop and change individual plans of care without requiring LDSS approval will significantly reduce the role of local districts (LDSS) in assessing and providing long term care services which raises procedural and institutional questions. The *Catanzano* Implementation Plan, which is an appendix to state CHHA regulations at 18 NYCRR 505.23, contemplates that CHHAs refer determinations to reduce or terminate services to the LDSS, which in turn reviews the matter. Under the *Catanzano* plan, if the LDSS agrees with the CHHA, it will issue the requisite written notice with aid continuing and hearing rights to the consumer. The LDSS of course issues such notices now to personal care recipients directly. Elimination of LDSS involvement leaves open to question whether the MLTC plans will be delegated the responsibility for directly providing the requisite written notices of adverse determinations and hearing rights to their consumers, or whether the State will assume some responsibility in this area. Total delegation of this function to the MLTC plans may violate federal law and regulations.[2]

3. <u>Substantive entitlement to the State plan services provided by the MLTC</u>

Although consumers will continue to be entitled to all State plan services such as CHHA, personal care, and other services, under the new law these services will now be authorized by a different entity and reimbursed under a different mechanism. Standards and safeguards for the provision of services that are medically necessary and comply with federal and state law and regulations have developed over many years and even decades. Compliance with these standards and procedures must be ensured. In just one example, the MLTC model contract requires involuntary disenrollment by the plan when a consumer is hospitalized for 45 days or

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[1] As you know, a class action lawsuit was filed last week challenging these actions by CHHAs.

[2] Federal regulations at 42 CFR 431.211 require that notice of Medicaid determinations be provided by the State or local agency.

longer.[3] If this requirement continues when MLTC becomes mandatory, it potentially violates several court decisions and settlements which have been incorporated into State directives.[4] Other examples are regulations regarding task-based assessment that incorporate the settlement known as "Mayer-Three" in *Mayer v. Wing*, set forth at 18 NYCRR 505.14(b)(5)(v), and a directive ensuring that consumers are not wrongfully and illegally denied personal care services when they need assistance to safely perform basic activities of daily living. *See* NYS Dep't of Health GIS 03 MA/003.

4. Standards for High-Hour Personal Care Cases

As required by the budget law, DOH will be promulgating regulations for the provision and management of personal care services "...for individuals whose need for such services exceeds a specified level to be determined by the commissioner." L. 2011, Ch. 51, Part H § 89. These standards will presumably apply to the existing personal care and voluntary MLTC programs until a federal waiver is approved for mandatory MLTC, and to MLTC programs under the future waiver. Since people needing high hours of service are particularly at risk of institutionalization without adequate community-based services, we are particularly concerned that these standards be written so as to maximize availability of home care services and to comply with *Olmstead*. While the law authorizes that these regulations be promulgated on an emergency basis, we ask that the Department solicit input from consumers before they are issued.

5. Safeguards against Excessive or Unnecessary Institutionalization

Both for transitioned existing personal care/CHHA recipients, and for new enrollees who enter the system, there must be safeguards to prevent unnecessary and unwanted nursing home utilization, which could violate the integration mandate of the Americans with Disabilities Act as defined in the United States Supreme Court's *Olmstead* decision. Adequate standards, procedures, and contract provisions adopted in response to all of the points described above will help ensure that consumers receive medically necessary services in the home and minimize nursing home usage. However, other specific safeguards are needed, since consumers will no longer have the right to disenroll from an MLTC plan at will.

The MLTC model contract, as written, attempts to give MLTC plans total discretion in determining when to utilize nursing home services that are included in the capitation rate.[5]

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[3] www.nyhealth.gov/health_care/managed_care/mltc/pdf/mltc_contract.pdf at p. 14, par. D.4(c) (2007)

[4] Granato v. Dowling, 74 F.3d 406 (2d Cir. 1996), Burland v. DeBuono, NYS Dept. of Health Local Comm'r. Mem. 99-OCC-LCM-2 (4/20/99); Catanzano v. Dowling, *supra*, App. II to 18 NYCRR 505.23.

[5] *See*, www.nyhealth.gov/health_care/managed_care/mltc/pdf/mltc_contract.pdf at p. 14, par. D.4(c).

Indeed, the cost reports filed with DOH show that the percentage of the capitation rate spent by MLTC plans on nursing home services varies widely -- from as little as 1.6% to as much as 10%.[6] We question how and why such high usage of nursing home services is permitted now, and are extremely concerned that this usage will only increase when the pool of consumers entering MLTC programs includes those now receiving high hours of personal care or CHHA services.

