FINAL DRAFT

Medicaid Matters New York

New York State
Medicaid Managed Care Ombudsman Program
(Name to be determined)

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EXECUTIVE SUMMARY

The work of the MRT has been far-reaching in scope, but in our view, no initiative will affect so many vulnerable New Yorkers as deeply as the unprecedented plan to enroll virtually all Medicaid recipients in Medicaid Managed Care and related care management programs over the next few years.

While the majority of New York's Medicaid recipients are enrolled in Medicaid Managed Care, there are several populations that have experienced limited, voluntary enrollment to date. These populations include recipients with disabilities or complex health needs; people who receive both Medicaid and Medicare (dual eligible recipients); and those experiencing barriers to care such as homelessness.

In addition to mandatory enrollment in mainstream Medicaid Managed Care for most previously exempt or excluded populations, the MRT recommendations and related policies will result in the development of an array of new care management initiatives. These include the establishment of Behavioral Health Organizations; mandatory enrollment in Managed Long Term Care; a new Medicaid Managed Care program for those with intellectual and developmental disabilities; and integrated managed care for the dual eligible group.

The Need and Vision for a New York State Medicaid Managed Care Ombudsman Program

Clearly, this sea change in how and where people with disabilities or chronic illnesses access care through the Medicaid program creates the need for an advocacy program specializing in consumer education, community training, and advocacy services tailored to meet the unique needs of these populations.

Recipients would benefit from: learning how to access services in a managed care environment; help in securing a change in or restoration of benefits, services, or supports; advocacy to obtain accommodations for their disabilities; and the fruits of systemic advocacy addressing patterns such as improper notices, inadequate networks or accommodations, or unlawful care management practices. Further, recipients in managed care generally would benefit from the ability to access an enhanced information and referral system with automated guidance by telephone as well as general advice and referrals from well trained advocates situated in their own communities.

There are various programs and services currently provided to the target population that offer similar elements contemplated by the program design. There is not, however, sufficient capacity within the current disability and legal services networks to provide the proposed level of service without a significant increase in resources.

This proposal is designed to expand and target advocacy services to reach a group of people numbering as many as 1.5 million who will be entering managed care for the first time in the next few years. It is intended to drive resources to the various groups in local communities that serve the newly mandated populations in order to strengthen their capacities and competencies and target help for this new wave of people as they enter and adjust to various

managed care programs. The emphasis of the program is to strengthen local capacity and improve disability literacy and accommodations in managed care settings, and it recognizes the complexity of the work involved in serving those with multiple and profound needs.[i]

> Need to coordinate with OPWDD to incorporate MMCOP into OPWDD's new managed care structure, as well as ensure that MMCOP successfully addresses the unique needs of people with developmental disabilities.

> Awaiting info on how to address the 1915 waiver populations in the paper, if at all.

A recipient who uses a wheelchair because of an amputation might use the services of an ombudsman program to help appeal a denial of prostheses that a Medicaid Managed Care entity had issued based on her advanced age. A peer support group comprised of people with developmental disabilities might receive training in how to request changes in their supports and when to contact the ombudsman about care management problems.

An organization serving people with hearing disabilities and its clients might work with the ombudsman program to bring to light the absence of any sign language interpretation support for their clients enrolled in a certain health plan. An ombudsman program might spot a spike in the number of clients coming in with complaints about receiving reduced home health care services or certain medications and initiate an investigation and negotiations to address inappropriate or unlawful limitations. The parent of a child recipient with a serious emotional disturbance might seek the help of an ombudsman to obtain an appointment with a child psychiatrist sooner than the one she has for six months later.

Medicaid Matters New York recommends the establishment of a Medicaid Managed Care Ombudsman Program (MMCOP) for people with disabilities or chronic illness modeled in part on the successful ombudsman statute and contract used in Wisconsin.

MMCOP services should assure timely and adequate access to needed care, supports, and services from all Medicaid Managed Care organizations and care coordination entities. MMCOP would help recipients resolve disputes with managed care entities; monitor, document, and investigate systemic problems; provide timely systemic advocacy; offer information, guidance, and support; and provide direct representation in grievances, Fair Hearings, and appeals. These centers and their centralized support office would be positioned to handle general Medicaid managed care information and referrals and posses technical expertise in all aspects of both Medicaid and Medicare.

By intervening in these ways at the local level, the program would help resolve problems as they arise and save scarce public resources that would otherwise be spent on costly litigation and financial penalties for unlawful practices and procedures employed by Medicaid managed care entities. Further, it would provide a cost-effective way to improve managed care "literacy"

for the neediest recipients who have not previously had to make their way through the various managed care processes. This program will benefit enrollees, managed care organizations, and the Department. There is no statewide system yet in place to reach out to the new target populations and help them secure and retain needed services and supports as they move into managed care.

Target Population, Structure, Services, and Financing

There are at least 1.3 million New Yorkers with disabilities or chronic illnesses in the Medicaid program, including those eligible for both Medicaid and Medicare. The care of those with high costs is $31.1 billion per year. In addition, other recipients with lower costs or other disabilities also likely require some degree of assistance in accessing services and supports, as well as protecting their rights in the new care management settings.

New York's MMCOP should be established in statute with a minimum staffing ratio of one advocate for every 2,500 recipients with disabilities or chronic illnesses. The program should be phased in over four years, and the initial populations to be served should be the managed long term care group, followed by the behavioral health, chronic medical, intellectual/developmental disability, and other groups. The State should include a limited-term, upfront development grant to facilitate timely establishment of the program.

