Ad Hoc Coalition of Consumer Advocacy Organizations in New York State

VIA ELECTRONIC MAIL

August 28, 2012

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Dear Ms. Mann et al,

We are writing on behalf of a coalition of disability rights and seniors' rights advocates and community-based organizations in New York State regarding New York's application for expansion of its 1115 Medicaid Waiver to include mandatory enrollment of Dual Eligibles who receive community-based long-term care services into Managed Long-Term Care (MLTC) plans. We have been working with the State to meet the laudable goals of this program and it is in this spirit that we write to you now.

We urge CMS to ensure that there is appropriate time to educate consumers and their advocates, implement consumer protections (some of which we detail below and others we communicated in our December letter to CMS, which is attached hereto) and ensure plan compliance with all program requirements before this program is implemented. Below we suggest that the program only include new applicants in its first year. If it does include current service recipients, at a minimum, we believe that a six-month transition period, rather than the proposed 30-day period, is critical to protect the most vulnerable high-need consumers when they shift into this new system.

This ambitious program imposes massive changes to an already complex system used by tens of thousands of consumers and their families and advocates. Now, individuals who depend on personal care services they have received for years are receiving notices that they must select an entirely new method of receiving services within 60 days or they will be auto-assigned -- some as soon as September 6th. Needless to say, they are confused, upset and do not understand what is happening. The packet of information being sent with the notice provides a summary description of the different models and lists of individual plans to choose from. Not only are individuals daunted by the distinctions between the "partially capitated" plans and "fully capitated" PACE/Medicaid Advantage Plus models that they don't understand, there is no concrete advice on choosing between individual plans within the models. Although the packet includes the telephone number of New York Medicaid Choice, this is insufficient to meet the needs of 30,000 high-need enrollees.

In December 2011, we submitted extensive comments to CMS regarding our concerns that the State had not provided sufficient safeguards to ensure that enrollees receive needed services in the community and avoid institutionalization.[1] We write again to ask that critical protections be expanded before implementation of the waiver program, in light of serious continuing concerns about consumer protections and lack of readiness to ensure a smooth transition.

- **The implementation should begin only with new applicants**, in order to publicize and test the new procedures and systems before shifting over 30,000 current stable personal care recipients to this new and untested program in the next few months, and another 50,000 next year.

- **Alternatively, the transition period should be expanded to a six-month safe harbor**, at least for those vulnerable individuals currently receiving 12 or more hours per day five or more days per week. The 30-day transition period in the State's proposal is not enough. As proposed, the plan is only required to continue the previous plan of care for someone currently receiving personal care services until they reassess the consumer's needs, which they must do in 30 days. Thus an individual who has received 24-hour/day care for ten years could be reassessed within a week of being assigned to an MLTC plan, and could have services sharply reduced immediately. While there are appeal rights, this is an entirely new system, and as stated below, the appeal rights are reduced from those which have existed. Providing a six-month safe harbor would allow time for the confusion of the initial months of mandatory enrollment to calm down, for consumers, their advocates. It would also allow time for plans to learn and adapt to the new systems, and ensure that vital services are not interrupted resulting in unnecessary institutionalization.

- **Fair hearing procedures must comply with due process rights guaranteed by the Fourteenth Amendment of the Constitution**, as interpreted in *Goldberg v. Kelly*, 397 U.S. 254 (1970). This must include the right to continue receiving long-term care services unchanged while a fair hearing is pending regarding the MLTC plan's proposed reduction or termination of these services, and timely and adequate notice of the proposed action. Many consumers transitioning to MLTC have received stable personal care services for years and even decades, because their chronic conditions have not changed. As proposed, an MLTC plan may reduce or even terminate these long-term services, and need not continue them while a hearing is held and decided, simply because an arbitrary "authorization period" for these services happened to expire. The right to a pre-termination hearing is the most fundamental requirement of due process as interpreted by the United States Supreme Court. See letter of December 2011 attached.

[1] December 2011 Letter attached and posted at http://wnylc.com/health/download/296/ .

- **Advance public information explaining these changes is vital**, such as articles in newspapers, public meetings in various parts of the state on the changes, or clear, consumer-friendly online information. The State has said it will conduct such education once it receives approval from CMS. However, as you know, the State is moving ahead to enroll over 30,000 NYC personal care recipients into MLTC plans as early as September 6th and in the next few weeks and months. The State's only online information is generally inaccessible to the public. One must find this webpage and then know to scroll down to MRT Number 90 – http://www.health.ny.gov/health_care/medicaid/redesign/supplemental_info_mrt_proposals.htm. In this void, some consumer organizations have posted information online[2] and conducted training programs for dozens of community-based organizations whose staff help consumers. But these organizations lack the resources to educate the thousands of people who need this information – much of which is still undefined. The State only recently (on August 17th and 24th) posted its first "Q & A's" online, answering only some of the many questions posed over the last few months.

- **State oversight must be expanded**. Before reducing or terminating 24-hour/day home care services previously authorized, and before placing a member in a nursing home, in order to avoid the grave risk of harm, plans should be required to report these cases to the State and to a designated independent ombudsprogram or advocacy organization, and afford time for investigation and representation. The State proposal lacks sanctions on plans with high rates of nursing home, hospital or adult home placements or low amounts of home care.[3] Only if the consumer manages to file a complaint or grievance, which requires learning an entirely new system that has not been publicized, might the issue come to the State's attention.