An important safeguard for SDOH to include is mandatory reporting by the MLTC plan to an external review entity that will review any placement in a nursing home for other than short-term rehabilitation services, which would be defined as a placement beyond a specified time period, and/or beyond the period covered by Medicare.

6. Entitlement to Consumer Directed Personal Assistance Program [CDPAP] Services

The enacted budget law will require MLTC plans "to offer and cover Consumer-Directed Personal Assistance (CDPAP) services for eligible persons who elect such services pursuant to Soc. Serv. L. 365-f." Part H, § 41-a. This provision holds the promise that consumers will continue to have the guaranteed option to self-manage their services through the CDPAP, as required by Soc. Serv. L. 365-f. However, we have concerns about how this requirement will be implemented. Indeed, there is an inherent conflict in the notion of having a nurse manage a care plan for a consumer who is directing his or her own care. The recent release of CDPAP regulations[7] recognizes this unique attribute of the model which is contradictory to nurse management and supervision of the consumer's care needs as delivered by consumer employed and trained Personal Assistants.

Other potential conflicts arise in who will determine whether the consumer is self-directing or has a designated representative who is available and willing to direct his or her care plan. That the MLTC plan may have a conflict of interest in being the decision maker on this issue must not be ignored. Consumers must receive notice of and the opportunity to appeal denial of eligibility for CDPAP services at a fair hearing, as they do now. DOH must consider the serious implications under the state and federal regulations discussed above as to whether the entity that provides such notice is the MLTC plan, the LDSS or another entity designated by DOH.

Also, we question whether MLTC plans will be required to contract with an independent CDPAP provider or will they or their existing sub-contractors of home care services be allowed to develop in-house CDPAP programs? If the latter, we have serious concerns that there are legal, regulatory, and values-based barriers that may impede traditional agencies that provide home care, whether licensed home care services agencies, CHHAs, or MLTC plans, from fully embracing the idea of and providing consumer-directed personal assistance services. There is a specific balance of responsibility between the consumer and the provider that is essential to maintain both the consumer's empowerment and to mitigate the provider's exposure to

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[6] Based on 2009 4th quarter MMCOR Filings.

[7] NYCRR Title 18 Section 505.28 (g)(1).

liability. In this way, it is imperative to ensure that the Department receives substantive feedback from consumers currently receiving CDPAP services and individuals who have expertise in providing specialized CDPAP administration.

The confusion and inconsistency surrounding the current Consumer Directed Personal Assistance Program will only become more pronounced if the Department does not clarify standards and expectations before its inclusion into a different system altogether.

7. Enrollment Issues

A transition from voluntary enrollment to mandatory enrollment poses major challenges and must be done in a way that ensures consumer choice and rights. Additional questions include:

a. If the LDSS is no longer involved, what entity will handle enrollment -- providing the information about plan choices to consumers, assigning them to plans if they do not make a choice, handling requests for exemptions, disenrollments? DOH must ensure that the entity that handles this task meets the criteria discussed in the section below on Disability Competency. If that entity has authority to deny applications for home care services, then, again, this raises questions under federal and state law about improper delegation of governmental duty.

b. Will consumers still apply for Medicaid at the LDSS? Procedures must ensure that consumers receive services within 45 days of applying for Medicaid. There are many logistical procedures to define, such as whether an application for services will still be initiated by filing a physician's order or a Medicaid application, and where the consumer files such documents. Time periods and duties must be defined for transmittal of these documents to be timely processed.

c. What information will be provided to consumers about their plan choices? The cost reports filed by MLTC plans every year provide crucial information that should be analyzed summarized and made available to all consumers. This includes:

    - The percentage of each plan's total medical expenses -- and the percentage of the plan's capitation rate -- paid for each of its various services, including personal care, home health aide, nursing facility, durable medical equipment, and transportation.

    - The average hours per week of personal care and home health aide services each plan provided in the previous year.

    - A breakdown of the percentage of each plan's members who receive various amounts of hours of personal/home health aide services each week,

such as continuous 24-hour care in two 12-hour shifts, sleep-in care, 12 hours/day, 10-12 hours/day, and so on.[8]

Additional information would include the type and breadth of case management services provided, the procedures and standards for approving Durable Medical Equipment and transportation (does the plan subcontract approval of DME or transportation?). These are just examples.