The MMCOP should be configured as a "hub and spokes" support system with centralized advisory, management, procurement, training, and quality assurance functions (*MMCOP Coordinator*); and subcontracts with local community-based programs (*MMCOP Centers*). All contracts should be awarded through competitive processes, and no less than 80 percent of the program funds should be allocated to MMCOP Centers.

MMCOP Centers each should provide all of the following services[ii]:

a. Information, technical assistance, consumer education, and community training on obtaining Medicaid and Medicare services and coordination, supports, and protection of due process rights.
b. Advice and assistance in preparing and filing complaints, grievances and appeals of complaints or grievances, including preparation of documents and guidance for self-advocacy.
c. Negotiation on behalf of both individuals and groups.
d. Individual case advocacy services including interpretation of statutes, rules, or regulations, as well as accompaniment and legal representation in administrative hearings or any other judicial proceedings relating to managed care services, coordination, or benefits.
e. Systemic advocacy to ensure timely and adequate access to all services or supports a beneficiary is eligible to receive, including accessible and effective notices; the Federal Americans with Disabilities Act, as well as State and local laws regarding accommodations; adequate translation and interpretation assistance; preservation of due process rights; and identification of and referrals to outside resources to address any systemic issues that fall outside the scope of MMCOP.

The funds needed to support the program would come from the State's forthcoming 1115 Medicaid amendment proposal ("Super Waiver"), submitted in August 2012, and potentially administrative funds for Medicaid.

NEW YORK STATE MEDICAID MANAGED CARE OMBUDSMAN PROGRAM

In January 2011, Governor Andrew M. Cuomo established by Executive Order a Medicaid Redesign Team (MRT) for New York State. The work of the MRT has been far-reaching in scope, but in our view, no initiative will affect so many vulnerable New Yorkers as deeply as the unprecedented plan to enroll virtually all Medicaid recipients in Medicaid Managed Care and related care management programs over the next few years.

Recognizing New York's historic expansion of Medicaid Managed Care, Medicaid Matters New York recommends the establishment in New York of Medicaid Managed Care Ombudsman Program[iii] for people with disabilities or chronic illness modeled in part on the successful statute and contract used in Wisconsin's ombudsman program.

Medicaid Managed Care Context

New York's Medicaid program now costs $57.4 billion per year and accounts for 18 percent of State funds ($22.8 billion) in the Executive Budget. As of the end of January 2012, there were 5,012,919 New Yorkers enrolled in Medicaid, including 3.5 million enrolled in Medicaid Managed Care, and more than 1.3 million recipients with a disability or chronic illness.

While the majority of New York's Medicaid recipients are enrolled in managed care, there are several populations that have experienced limited, voluntary enrollment to date. These populations include recipients with disabilities or complex health needs; people who receive both Medicaid and Medicare (dual eligible recipients); and those experiencing barriers to care such as homelessness.

For these and other groups, enrollment has been limited to certain eligible volunteers. Most have not enrolled due to their status as either categorically exempt or excluded from previous managed care mandates. Nearly all of the exemptions and exclusions have now been repealed and several different models of care coordination are under development to serve Medicaid recipients in both voluntary and mandatory structures.

In addition to mandatory enrollment in mainstream Medicaid Managed Care for most previously exempt or excluded populations, the MRT recommendations and related policies will result in the development of an array of new care management initiatives. These include the establishment of Behavioral Health Organizations; mandatory enrollment in Managed Long Term Care; a new Medicaid Managed Care program (under a separate waiver) for those with intellectual and developmental disabilities; integrated managed care for the dual eligible group; a return to New York settings for many living in out-of-state institutions; and the establishment of Health Homes,[iv] a voluntary care coordination program, for about one million recipients with mental illnesses or multiple chronic illnesses.

Numerous other changes to consumer direction and long term care, as well as new housing incentives and supportive housing opportunities will present further challenges for those with special needs seeking assistance through Medicaid.

People with Disabilities or Chronic Illness

The access challenges recipients with disabilities and chronic illnesses face in the coming months and years are extraordinarily complex. For those eligible for both Medicaid and Medicare, two different payment systems often result in billing errors and confusion, and there are two different sets of rules for challenging service denials. For people with disabilities and chronic illnesses with various impairments, there is a need for proper notice and protection of the right to reasonable accommodation or assistance in accessing services and supports.

Securing "aid-to-continue" for those relying on vital services that may be limited, changed, or terminated will be of great importance given that these decisions will now be once removed from the customary decision makers.

Further, by 2014, New York's Medicaid program is likely to expand as health reforms are implemented and tens of thousands of uninsured individuals including people with disabilities and chronic illnesses are enrolled in Medicaid.

While the advent of universal managed care holds the promise of improved access to care for many, the extension of Medicaid Managed Care to the most significantly disabled recipients will not be without serious challenges. Access problems may emerge with networks that lack specialists or adequate capacity of pediatricians, psychiatrists, or geriatricians. Managed care organizations may not have adequate means of communication or accessible accommodations for the hundreds of thousands of recipients with various disabilities whom they will be serving. A recent paper from the *Kaiser Commission on Medicaid and the Uninsured* noted that people with disabilities in managed care already experience problems accessing specialists.[v]

There is also a need for information to help recipients understand the managed care environment. Recipients will need to know how to access various services and supports. They will benefit from systemic advocacy to assure that their complex needs are adequately met and any barriers to their care, services, and supports are removed and remedied. Again, the *Kaiser Commission*[vi] report calls upon states to help people with disabilities become informed about receiving services and supports in a managed care setting.