Most of the concerns raised in our December 2011 letter remain – and new ones have emerged as the daunting complexity of this roll-out becomes more evident. The State's process has lacked sufficient stakeholder inclusion. The weekly or bi-weekly "stakeholder conference calls," during which the State gives updates to hundreds of people, are not a substitute for active ongoing workgroups on key topics, such as rate-setting, quality, oversight, consumer rights, network adequacy, and contracts. Although the State has indicated that it will be creating some workgroups in the future, this should have been done before the roll-out. We do acknowledge having input on the language of the notices being sent to consumers[4] and individual discussions with policy makers, but

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[2] See http://wnylc.com/health/news/37/ and http://www.ltccc.org/MandatoryManagedCare.shtml .

[3] As an example of inadequate oversight, the State has not addressed warning signs that some plans may not be authorizing sufficient hours of home care, evident from quarterly cost reports filed by the plans, which were obtained through freedom of information requests. See, e.g. Home Health Care and Personal Care Services Hours Provided by MLTC and PACE Plans in NYS (2010), compiled from MLTC Cost Report Data for CY 2010, posted at http://wnylc.com/health/afile/169/324/. See also http://wnylc.com/health/afile/169/325/.

[4] The notices and brochures fail to explain all consumer options and exemptions from mandatory enrollment, such as that consumers may still enroll in the Lombardi (long term home health care) 1915(c)

more input is needed to ensure success of the program. In some key areas, such as "continuity of care" requirements to ensure that plan contracts with home care agencies to ensure that consumers keep their long-time home care aides, there is still ambiguity and confusion.

We are also particularly concerned about the need for financial incentives, contractual requirements and oversight to offset the inherent incentive in the capitation model for plans to avoid giving costly services. We submitted concrete proposals to the State in March 2012 to incentivize community-based care and prevent diversion of high-need members to nursing homes. See http://wnylc.com/health/download/304/. These proposals are vital to enforce *Olmstead's* mandate to provide services in the most integrated setting. Although the State met with us once to discuss our proposals, they have not made any significant changes.

Those most at risk are the approximately 5000-7000 people who, because of chronic health conditions, have been receiving 12-24-hour/day personal care services through the existing Medicaid prior authorization system in New York City. Many of them have received these services for years and even decades. Incentives and safeguards are needed to ensure that plans continue to provide the services needed to prevent nursing home placement. As stated above, the right to appeal a plan's decision to reduce or terminate long-term services is rendered meaningless if the consumer has no right to continue to receive these services unchanged pending a State hearing, *and* if the consumer must exhaust the plan's internal appeals before seeking a State fair hearing.

***Olmstead* is implicated not only in the lack of monitoring and safeguards, and in curtailed appeal rights, but in the inadequate ADA compliance plans** submitted by the plans that show a serious lack of compliance with the ADA. One of the undersigned organizations, the Center for Independence of the Disabled/NY, has analyzed these compliance plans. Among its findings are that MLTCs are not providing adequate notice of the right to reasonable accommodations, examples of those accommodations, and the right to appeal failure to provide accommodations. Plans are not all providing training to staff regarding member rights under the ADA. The plans cite agencies that no longer exist (and haven't for years) as providing assistance with accommodations. They confuse the provision of Medicaid services required by contract with provision of accommodations. Some of the plans omit mention of accommodations to some groups altogether. They do not provide information on their procedures. The information on provider compliance with the ADA is scant.

Support for Community First Choice Option & Ombuds program – While there are clearly grave concerns about the expedited implementation on mandatory MLTC, the State is simultaneously pursuing positive reforms that will have a direct impact on MLTC and the consumers enrolled in MLTC. We commend the State for pursuing the Community First Choice Option, 1915(k), to expand personal assistance services and streamline the service delivery system to support people regardless of age or diagnosis in

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waiver program, instead of an MLTC program. Nor do they explain that people in consumer-directed personal assistance programs are not yet required to enroll.

the community. We are also pleased that the State recognizes the need for an independent, statewide ombudsman program for people with disabilities and multiple chronic illnesses as these populations get mandatorily folded into managed care.[5] However, we are concerned that the State does not see the ultimate connection to advancing these initiatives that support people's rights, and the potential problems with MLTC that could prove to violate the Olmstead decision.

Please let us know if there are any other ways that we can help to ensure that the State's MLTC initiative is a success for all stakeholders.

Sincerely,

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[5] New York State 1115 Medicaid waiver proposal submitted August 6, 2012, "Ombudsperson Program – Supporting Choice," page 68.