8. Disability Literacy and Competency

With its emphasis on interdisciplinary care coordination and avoidance of inappropriate reliance on institutional settings, managed long-term care presents some opportunities to improve the care of people with disabilities. However, it will only achieve this promise if it attends to the disability literacy of managed long-term care plans.

Disability literacy for managed long-term care plans may be defined as understanding, communicating, and partnering with people with disabilities with demonstrated understanding of their perspectives and beliefs concerning health behavior. An example would be recognition of the preference for self-direction and informed choice. It means eliminating the programmatic, physical, communications, administrative, and attitudinal barriers to health care faced by people with disabilities. Lack of training on disability literacy issues and problem-solving to remove barriers for health plan administrators, staffs and care practitioners is a very significant barrier to effective health care.

Why should disability literacy matter to the managed long-term care program? New York State has recently observed that people with disabilities requiring significant assistance have a lower health quality of life, engage in behaviors such as smoking that present health risks and engage in fewer health promoting activities such as exercise. They experience chronic conditions at a higher rate than people without disabilities.[9]

They experience health disparities and face significant problems accessing health services. For example, women with disabilities are less knowledgeable about risk factors for cardiovascular disease. They are less likely than women without disabilities to receive preventive screening than women without disabilities. Adults who are deaf report poor health with greater

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[8] The Department should compile this data, which is available from the reports that the MLTC plans must report under their contracts, and make it available to consumers in the enrollment process. Other information that should be made available to consumers from the plans reports includes the availability, accessibility of services; enrollment; enrollee demographics; disenrollment; enrollee health and functional status; service utilization; encounter data, enrollee satisfaction; marketing; grievance and appeals; and fiscal data. *See* n 1, supra, Model Contract p. 35 § E.2.

[9] New York State Department of Health, Disability and Health Program, "Chartbook on Disability in New York State, 2007, Results from the Behavioral Risk Factor Surveillance System." 2008.

frequency than people who are not deaf, lack interpreters in health settings and fail to receive health information and instructions from practitioners. Adult with developmental disabilities are at higher risk of obesity, cardiovascular disease and hypertension than people without developmental disabilities. They encounter problems working with providers who do not give them enough time to undress, communicate and understand instructions.[10]

Managed long-term care can only, therefore, fulfill its promise of coordinating care and avoiding expensive and overly restrictive institutional placement if it addresses disability literacy issues. Working with consumers and their advocates, DOH must create an Americans with Disabilities Act Compliance Appendix to the contract, scrutinize and evaluate its components, and monitor its implementation as a step towards disability literacy. Such a plan would make provision for eradication of barriers that are physical, communications-related, programmatic and attitudinal.

For example, MLTC Plans must be required to have and/or develop an experience and knowledge base to serve people with significant disabilities. Among issues to be considered are:

a. the physical accessibility of administrative and provider facilities;

b. willingness and capacity to provide written materials in alternate formats;

c. expertise in assessing needs for adaptive equipment and environmental modifications, including wheelchair fitting and seating and home modifications, with policies and practices for approval of durable medical equipment and transportation that are consistent with applicable laws and promote independent living;

d. understanding of and the capacity to address the housing and social service needs of participants;

e. a proven and documented commitment to maintaining people in the most integrated setting;

f. and a policy that facilitates the provision of reasonable accommodations to people with disabilities;

g. provision of an opportunity to plan participants to participate in a significant manner in the development of plan policies and practices.

We would welcome the opportunity to discuss these issues at greater length.

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[10] The Current State of Health Care for People with Disabilities," National Council on Disabilities, 2009

9. What Other Care Coordination Models will the Commissioner Approve in Addition to the MLTC providers?

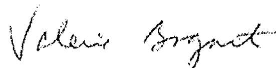
The budget law requires the Commissioner to develop guidelines for program models that support coordination and integration of services, such as long term home health care programs. Such program models would allow consumers to choose and enroll with entities other than MLTC plans to coordinate their care. Consumers should have a voice in development of these guidelines. Consumers whose complex health conditions have been effectively managed by special needs CHHAs, such as those serving people with HIV/AIDS, for example, should be able to continue receiving that care, which minimizes costly hospitalizations.

* * *

We welcome the opportunity to be appointed to the workgroup(s) that will develop the waiver and guidelines for this initiative, and ask to be notified of any meetings or opportunities to provide input.

Thank you.

Very truly yours,



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