Finally, there are vast disparities among recipients with disabilities already enrolled in mainstream managed care or HIV Special Needs Plans. Some have found access to excellent care, while others have encountered obstacles that require attentive consumer education, advocacy, and support.

The Need for a New York State Medicaid Managed Care Ombudsman Program for People with Disabilities or Chronic Illness

Clearly, this sea change in how and where people with disabilities or chronic illnesses access care through the Medicaid program creates the need for an advocacy program specializing in consumer education, community training, and advocacy services tailored to meet the unique needs of these populations. Recipients would benefit from: learning how to access services in a

managed care environment; help in securing a change in or restoration of benefits, services, or supports; advocacy to obtain accommodations for their disabilities; and the fruits of systemic advocacy addressing patterns such as improper notices, inadequate networks or accommodations, or unlawful care management practices.

A recipient who uses a wheelchair because of an amputation might use the services of an ombudsman program to help appeal a denial of prostheses that a Medicaid Managed Care entity had issued based on her advanced age. A peer support group comprised of people with developmental disabilities might receive training in how to request changes in their supports and when to contact the ombudsman about care management problems.

An organization serving people with hearing disabilities and its clients might work with the ombudsman program to bring to light the absence of any sign language interpretation support for their clients enrolled in a certain health plan. An ombudsman program might spot a spike in clients coming in with complaints about receiving reduced home health care services or certain medications and initiate an investigation and negotiations to address inappropriate or unlawful limitations. The parent of a child recipient with a serious emotional disturbance might seek the help of an ombudsman to obtain an appointment with a child psychiatrist sooner than the one she has for six months later.

MMCOP Centers should assure timely and adequate access to needed care, supports, and services from all Medicaid Managed Care organizations and care coordination entities including Health Homes. MMCOP Centers would help recipients resolve disputes with managed care entities; monitor, document, and investigate systemic problems; provide timely systemic advocacy; offer information, guidance, and support; and provide direct representation in grievances, Fair Hearings, and appeals. These centers and their centralized support office would be positioned to handle general Medicaid managed care information and referrals and posses technical expertise in all aspects of both Medicaid and Medicare.

MMCOP Centers will serve as *real-time* barometers of trends affecting large numbers of disabled and chronically ill recipients, and as expert informants for policy makers to help assure that access to health care services and supports as well coordination services are as complete and free of obstacles as possible.

By intervening in these ways at the local level, the program would help resolve problems as they arise and save scarce public resources that would otherwise be spent on costly litigation and financial penalties for unlawful practices and procedures employed by Medicaid managed care entities. Further, it would provide a cost-effective way to improve managed care “literacy” for the neediest recipients who have not previously had to make their way through the various managed care processes. There is no statewide system yet in place to reach out to the new target populations and help them secure and retain needed services and supports as they move into managed care.

The *Kaiser Commission*[vii] report recommended the establishment of ombudsman programs as a key way for states to enhance supports for people with disabilities in Medicaid Managed Care, and the State of Wisconsin has a model ombudsman program that is reportedly[viii] working quite well.

A PROGRAM MODEL FOR NEW YORK

In New York, like Wisconsin, the program should be created in statute. The contractor (*MMCOP Coordinator*) and local subcontractors (*MMCOP Centers*) should be selected through a public process. The statute should establish minimum staffing ratios for local centers of one advocate for every 2,500 recipients with disabilities or chronic illnesses; and one attorney and one disabilities specialist for each MMCOP Center contract.

Target Population

There are at least 1.3 million New Yorkers with disabilities or chronic illnesses in the Medicaid program, including those eligible for both Medicaid and Medicare. All of these individuals would eventually be eligible to receive MMCOP services for help in accessing Medicaid Managed Care and Medicare services, supports, and coordination. The care of those with high costs is $31.1 billion per year, and they have been classified by the Department of Health in the development of Health Homes[ix] as follows:

- Intellectual/Developmental Disabilities (52,000)
- Behavioral Health (408,000)
- Long Term Care (209,000)
- Chronic Medical (306,000)

In addition, there are other recipients among the 1.3 million with disabilities or chronic illness with lower costs who also will likely require some assistance in accessing services and supports, as well as in protecting their rights in the new care management settings.

The MMCOP program should be established as soon as possible, ideally in 2012, and phased-in over four years. The State should include a limited-term, upfront development grant to facilitate timely establishment of the program. The initial population to be served should be the managed long term care group, followed by the behavioral health, chronic medical, intellectual/developmental disability, and other groups.

This sequence is suggested by the timeframes in which the various populations will be entering into care management structures. Following this sequence is logical and would enable the resources focused on managed long term healthcare recipients to later be shifted or supplemented to provide advocacy services during the phase-in of Behavioral Health Organizations or Special Needs Plans as well as the new program under development for people with intellectual or developmental disabilities.

Structure and Services
The MMCOP statute (*See Appendix A*) should configure the program as a "hub and spokes" support system with centralized advisory, management, procurement, training, and quality assurance functions, and subcontracts with local community-based programs (*See* MMCOP *Coordinator and* MMCOP Centers *below*).