On behalf of the following organizations:

504 Democratic Club
Alzheimer's Association, New York City Chapter
Bronx Independent Living Services
Brooklyn Center for Independence of the Disabled
Cardozo Bet Tzedek Legal Services
Center for Disability Advocacy Rights
Center for Disability Rights
Center for Independence of the Disabled, NY (CIDNY)
Commission on the Public's Health System
Disabled In Action
Empire Justice Center
JASA/Legal Services for the Elderly in Queens
The Legal Aid Society
Legal Services NYC - Bronx
Legal Services NYC, Brooklyn Branch
Lenox Hill Neighborhood House
Long Term Care Community Coalition
Medicaid Matters NY
Medicare Rights Center
Metropolitan Council on Jewish Poverty
MFY Legal Services, Inc.
New York Legal Assistance Croup
New York Lawyers for the Public Interest
United Spinal Association

cc: Jason Helgerson, New York State Medicaid Director, jah23@health.state.ny.us
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Henry Claypool, HHS Administration on Community Living

Enclosure: Letter from Legal Aid Society, NYLPI, and Cardozo Bet Tzedek Legal Services to Victoria Wachino at CMS (December 27, 2011)

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VIA FIRST CLASS & ELECTRONIC MAIL

December 27, 2011

Victoria Wachino
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Dear Ms. Wachino:

We are disability rights and seniors rights advocates, consumers, community advocacy organizations, and lawyers representing people with disabilities and older New Yorkers. We write to express concerns about the expansion of the 1115 waiver in New York State to include mandatory enrollment of Dual Eligibles who receive Medicaid personal care and other community-based long-term services in Managed Long Term Care ("MLTC") plans, as set forth in the letter to you from Jason Helgerson (letter dated April 13, 2011,) and in the documents accompanying that letter.

The MLTC plans, providers, and consumers all want a system that achieves the common goal of providing adequate and necessary services to enable people to live in the community, in furtherance of the goals of the ADA and *Olmstead*. However, the State proposes to rush into implementing a monumental change in how at least 85,000 individuals now receive Medicaid community-based services in New York City, to be followed later statewide, without sufficient safeguards to ensure that enrollees will receive the services they need in the community to avoid institutionalization. We are particularly troubled by anticipated problems with capacity, enrollment, gaps and interruptions in coverage, as well as with the program's lack of proper incentives, due process protections, oversight, and ability to absorb special programs currently providing critically important services. Our concerns and our recommendations are set forth in detail below.

SUMMARY OF RECOMMENDATIONS

1. Timing and Capacity -- Mandatory enrollment should not begin until other systemic concerns described below are addressed, and then solely with new applicants -- over 1,000 persons per month in NYC alone, which would provide an opportunity to work out and test the new systems. **Enrollment of current personal care and other program recipients should not begin until at least six months later**, after the State, in consultation with stakeholders, has monitored the impact of mandatory enrollment upon new applicants and adjusted the capitation rates and other systems as necessary.

2. Adequate Information Must be Provided to Consumers for Informed Choice in Enrollment, and the Network of Community Partners Must be Educated About the Sweeping Changes.

3. Increased Consumer Protections & State Oversight Are Needed to Ensure Compliance with Olmstead.

A. **MLTC Plans must be at risk for nursing home costs as well as community-based services costs,** and must not be permitted to dis-enroll members whom they determine require nursing home placement. Plans must incorporate risk adjustments or other mechanisms that incentivize community-based services.

B. **Plans must be given uniform standards for determining medical necessity that are consistent with established policy and precedent.** Mandatory enrollment must be postponed at least until the State has tested, revised, solicited input from consumers and other stakeholders, and conducted the necessary training for a new **Uniform Assessment Tool** that will be used by MLTC plans.

C. **When a plan determines that community-based services are not appropriate and that nursing home placement is necessary, the plan must give notice of such proposed placement both to the consumer, with appeal rights, and to an outside review entity,** such as an independent living center, who will be funded to ascertain whether the member voluntarily agrees to placement based on an informed choice, and whether community-based services could be provided.

D. **More robust state oversight is needed, including expansion of Quality Assurance Reporting Requirements (QARR)** to include additional metrics applicable to members who need long-term care.

E. **The State must ensure that an MLTC member has the due process right to continue receiving services unchanged, as "aid continuing" pending a hearing, before an MLTC plan reduces or terminates services** that were previously authorized by the plan or by the prior-approval procedure for the services that the individual previously received before mandatory MLTC enrollment.

F. **DOH must create, in partnership with consumers and their advocates, an Americans with Disabilities Act Compliance Appendix to the contract,** and monitor its implementation as a step towards disability literacy.

4. Access to Special Program Services -- Long-Term Home Health Program (LTHHP) and Consumer-Directed Personal Assistance Program (CDPAP) recipients should be excluded from mandatory managed long term care. LTHHP recipients are already enrolled in a 1915(c) waiver with cost neutrality requirements and care management, and stand to lose spousal impoverishment protections as well as waiver services. CDPAP recipients and applicants also should be exempted until the State develops adequate requirements to preserve the CDPAP model as developed in New York State.

5. A new point of entry that is accessible for NYC residents with disabilities seeking community-based long-term care services to apply for and renew Medicaid is not yet developed, tested or publicized, threatening to disrupt care and deny access. It is critical that mandatory enrollment not commence until procedures are established to ensure that no vital Medicaid home care will be discontinued during temporary lapses in Medicaid pending resolution of renewal errors, and to ensure

that Medicaid applications and requests for home care services are processed expeditiously in ways that reasonably accommodate the disabilities of the applicants.

DETAILED RECOMMENDATIONS

1. TIMING AND CAPACITY

The State's recent *Draft Enrollment Plan* proposes to implement mandatory MLTC much more rapidly than originally proposed. Beginning April 2012, all new applicants for personal care in NYC -- about 1170 per month[1] -- will be required to enroll in a Managed Long Term Care plan, and within only six months – instead of the original 36 months -- all 45,000 current personal care recipients [2] -- will be enrolled in MLTC. The transfer of current personal care recipients alone will increase by 150 percent the number now voluntarily enrolled in MLTC -- 29,000 in NYC. Similarly, the State does not specify the numbers of individuals to be enrolled in the second phase, when the draft plan proposes to enroll *all* CHHA recipients, Long Term Home Health Plan (1915 waiver) recipients, adult day health care and private duty nursing recipients in NYC during only two months—November and December 2012. We estimate that these enrollees will number at least 40,000 – 60,000 in New York City alone.[3]

The rushed enrollment challenges not only the plans' capacity to absorb large numbers of enrollees, but also their ability to serve enrollees with more extensive needs for home care and other services. We question the State's claim that the current voluntary MLTC plans are equipped to serve the influx of new members because they already serve members with a "high level of impairment." The State admits that the current population served by MLTC "…is less impaired than the nursing home population," yet it fails to compare the MLTC population to the Medicaid personal care population about to be enrolled *en masse*. According to the United Hospital Fund, "…two-thirds of New York City's personal care beneficiaries had comparable levels of need [to nursing home residents] on key indicators, such as functional and cognitive status, as indicated by resource utilization group ("RUG") scores…."[4] Moreover, we firmly believe that

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[1] NYC HRA Home Care Services Program, "Screen, Intake & Pending (SIP) Unit CASA by CASA REPORT" (average 1170 applications filed per month for the six months ending January 2010, of which about 250 new cases per month approved for service)(provided in April 2010 to Selfhelp Community Services, Inc. in response to Freedom of Information request.)

[2] An average of 50,410 people received personal care in NYC per month in the First Quarter 2010. NYS Dept. of Health, Medicaid Quarterly Reports of Beneficiaries, Expenditures, and Units of Service by Category of Service by Aid Category by Region, posted at http://www.health.ny.gov/nysdoh/medstat/quarterly/aid/quarterly.htm; scroll to 2010 – First Quarter, direct link at http://www.health.ny.gov/nysdoh/medstat/quarterly/aid/2010/q1/docs/2010_q1_aid.xls. (Note that the number receiving personal care services for First Quarter 2010 has been reduced by about 5,000 to reflect the number of mainstream Medicaid managed care recipients whose personal care services were newly carved into their managed care benefit package on August 1, 2011.)

[3] This is based, in part, on an estimated 49,989 people receive long-term CHHA services in NYC. (This is 69% of the 59,405 people receiving CHHA services per month in NYC in Q1 2010, excluding 31% estimated by the United Hospital Fund to be short-term users). See NYS DOH Medicaid Quarterly Reports, supra, n 2; and Alene Hokenstad et al., *An Overview of Medicaid Long-Term Care Programs in New York* (United Hospital Fund 2009)(p. 9), posted at http://www.uhfnyc.org/publications/880507. In addition to the CHHA recipients, in Calendar Year 2008 the following numbers of NYC residents received other long-term care services: Long Term Home Health Care Program --16,289; Adult Day Health Care --10,524; Assisted Living Program -- 1,932.; private duty nursing – unknown. NYS DOH, *Interim Report Home Health Care Reimbursement Work Group* (Dec. 2009)(Table 2-A: NYS Medicaid Recipient Counts for Long Term Care Services – NYC)(posted at http://www.health.ny.gov/facilities/long_term_care/reimbursement/docs/hcrw_interim_report.pdf). The total potential non-personal care enrollees, then, are 69,734. Even a reduction by 30% to eliminate any duplication and short-term usage still leaves 50,000 people to enroll in two months.

[4] Alene Hokenstad et al., *An Overview of Medicaid Long-Term Care Programs in New York* (United Hospital Fund 2009), posted at http://www.uhfnyc.org/publications/880507; *see also* S. Samis & M. Birnbaum, *Medicaid Personal*

in the last six years of voluntary MLTC enrollment, many of the MLTC plans have "cherry-picked" a lower need population, in effect siphoning off people from the low end of the bell curve of personal care and CHHA recipients, and thereby leaving a higher-acuity population in the personal care and CHHA programs.

The personal care services provided to the New York City residents who will be mandated to enroll in MLTC plans were authorized under a tightly regulated prior authorization procedure that strictly limits services to those that are *medically necessary* under state law – any reduction by the MLTC plans threatens their health and safety**.** These strict utilization controls, which entail an onerous multi-assessment regime conducted by the local Medicaid offices (the Human Resources Administration, or "HRA," in New York City) and subject to review by the State when consumers request administrative hearings, already ensure that only "medically necessary" services are provided. This strict prior approval mechanism prevents any excessive usage that might occur in other **"**fee for service" systems. A sense of the rigor of this process—and the vulnerability of this high-need population—can be gleaned from sampling the thousands of hearing decisions issued by the State, finding that HRA *denied* adequate services. *See*, *e.g.*, Hearing No. 5874576L decision dated Oct. 14, 2011.[5] Therefore, any reduction by MLTC plans in the personal care services that have been determined to be medically necessary is potentially life-threatening. Over 40 percent of personal care recipients have been receiving personal care services for at least seven years due to long-term chronic conditions.[6] Therefore, any reduction by MLTC plans in the personal care services that have been determined to be medically necessary is potentially life-threatening.