All contracts should be awarded through competitive processes, and no less than 80 percent of the program funds would be allocated to MMOP Centers. Each provider should provide all of the services[x] outlined in the statute through each local center. There should be a preference for contracts of sufficient scope to adequately and effectively offer services that reach all eligible households, including multi-county service areas in upstate regions.

MMCOP Coordinator
The statewide "hub" agency, or MMCOP Coordinator, should be a non-profit corporation in good standing with tax-exempt status under the Internal Revenue Code. The Department should select the contractor through a public process. The organization with which the Department contracts for these services should not be a provider, or an affiliate of a provider, of Medicaid Managed Care, care management, Health Home, long term care, or health care services.

The MMCOP Coordinator would establish and manage the New York State MMCOP contract with the guidance of an Advisory Board (*See MMCOP Advisory Board below*). It should ideally maintain two offices (upstate and downstate, possibly with one secured by sub-contract for some functions such as training and technical assistance). Suggested co-location of centralized Medicaid managed care functions by the Department of Health and its sub-contractors merits planned further discussion.

The MMCOP Coordinator will be responsible for a robust program of monitoring access to care, supports, coordination, and services through Medicaid Managed Care and other Medicaid care management structures serving all recipients with disabilities or chronic illnesses. It will establish policies to address any potential conflict of interest on the part of MMCOP Centers.

The Coordinator will be ideally situated to monitor trends in complaints and appeals through the individual advocacy work of the MMCOP Centers and will be positioned to react to systemic barriers in real time.

The Coordinator should be empowered to receive and analyze data collected by the Department and to set guidelines for the collection and reporting of data by the MMCOP Centers to help inform its systemic advocacy work.

Examples include data on key programmatic issues such as managed care and care coordination organizations' compliance with the requirements of the Americans with Disabilities Act (ADA), as well as State and local laws regarding accommodations; access to specialists (wait time and network adequacy measures); and consumer communications (notices). MMCOP Centers will

play a key role in working with plans to ensure both plan and provider compliance with plan contract requirements regarding accessible accommodations.[xi]

The Coordinator will direct the delivery of all MMCOP services; identify, document, investigate, and resolve (directly and through MMCOP Centers) systemic problems; and serve as a statewide, independent advocate for disabled and chronically ill Medicaid applicants and recipients.

It will convene public meetings to help identify problems requiring monitoring or investigation and to discuss findings and recommended remedies to documented problems; monitor, analyze and publish reports on Medicaid Managed Care trends and emerging issues; review periodic MMCOP and managed care and care coordination data and reports; and develop in consultation with the Advisory Board and MMCOP Center reports on urgent problems as well as program milestones and successes.

It will possess legal expertise to consult regularly with MMCOP Centers regarding difficult Medicaid Managed Care and care management problems and the best approaches to protect recipient rights under Federal and State laws, rules, regulations, and contracts.

The Coordinator will assure that all reporting requirements use widely available software and other technology in order to obviate the need to incur the expense and staff time needed to train MMCOP Centers in the use of unique software, and make the reporting platform as compatible as possible with software that community based programs are already using for other contracts and programs.

The Coordinator will issue quarterly reports to the Department of Health on the data collected and will issue an annual report to the Governor and Legislature. The annual report will include findings regarding the implementation and operation of Medicaid managed care for people with disabilities or chronic illness; recommendations to improve Medicaid managed care program services and accommodations for people with disabilities or chronic illness; and any actions taken by the agencies of the State or managed care entities to carry out the Coordinator's recommendations.

MMCOP reports might include some of the following metrics: client satisfaction survey results; training statistics; trend analyses; public trainings and community education event statistics; individual case advocacy analyses with examples; systemic advocacy outcomes; distribution of publications including purpose, target audience, and method of dissemination; and a summary of outreach efforts.

MMCOP Advisory Board

An Advisory Board should be established to help guide the MMCOP. It would consist of thirteen voting members recruited and appointed by and including the Coordinator.

Five of the appointees should be persons with disabilities or chronic illness enrolled in Medicaid Managed Care; two members should be persons representing organizations serving persons with disabilities; two members should be persons representing organizations serving senior citizens; two members should be attorneys knowledgeable in disability, public health, or related areas of law; one member should be a health care practitioner with experience serving persons with disabilities. The Coordinator would serve as convener of the Advisory Board. The Advisory Board's role would be to:

- Provide leadership and guidance to ensure that the Coordinator fulfills its mission and obligations
- Consult with and advise the Ombudsman Coordinator in the development of its contracting process, policies, and procedures
- Advise the Coordinator to help align its operation, communication, and strategies with community needs
- Monitor community concerns and ensure that MMCOP services and manner of their delivery are responsive community needs
- Aid in monitoring and evaluation of MMCOP
- Participate in long-range planning for the future of MMCOP and the Medicaid Managed Care program.

MMCOP CENTERS

MMCOP Centers will eventually provide services in every county in New York State. They will constitute a workforce of about 400 trained advocates uniquely positioned to help individual recipients, while at the same time analyzing and addressing systemic problems and obstacles that can be removed through negotiation directly with managed care organizations and other care managers.

MMCOP Centers will employ staff to provide advocacy services to potential or actual recipients with disabilities or chronic illnesses or their families or guardians, and assist these persons in protecting their rights under all applicable Federal, State, and local statutes, regulations, and rules.