The capacity of these MLTC plans to receive and serve an influx of at least 85,000 new members in--many of whom have higher level needs—is not clear, especially not on the implementation timeline proposed. The risk-adjusted capitation rates that have been calculated for plans currently are based on the acuity of their current voluntary enrollees – the State has not projected whether the acuity of the anticipated increased enrollment will require adjustment of these rates – without adequate rates or risk adjustments such as outlier payments or stop-loss mechanisms, both plans and consumers are at risk.

In the summer of 2011, some MLTC plans in New York City were backlogged in processing the influx of a few thousand clients transitioned from fee-for-service CHHA care resulting from reimbursement cuts enacted by the State that became effective in April 1, 2011. Considering the delays in absorbing this relatively small influx of new members, we are fearful of the delays to come when tens of thousands of new members are enrolled. The State should obtain from the MLTC plans the information that is needed to assess the respective plans' capacity to process and initiate service on cases referred since April 1, 2011, and to meet the enrollment demand under the mandatory transition timeline.

RECOMMENDATION: Mandatory enrollment should begin solely with new applicants -- over 1,000 persons per month in NYC alone, which would provide an opportunity to work out and test the new systems. **Enrollment of current personal care and other program recipients should not begin until at least six months later**, after the State, in consultation with stakeholders, has monitored the impact of mandatory enrollment upon new applicants and adjusted the capitation rates and other systems as necessary.

Care in New York City: Service Use and Spending Patterns (United Hospital Fund 2010), posted at http://www.uhfnyc.org/publications/880720 (Over 70 percent of New York City personal care recipients in a 2003 cohort had at least one chronic disease, and over half had multiple chronic diseases, with one in four recipients having a mental health diagnosis.)

[5] Decision posted online at http://www.otda.ny.gov/fair%20hearing%20images/2011-10/Redacted_5874576L.pdf.

[6] S. Samis & M. Birnbaum, *Medicaid Personal Care in New York City: Service Use and Spending Patterns* (United Hospital Fund 2010), *supra*, at pp. iii-iv, 6-8.

2. ADEQUATE INFORMATION MUST BE PROVIDED TO CONSUMERS FOR INFORMED CHOICE IN ENROLLMENT, AND THE NETWORK OF COMMUNITY PARTNERS MUST BE EDUCATED ABOUT THE SWEEPING CHANGES.

With mandatory enrollment slated to begin in only three months, to date there are no stated plans for informing consumers of their choices, or for educating the huge network of community-based social services and health care providers who assist consumers in accessing Medicaid home care services. Nor is it clear how auto-assignment will work where the existing plans have very different capacities and different specialties (e.g. Guildnet specializes in visually impaired, while Independence Care Systems specialized in physical disabilities.)

The State claims that consumers will receive a description of the types of plans available to make an informed choice. However, the State has *not* circulated drafts of this information for input from stakeholders, including consumers. Information provided to consumers about their choices must include information about the track record of each plan in authorizing services. Consumers need to know the information set forth in Exhibit A (a copy attached hereto) – now available only through Freedom of Information requests. This includes the percentage of members receiving 700+ hours per month (meaning continuous 24-hour care, i.e. 168 hours/ week) and other ranges of hours. Exhibit A shows that four MLTC plans in NYC ranged from 0.2% to 8% in the number of members provided 700+ hours per month. For someone who had been receiving that amount of personal care services for years through the NYC personal care program, this is certainly crucial information in selecting a plan. Similarly, consumers have the right to know the percentage of the capitation rate spent on nursing home care, home care, durable medical equipment, and transportation (*See* Exhibit A.)

Additionally, statewide consumer and professional education and training are needed; consumer advocacy organizations should be funded to provide such training to the myriad grassroots neighborhood-based organizations that provide services to the aging and disabled.

3. LACK OF CONSUMER PROTECTIONS & STATE OVERSIGHT TO ENSURE COMPLIANCE WITH OLMSTEAD

We have the following critical concerns, all of which raise serious implications under the Americans with Disabilities Act (ADA) as interpreted in *Olmstead v. L.C., 527 U.S. 581 (1999).* Terms and conditions of the waiver must incorporate these elements:

A. **MLTC plans must be at risk for nursing home costs as well as community-based services costs, and must not be permitted to dis-enroll members whom they determine require nursing home placement.** Risk adjustments or other mechanisms must be incorporated into the capitation rates and contracts that incentivize community-based services and offset incentives for nursing home placement for high-need individuals who are "outliers" in terms of need.

   Currently, MLTC plans may dis-enroll a member on the basis that he or she requires long-term nursing home placement; this creates an incentive to place higher-cost members into nursing homes rather than to provide adequate community-based services to prevent institutionalization. Moreover, for the small number of recipients for whom nursing home care is less costly than community-based care – roughly two percent of the current personal care population -- there are no mechanisms to counter the financial incentive for the MLTC plans to institutionalize them, in violation of *Olmstead* and the ADA. There are about 1,200 people in NYC who now receive continuous 24-hour services (2 – 12-hour shifts/day), out of about 50,000 personal care recipients. In addition, an unknown but presumably small number of the 59,000 home health recipients receive 24-hour care because they need round-the-clock assistance with toileting, ambulation,

turning and positioning and other (activities of daily living ("ADLs") because of dementia, stroke, multiple sclerosis, or other severe chronic conditions. *The State has proposed no mechanism to counter the incentive created by capitation for the plans to institutionalize these individuals*, despite its articulation of the need for such mechanisms in "care coordination principles."[7] Under the current "voluntary" MLTC system, some MLTC plans already have informed prospective members that they have a limited number of "slots" for 24-hour care. The State has not responded to our requests to consider risk adjustments such as stop-loss mechanisms or outlier payments to ensure access to community-based care.