MMCOP Centers will help consumers, Medicaid Managed Care plans and their providers, and the NYS Department of Health by assuring that New Yorkers with disabilities and chronic illnesses, as well as others, are able to access the care, services and supports to which they are entitled as they enter the mandatory Medicaid Managed Care environment. They will help consumers learn about managed care and their rights and responsibilities, and help the plans and their providers to properly meet the needs of their members and patients. They will help hold plans accountable for fulfilling their responsibilities under the contract and applicable laws and regulations.

By possessing the most up-to-date information on the Older Americans Act, Americans with Disabilities Act, Medicaid, Medicare, and managed care rights, as well as familiarity with plan contracts and procedures, the Centers will help all parties by collaboratively addressing any

barriers that prevent recipients from accessing care, services and supports to which they are entitled.

A staffing ratio of one advocate for each 2,500 recipients with disabilities or chronic illnesses, and a minimum of one Full-time Equivalent (FTE) attorney and one FTE disabilities specialist for each MMCOP Center contract should be established in statute.[xii] The structure beyond this, however, would be flexible to allow the centers to tailor their services by region and targeted sub-populations.

The staffing ratio would form the basis for proportional geographic allocation of at least 80 percent of MMCOP funds to MMCOP Centers. The workforce would consist of a mix of lawyers, paralegals, advocates, and community educators. There should be a preference for contracts of sufficient scope to adequately and effectively offer services that reach all eligible households, including multi-county service areas in upstate regions.

The MMCOP model is intended to be flexible enough to allow for different local contract designs. While some may be cross-disability, it may make sense in certain regions to have a disability/disease-specific local contract (e.g. an Alzheimer's Association, Multiple Sclerosis group, an organization serving those with visual and/or hearing disabilities, etc). Or, perhaps a legal services entity might operate a Center and sub-contract certain services to an independent living center (ILC) or contract with a disability-specific organization for interpretation services, for example.

A qualified non-profit, tax-exempt organization may be selected as a MMCOP Center.

MMCOP Centers will work closely and collaboratively with the MMCOP Coordinator, the Advisory Board, Department of Health staff, and internal ombudsmen called Access Guides situated within each Medicaid Managed Care and care coordination organization (*See Managed Care Organization Responsibilities below*) to address and resolve all individual and systemic barriers. MMCOP Centers[xiii] will provide all of the following through each center:

- Information, technical assistance, consumer education, and community training on obtaining services and coordination, supports, and protection of due process rights.
- Advice and assistance in preparing and filing complaints, grievances and appeals of complaints or grievances, including preparation of documents and guidance for self-advocacy.
- Negotiation on behalf of both individuals and groups.
- Individual case advocacy services including interpretation of statutes, rules, or regulations, as well as accompaniment and legal representation in administrative hearings or any other judicial proceedings relating to managed care services, coordination, or benefits.
- Systemic advocacy to ensure timely and adequate access to all services or supports a beneficiary is eligible to receive, including accessible and effective notices; the Federal Americans with Disabilities Act, as well as State and local laws regarding

accommodations; adequate translation and interpretation assistance; preservation of due process rights; and identification of and referrals to outside resources to address any systemic issues that fall outside the scope of MMCOP (*See Cooperation and Coordination with External Entities below*).

These frontline providers will possess a high level of expertise in their local health care systems; legal rights of Medicaid and Medicare applicants and recipients; systems change advocacy; disability rights and the ADA; all managed care rights and special rules for moving among entitlement programs and care management entities; and the forthcoming health insurance exchange.

MMCOP Centers will conduct ongoing outreach to entities that provide services to individuals eligible for these services, both in managed care and outside of managed care settings, including, but not limited to, physician offices, nursing facilities, affordable housing agencies, independent living centers, and other provider agencies, as well as to consumer advocates.

Many of New York's non-profit organizations, including Independent Living Centers, legal services offices, advocacy groups helping special populations such as those who are homeless, or those with Multiple Sclerosis, mental illness, Sickle Cell Anemia, HIV/AIDS, or Alzheimer's (for example), as well as other groups helping people with disabilities or chronic illnesses, are ideally positioned to become MMCOP Centers.

Such groups should be invited to apply to become MMCOP Centers so that these services reach the most isolated recipients. There should be a rich variety of agencies selected as MMCOP Centers in order to strengthen the capacities of organizations serving groups within the target population with unique needs and to enhance and bolster both lay and legal advocacy services at the local level for the benefit of recipients with disabilities or chronic illnesses.

Because MMCOP Centers will serve Medicaid Managed Care recipients with disabilities and chronic illnesses, one of the primary systemic advocacy objectives will be the protection of applicant and recipient rights under the ADA, as well as State and local laws, including managed care organizations' issuance of notices regarding individuals' rights to reasonable accommodations; responses to reasonable accommodation requests; and compliance with physical accessibility requirements and accessibility standards for all print and online materials.

Each Center will possess a high degree of expertise in this area and work directly with managed care plans to ensure both plan and provider compliance with plan contract requirements regarding accessible accommodations.[xiv] Plans will be prompted, where appropriate, to update their procedure, practices, and plans to ensure full and equal access for people with disabilities.

Cooperation and Coordination with External Entities

In addition to defining MMCOP, it is important to define what it will not be, and how MMCOP Centers will interact with external entities. MMCOP will not duplicate services provided by other entities that may be serving the same recipients.