B. **Plans must be given uniform standards for determining medical necessity that are consistent with established policy and precedent.** Mandatory enrollment must be postponed at least until the State has tested, revised, solicited input from consumers and other stakeholders about, and conducted the necessary training for a new **Uniform Assessment Tool** that will be used by MLTC plans.

Unlike much of the primary and acute medical care authorized under traditional managed care plans, the authorization of long-term care, particularly home care services, must take into account myriad factors that are not solely medical – e.g. the individual's available social network of informal caregivers, his or her housing situation, the logistics needed for basic housekeeping, shopping, and other tasks. **Mandatory enrollment must be postponed at least until the State has tested, revised, and solicited consumers' and other stakeholders' input about, a new Uniform Assessment Tool that will be used by MLTC plans.**[8] The State has said this tool will not be ready for implementation until October 2012. Until then, MLTC plans may simply make up their own rules and guidelines, which will result in inconsistent and arbitrary determinations.

In addition to a uniform assessment tool, the standards used to assess the amount of services necessary must comply with standards set by regulation, litigation and administrative precedent in New York State over decades. In just one example, the MLTC model contract requires involuntary dis-enrollment by the plan when a consumer is hospitalized for 45 days or longer.[9] This requirement potentially violates several court decisions and settlements which have been incorporated into State directives.[10] Similarly, state regulations restrict the use of "task-based assessment" for people determined to have 24-hour a day needs (18 NYCRR 505.14(b)(5)(v)), and a State directive prohibits the denial of personal care services needed to assist a consumer to safely perform basic activities of daily living –a policy that is vital to protect people who have dementia. *See* NYS Dep't of Health GIS 03 MA/003, http://www.health.state.ny.us/health_care/medicaid/publications/docs/gis/03ma003.pdf. The fair hearing decision example provided on page 5 above cites this directive in reversing the City's denial of personal care services. The same clear authority must control when MLTC plans determine eligibility and need for services.

C. **When a plan determines that community-based services are not appropriate and that nursing home placement is necessary, the plan must give notice of such proposed placement, with appeal rights, both to the consumer and to an outside review entity,** such as an independent living center, who will be funded to ascertain whether the member voluntarily agrees to placement based on an informed choice, and whether community-based services could be provided to maintain the individual in the community.

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[7] *See* http://www.health.ny.gov/health_care/medicaid/redesign/docs/2011-11-15_care_coord_model_guidelines.pdf at p. 8 (providing no explanation for how rates will "incentivize community-based services.)

[8] The State also must conduct training in order to effectively implement such a uniform assessment tool.

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

[10] 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.

There are insufficient procedural and oversight mechanisms to prevent MLTC plans from utilizing excessive nursing home services instead of community-based care. Even now, with a lower-acuity voluntary enrollment population, some MLTC plans spend as much as 11.4% of their capitation on nursing home care.[11] We question how and why the State currently permits such high usage of nursing home service, and we are extremely concerned that this usage will only increase when the pool of consumers entering MLTC programs expands to include those now receiving high hours of personal care or CHHA services. The MLTC model contract gives MLTC plans total discretion in determining when to utilize nursing home services that are included in the capitation rate. The State has not proposed any safeguards to ensure access to community-based care.[12] In addition to possible risk adjustments as described above, the SDOH should also implement mandatory reporting requirements, so that an external review entity must first review—and approve—any proposed placement in a nursing home, for services other than short-term rehabilitation services.

D. More robust state oversight is needed, including expansion of Quality Assurance Reporting Requirements (QARR) to include additional metrics applicable to members who need long-term care.

The State must do more pro-active monitoring than simply obtaining reports from MLTC plans on the numbers of grievances or hearings filed, or conducting consumer satisfaction surveys. The vast majority of consumers, who by definition are elderly and/or disabled, many with mental illness, will not utilize the grievance and hearing systems. As the court found in *Mayer v. Wing*, 992 F. Supp. 902 (S.D.N.Y. 1996):

> …Although some Medicaid recipients are able to successfully challenge reductions at fair hearings, such hearings are not enough to assure Plaintiffs due process… 'The administrative appeal process is not a substitute for proper prior procedures at the agency level. Whatever its value in individual cases, the administrative appeal process may not regularly be used as a vehicle to conduct a requisite inquiry which the agency continually fails to institute'….

992 F. Supp. at 912. Initially, for the at least 85,000 people currently receiving services that are being transferred to MLTC plans, the State must require MLTC plans to report every decision to reduce services from the amount previously authorized under the regulated prior approval system, and every decision to terminate community-based services. The State must then arrange for an independent oversight entity to review such cases to ensure that MLTC plans are not improperly denying services and/or placing people in institutions. Additionally, the State must sample, randomly, approvals and denials for other services – i.e. motorized wheelchairs and other durable medical equipment, transportation for medical care, dental care and eye care, and other services covered in the package. Oversight is also needed to ensure timely authorizations for services.

Quality Assurance Reporting Requirements ("QARR") reporting data must be expanded to include additional metrics that are applicable to members who need long-term care (e.g. ability to perform activities of daily living, prevalence of decubitus conditions, usage of incontinence pads

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[11] *See* Personal Care Aid Utilization Comparison in MLTC Plans in NYC, page 2 (Based on MLTC Cost Reports filed with State DOH for 2009 Q4)(Two-page summary attached as Exhibit A.) Note that this data was obtained in a Freedom of Information request, and is not readily available to consumers.

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

as opposed to assisting with toileting, incidence of falls and other accidents, temporary and permanent nursing home placement.)

E. **The State must ensure that a MLTC member has the due process right to continue receiving services unchanged, as "aid continuing" pending a hearing, before an MLTC plan reduces or terminates services** that were previously authorized by the plan or by the prior-approval procedure for the services that the individual previously received before mandatory MLTC enrollment, regardless of when any authorization period for such services expires.

The proposed procedures deny Medicaid beneficiaries due process protections of advance notice and a hearing before any adverse changes by the MLTC plan in the long-term-care services plan.[13] Reduction or termination of Medicaid services must comply with the rights established in *Goldberg v. Kelly*, 397 U.S. 254 (1970), including advance notice and a right to a pre-termination hearing before any change in services is implemented. In this context, this means that before an MLTC plan can change a service plan previously authorized by the former utilization review system, the MLTC plan must provide advance notice and the individual must have a right to a pre-termination hearing, with Aid Paid Pending (known as "aid continuing" in NYS) pending the hearing. The State has indicated that now it is interpreting the federal Medicaid managed care regulations at 42 CFR §438.420(b)(4) to mean that the MLTC plan must only continue the enrollee's benefits if the original period covered by the original authorization has not expired. The end result for this fragile population is that the MLTC plan may reduce hours sharply or even terminate services altogether after the standard six-month authorization period expires, with no advance notice and no right for the consumer to receive aid pending a hearing, even for an individual who was found by the NYS Department of Health after an administrative hearing to need 24-hour/day care.

The State incorrectly relies on this federal regulation, promulgated almost a decade ago, which was written for short-term primary and acute medical services, where the individual would have no expectation that services would continue once that medical condition has been treated. At the time, Medicaid-managed care benefit packages did not include *long-term* home care services. Since an individual's chronic conditions rarely will improve, the need for ongoing long-term home care services likely will continue for an indefinite time period. Indeed, the average period of receiving Medicaid personal care services in NYC was found to be 4.75 years in December 2008, with over 40 percent of personal care recipients receiving personal care services for at least seven years.[14]

Failure to accord consumers the right to aid continuing pending a hearing on proposed adverse changes in their service plan would violate due process, as interpreted in *Mayer v. Wing*, *supra* (holding due process prohibits arbitrary reductions in Medicaid personal care services previously approved, even where beneficiary receives advance notice with the right to receive services unchanged as aid-continuing pending a pre-reduction hearing.)

Even if the MLTC plans are not required to pay for services during the "aid continuing" period pending the hearing, the State cannot be absolved of its constitutional duty to provide due process, and must establish a mechanism to pay the MLTC plans or the providers directly to provide services pending the hearing. As is true with fee-for-service Medicaid, the beneficiary

[13] Exemplifying the lack of consumer input in the development of the MLTC system, the State Medicaid Redesign Team Subcommittee on Managed Long Term Care designated a Workgroup charged with developing and recommending Fair Hearing and Due Process procedures. The State convened this Workgroup to meet only one time, precluding it from adequately addressing these key issues.

[14] S. Samis & M. Birnbaum, *Medicaid Personal Care in New York City: Service Use and Spending Patterns* (United Hospital Fund 2010), *supra*, at pp. iii-iv, 6-8.

may be liable to repay the cost of services provided pending the hearing if the proposed reduction is upheld by the hearing decision.

F. DOH must create, in partnership with consumers and their advocates, an Americans with Disabilities Act Compliance Appendix to the contract, and monitor its implementation as a step towards disability literacy.

With its emphasis on interdisciplinary care coordination and avoidance of inappropriate reliance on institutional settings, MLTC presents some opportunities to improve the care of people with disabilities. However, MLTC will only achieve this promise if it attends to the disability literacy of MLTC plans. Disability literacy for MLTC plans may be defined as the capacity to understand, communicate, and partner 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. Lack of training on disability literacy issues and problem-solving to remove barriers for health plan administrators, staff and care practitioners creates a very significant barrier to effective health care.

Disability literacy is critical to the success of the MLTC program. New York State recently has 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.[15] They also experience health disparities and face significant problems accessing health services. For example, adults who are deaf report poor health with greater frequency than people who are not deaf, lack interpreters in health settings and fail to receive health information and instructions from practitioners. Adults 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 or understand instructions.[16]

Managed long-term care can fulfill its promise of coordinating care and avoiding expensive and overly restrictive institutional placement, only if it addresses disability literacy issues.

An *Americans with Disabilities Act Compliance Appendix* to the contract would make provision for eradication of physical, communications-related, programmatic and attitudinal barriers. 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, accessible 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;

[15] 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.
[16] National Council on Disabilities, "The Current State of Health Care for People with Disabilities," 2009.

F. policies that facilitate the provision of reasonable accommodations to people with disabilities; and

G. provision of opportunities for plan participants to participate, in a significant manner, in the development of plan policies and practices.