For example, MMCOP will not provide facilitated enrollment services, health insurance exchange navigation, care coordination, Community Health Advocacy services, Health Insurance Counseling and Advocacy Program services, Protection and Advocacy services, existing ombudsman services such as those for OPWDD facilities, or health care services.

However nothing in the design of MMCOP is intended to prevent agencies selected as contractors from also operating separate and similar programs such as facilitated enrollment services, health insurance exchange navigation, Community Health Advocacy services, Health Insurance Counseling and Advocacy Program services, Protection and Advocacy services, existing ombudsman services such as those for OPWDD facilities, or other advocacy services.

The Coordinator will establish policies to address any potential conflict of interest on the part of MMCOP Centers. MMCOP Centers will provide basic Medicaid Managed Care information and referral services and make appropriate referrals to all suitable services that offer assistance outside their scope of work.

MMCOP Centers will work collaboratively to resolve individual and systemic problems with: Medicaid Managed Care organizations and care coordination entities; the Coordinator; the Department; and health care and social services providers as needed. The first point of contact should always be with the Medicaid Managed Care or care coordination organization, and it is generally expected that the relationship between centers and plans be collaborative.

However, where collaboration and administrative remedies fail, they may request that the Department initiate an investigation of a Medicaid Managed Care or care management organization when a pattern of inadequacies or non-compliance with Federal, State, or local law, regulation, or policy has been discovered, investigated, and documented by the Center.

Managed Care Organization Responsibilities

Each Medicaid Managed Care organization, care coordination entity and Health Home organization should be required to appoint an internal ombudsman/community liaison called an Access Guide to help people with disabilities and chronic illnesses work effectively with the organization and facilitate cooperation with MMCOP Centers and advocates.

The contact information for each Access Guide and each MMCOP Center should be included in all applicant and recipient notices, as well as in any electronic communication for consumers such as organization websites, handbooks, etc. Medicaid Managed Care and care coordination organizations should be required to cooperate with the Coordinator, MMCOP Centers, and other advocates. There should also be a vehicle for Department intervention where such cooperation cannot be secured.[xv]

Financing

The funds needed to support the MMCOP Centers could come from several sources, including the forthcoming 1115 State Medicaid amendment proposal (“Super Waiver”) submitted in

August 2012, or State and Federal administrative funds for Medicaid. When fully implemented, the program is expected to cost roughly $40 million per year. The initial program, therefore, should be established at no less than $5 million for the first full twelve months of operation. Anything short of this level will not supply sufficient funds to provide adequate services in the field for the phase-in populations, nor the robust infrastructure needed for the operations of the Coordinator.

Conclusion and Next Steps

Medicaid Matters New York is excited to offer this proposal for further consideration and action on our recommendation to establish a Medicaid Managed Care Ombudsman Program for New York. We are eager to get started with the next steps, which we envision as working with the Department of Health to:

Will align timeline with the Super Waiver's funding timeline, if it is not already.

- Announce the planned establishment of the MMCOP in October 2012
- Hold a series of consumer stakeholder sessions to discuss the proposal and gather community input on its design and name in October 2012
- Finalize proposed legislation needed to establish the program in November 2012
- Finance the program by January 1, 2013
- Implement the program in 2013
- Phase-in the program over four years through 2016 when it should be fully funded and operational

We stand ready to see this vision through to reality and look forward to continued collaboration with the Department.

Appendix
Bill Language

The social services law is hereby amended to add a new section xxx read as follows:

xxx. Medicaid managed care ombudsman program for people with disabilities or chronic illness

1. There is hereby created, under the auspices of the department of health, a Medicaid managed care ombudsman program for people with disabilities or chronic illness. Such program shall be administered by a coordinator, which shall be a tax-exempt, not-for-profit entity selected by the department pursuant to the provisions of this section and with the capacity to implement such program statewide. The department will select such coordinator pursuant to a public process in conformance with all applicable state statutory and regulatory provisions. Upon selection, the entity chosen shall serve for a term of no more than eight years. The department will enter into a contract with the coordinator that is adequate to support an advocate-to-beneficiary ratio of at least one advocate to every 2,500 beneficiaries. Such contract shall require the coordinator to allocate not less than eighty percent of the funds provided for the program to contract for advocacy services pursuant to paragraph c of subdivision 2 of this section. The department may, for cause, terminate the contract prior to the running of the eight-year period. Upon completion of the eight-year period or any earlier termination of the contract, the department shall conduct a new competitive process to select an entity to serve as coordinator for a new term of up to eight years. Nothing in this section shall preclude a contracted entity from competing for succeeding terms as coordinator. The department shall not contract under this section with any county or with any entity that is currently licensed by any state agency to provide managed care, care coordination, health home, long term care or health care services, nor shall it contract with any direct affiliate of any such state licensee. The department should provide a limited-term development grant to any new coordinator selected for an eight year period to facilitate timely establishment of the program.