4. ACCESS TO SPECIAL PROGRAM SERVICES:

A. Long-Term Home Health Plan ("LTHHP" 1915(c) waiver)

This 1915(c) waiver was renewed on Sept. 1, 2010 with new quality assurance and service package enhancements, along with new data collection and analysis requirements. *See* NYS DOH, 11 OLTC-ADM-1, *Long Term Home Health Care Program Waiver Renewal (*April 26, 2011) http://www.health.ny.gov/health_care/medicaid/publications/docs/adm/11oltcadm-1.pdf. The State has announced that MLTC plans will provide state plan services only. Thus LTHHP participants forced to enroll in MLTC will lose valuable waiver services. Additionally, married participants would lose spousal impoverishment protections approved in this waiver that are not available in MLTC programs.

RECOMMENDATION: Participants in this waiver should be excluded from mandatory managed long term care**,** since this 1915(c) waiver already has *cost neutrality* requirements and care management.

B. Consumer Directed Personal Assistance Program ("CDPAP") Services

The State law authorizing DOH to submit this waiver expansion request requires 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 state law. However, we have concerns about how this requirement will be implemented. 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[17] recognizes the unique self-management 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 are inherent in the question of 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. The MLTC plan may have a conflict of interest in being the decision maker on this issue. 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.

We also question whether MLTC plans will be required to contract with an independent CDPAP provider, or whether they or their existing sub-contractors of home care services will be allowed to develop in-house CDPAP programs. In the case of the latter, we would have serious concerns about the 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. A specific balance of responsibility must be achieved between the consumer and the provider in order to maintain both the consumer's empowerment and to mitigate the provider's exposure to liability.

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

<u>RECOMMENDATION</u>: Until the State develops adequate requirements to preserve the CDPAP model as developed in New York State, consumers enrolled in, or who wish to apply for the CDPAP program, should be exempted from mandatory enrollment in MLTC.

5. A NEW POINT OF ENTRY THAT IS ACCESSIBLE FOR NYC RESIDENTS WITH DISABILITIES SEEKING COMMUNITY-BASED LONG-TERM CARE SERVICES TO APPLY FOR AND RENEW MEDICAID IS NOT YET DEVELOPED, TESTED OR PUBLICIZED, THREATENING TO DISRUPT CARE AND DENY ACCESS.

Mandatory MLTC fundamentally alters the 30-year old system and entry point for 1,170 NYC residents to file Medicaid applications each month and 50,000 recipients to process annual Medicaid renewals. For over 30 years, New York City's Human Resources Administration (HRA) has maintained between one and three "one-stop" offices in each borough called "CASA offices," (also known as "CASAs") at which frail homebound seniors and people with disabilities can both apply for Medicaid and initiate a request for personal care services, and then annually renew eligibility for Medicaid.

These CASAs accommodate the disabilities of many applicants by having a caseworker visit the applicant at home to complete the applications for both Medicaid and home care. By simultaneously processing the dual applications for Medicaid and for personal care services, the CASA system is efficient and can approve Medicaid and home care within 45 -60 days. The State has not yet specified whether the CASAs will still accept and process the Medicaid applications through this system oriented for homebound people. If not, applications will have to be filed through the other Medicaid offices that serve all ages and populations. These offices do not have a reliable system for promptly accommodating the needs of people whose disabilities make travel difficult. If applicants are required to wait until Medicaid is approved—a period of at least 45 days—before they can apply to an MLTC plan, then such a waiting period will delay delivery of services significantly.

Systems are not developed or ready to ensure continuity of home care when inevitable bureaucratic glitches occur in routine renewals for Medicaid after April 1, 2012. Until now, NYC HRA CASAs handled the routine Medicaid renewals for personal care recipients to demonstrate continuing financial eligibility for Medicaid, accommodating their disabilities by assisting them with collecting documents via home visits. Given the huge volume of Medicaid renewals in NYC, errors commonly happen, with vulnerable clients experiencing lapses in Medicaid coverage due to renewal paperwork that was lost in the mail or was never processed. *The current NYC HRA policy ensures that vital personal care services are not disrupted during any temporary lapse in Medicaid due to such renewal errors.* HRA has exercised its contractual authority with personal care providers to direct them to continue providing services while the problem is being corrected. Under managed care, however, if the managed care plan does not receive their monthly capitation payment because Medicaid eligibility erroneously has lapsed due to a bureaucratic error, plans may and have been known to discontinue home care services, leaving vulnerable seniors and people with disabilities at risk of severe harm.

<u>RECOMMENDATION</u>: It is critical that mandatory enrollment not commence until procedures are established to ensure that no vital Medicaid home care will be discontinued during temporary lapses in Medicaid pending resolution of renewal/ recertification errors, and to ensure that Medicaid applications and requests for home care services are expeditiously processed in ways that reasonably accommodate the disabilities of the applicants.

*** * ***

Thank you for the opportunity to voice these concerns. We would welcome the opportunity to meet to discuss these issues.

Very truly yours,

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On behalf of the following organizations:

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Alzheimer's Association, New York City Chapter
ARISE Independent Living Center, Oswego NY
Bronx Independent Living Services
Brooklyn Center for Independence of the Disabled
Center for Independence of the Disabled, NY
Coalition of Institutionalized Aged and Disabled
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Southern Tier Independence Center
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Yad HaChazakah-The Jewish Disability Empowerment Center Inc.

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