2. The coordinator selected pursuant to subdivision 1 of this section shall have the following duties and responsibilities:
   a. Implement and operate the state Medicaid managed care help program pursuant to this section and any other applicable law or regulation.
   b. Establish a centralized advisory, management, procurement, training and quality assurance structure to oversee operation of the program.
   c. Select, through a competitive process, community based entities to be known as Medicaid managed care ombudsman centers. Such centers will contract with the coordinator for the provision of advocacy services pursuant to subdivision 3 of this section. Each such center shall be provided sufficient funds to develop the capacity to provide an advocate-to-beneficiary ratio of not less than one advocate to every 2,500 beneficiaries and shall provide, directly or through contractual agreements, services of at least one full-time licensed attorney at law admitted to practice in the state and one full-time disabilities specialist. Each such center will serve an area or distinct population

of people with disabilities that includes not fewer than 5,000 Medicaid recipients with disabilities.

d. Establish systems for coordination between parties including, but not limited to, the Medicaid managed care ombudsman centers, any state agencies responsible for administering health and human services, and Medicaid managed care, care coordination, and managed long term care organizations
e. Ensure all reporting requirements use widely available software and other technology that comply with privacy laws and establish a reporting platform compatible with existing platforms used by community-based organizations for other contracts and programs.
f. Monitor performance of Medicaid managed care ombudsman centers and maintain a quality assurance system including annual evaluation of provider performance.
g. Conduct all contracting transactions in a manner that provides maximum transparency, and manage all contracts with Medicaid managed care ombudsman centers; contracts shall have a term of four years, after which term each contract will be subject to a new competitive process. The coordinator may, for cause, terminate any Medicaid managed care ombudsman centers contract prior to the expiration of the four-year term. Nothing in this section shall preclude any Medicaid managed care ombudsman centers from competing for a succeeding contract term following successful completion of such a term.
h. Develop education materials on the Medicaid managed care ombudsman program.
i. Establish train-the-trainer system for the Medicaid managed care ombudsman centers.
j. Provide expert legal training and technical assistance for Medicaid managed care ombudsman centers concerning Medicaid managed care and care management problems, and protection of recipient rights under federal and state laws, rules, regulations, and contracts.
k. Maintain a statewide toll-free call-in center for the availability and dissemination of information to interested Medicaid and Medicare beneficiaries.
l. Monitor the development and implementation of all federal and state laws, regulations, rules and policies related to Medicaid managed care for people with disabilities or chronic illness, testifying or otherwise commenting whenever appropriate on the development or impact of all such provisions.
m. Manage a database of statewide complaints and resolutions, as reported by Medicaid managed care ombudsman centers, pursuant to data collection standards established by the coordinator in conformance with all applicable reporting standards established in law or regulation. Nothing in this subdivision shall replace or be a substitute for any monitoring and reporting requirements of any other government agency.
n. Publish material assessing any inadequacies found in the provision of services by Medicaid managed care organizations, and recommending changes in state or federal practices, policies, rules, regulations or statutes relating to Medicaid managed care for people with disabilities or chronic illness.
o. Issue quarterly reports to the department of health on the data collected.
p. Issue an annual report to the governor and legislature that shall set forth the scope of the programs providing Medicaid managed care, services or supports to people with

disabilities or chronic illness. Such report shall include findings regarding the state's activities in the field of Medicaid managed care for people with disabilities or chronic illness, recommendations to improve effectiveness or efficiencies of the Medicaid managed care program and any actions taken by the agencies of the state to carry out coordinator's recommendations.

q. Establish and act as convener of a Medicaid managed care ombudsman program advisory board. Such advisory board shall consist of thirteen voting members including the Coordinator and twelve others to be recruited and appointed by the Coordinator. Five of the appointees should be persons with disabilities or chronic illness enrolled in Medicaid Managed Care; two members should be persons representing organizations serving persons with disabilities; two members should be persons representing organizations serving senior citizens; two members should be attorneys knowledgeable in disability, public health, or related areas of law; one member should be a health care practitioner with experience serving persons with disabilities. The duties and responsibilities of the advisory board shall include:
    i. Provision of leadership and guidance to help the coordinator fulfill its duties and responsibilities as provided in this section.
    ii. Consultation with the coordinator in the development of its contracting process, policies and procedures.
    iii. Provision of assistance to the coordinator in the alignment of its operations, communication and strategies with community needs.
    iv. Monitoring of community concerns to ensure that program services and their delivery are responsive to community needs.
    v. Aid in monitoring and overall evaluation of the program.
    vi. Participation in planning for the future of the program.

3. Medicaid managed care ombudsman centers shall employ staff, including attorneys, paralegals, disabilities specialists, community educators, and advocates to provide advocacy services to persons with disabilities or chronic illness who are potential or actual recipients of Medicaid managed care or care management services, or their families or guardians, where appropriate. Such centers shall assist these persons in protecting any rights under all applicable state and federal statutes, rules, and regulations. Advocacy services required by this subdivision shall include:
    a. Information, technical assistance, consumer education, and community training on obtaining services and coordination, supports and protection of due process rights.
    b. Advice and assistance in preparing and filing complaints, grievances and appeals of complaints or grievances, including preparation of documents and guidance for self-advocacy.
    c. Negotiation on behalf of both individuals and groups.
    d. Individual case advocacy services including interpretation of statutes, rules or regulations, as well as accompaniment and legal representation in administrative hearings or any other judicial proceedings relating to managed care services, coordination or benefits.

e. Systemic advocacy to ensure timely and adequate access to all services or supports a beneficiary is eligible to receive, including accessible and effective notices; the Federal Americans with Disabilities Act, as well as State and local laws regarding accommodations; adequate translation and interpretation assistance; preservation of due process rights; and identification of and referrals to outside resources to address any systemic issues that fall outside the scope of the Medicaid managed care ombudsman program.

4. Medicaid managed care organization cooperation with the coordinator, Medicaid managed care ombudsman centers and advocates.
   a. The department of health and each managed care or care management organization shall cooperate with any advocate selected by a Medicaid managed care enrollee under this section and disclose to such advocate any information related to the enrollee's eligibility, entitlement, cost sharing, care planning, care management, services, supports, or service providers to the extent that the information is pertinent to matters in which the client has requested the advocate's assistance. No enrollee shall be subject to any form of retribution for requesting the assistance of an advocate. Nothing in this section shall permit any unauthorized release of enrollee information or abridgement of an enrollee's right to privacy.
   b. Each Medicaid managed care or care coordination organization shall appoint an access guide to assist recipients and serve as a liaison with advocates including Medicaid managed care ombudsman centers.
   c. Each Medicaid managed care or care coordination organization shall include contact information for access guides and the local Medicaid managed care ombudsman centers in each organization's member handbook and all recipient notices.

Endnotes

i What distinguishes this concept from that which is already in place is not the model, or even the focus, but the fact that it would add capacity and flexibility to strengthen local advocacy efforts on behalf of people with disabilities or chronic illnesses. It is envisioned not as creating new entities, but rather as providing needed resources to support existing groups possessing expertise that would be strengthened by the addition of funds enabling them to focus on this particular population of recipients - who some observe have not received enough help because of budget constraints

ii The statutory establishment of the program (*See Appendix*) and the list of services to be provided have been adopted and adapted from Wisconsin statutes (Sections 16.009 (2) (p) 1. to 5 and 46.281 (1n)(e)) as well as guidance to managed care organizations found here: http://www.dhs.wisconsin.gov/dsl_info/infomemos/DLTC/CY2010/IMemo2010_07.pdf

iii The term "ombudsman" means an *independent advocate* who will assist individuals with disabilities or chronic illnesses in protecting their rights under all applicable Federal, State, and local statutes, regulations, and rules with respect to Medicaid Managed Care and care coordination services. Because the term itself is reportedly confusing, we have decided to search for a different name for the program and to refer to internal ombudsman within Medicaid Managed Care organizations as "Access Guides."

iv The New York State Department of Health is developing a model called Health Homes to provide care coordination services to nearly one million Medicaid recipients who qualify for Federally subsidized coordination services by virtue of having either mental illness or multiple chronic illnesses.

v People with Disabilities and Medicaid Managed Care: Key Issues to Consider. *Kaiser Commission on Medicaid and the Uninsured*, Kaiser Family Foundation, February 2012. http://www.kff.org/medicaid/8278.cfm *citing*: A Profile in Medicaid Managed Care Programs in 2010: Findings from a 50-State Survey. *Kaiser Commission on Medicaid and the Uninsured*, Kaiser Family Foundation, September 2011. http://www.kff.org/medicaid/8220.cfm and Burns M, Medicaid Managed Care and Health Care Access for Adult Beneficiaries with Disabilities, *Health Services Research*, Vol. 44, No. 5, 2009. *"The disabled population, which includes people with developmental, mental health, and physical conditions, requires both acute and long-term care from a wide array of specialists and specialized facilities that may not be represented adequately or at all in Medicaid MCOs' existing provider networks. In the recent Kaiser survey…States cited gaps in access to many different types of services, including dental care, pediatric specialists, psychiatrists and other behavioral health providers, and other specialists (e.g. dermatologists, ear-nose-and-throat specialists); provider shortages and other market factors were often given as the cause (footnote omitted). These access problems, encountered by the comparatively healthier Medicaid beneficiaries now enrolled in MCOs can be expected to be greater for beneficiaries with more extensive and diverse needs for care. Evidence from a recent national study indicates that working-age disabled Medicaid beneficiaries enrolled in mandatory managed care were significantly more likely than those in FFS to report a problem accessing a specialist (footnote omitted)."*

vi People with Disabilities and Medicaid Managed Care: Key Issues to Consider, op.cit. *citing* Hibbard J et al., Is the Informed-Choice Policy Approach Appropriate for Medicare Beneficiaries? *Health Affairs,* 2001 20(3): 199-203. *"Managed care, particularly capitated managed care, is unfamiliar to many Medicaid beneficiaries with disabilities, who have largely remained in FFS even as states have expanded managed care widely for low-income children and families. A priority for states enrolling persons with disabilities in managed care must be ensuring that these individuals are well-informed about how managed care operates. Persons with disabilities have higher rates of poor health status and lower rates of formal education, both factors associated with poorer health literacy (footnote omitted). Thus, special outreach, education, and assistance efforts are needed to ensure that these beneficiaries receive clear and accurate explanations regarding how to use services, restrictions on provider choice, pre-authorization requirements, grievance and appeals rights, and other aspects of enrollment in managed care."*

vii People with Disabilities and Medicaid Managed Care: Key Issues to Consider, op.cit.

viii Disability Rights Wisconsin tracks consumer satisfaction with the Ombudsman program, and reports these results:

- 78% of clients say ombudsmen were important in solving their problems

- 80% were satisfied with the assistance
- 85% were satisfied with explanations
- 90% would seek help again
- 91% would refer a friend

ix *See note ii supra.*

x The statutory establishment of the program (*See Appendix*) and the list of services to be provided have been adopted and adapted from Wisconsin statutes (Sections 16.009 (2) (p) 1. to 5 and 46.281 (1n)(e)) as well as guidance to managed care organizations found here: http://www.dhs.wisconsin.gov/dsl_info/infomemos/DLTC/CY2010/IMemo2010_07.pdf

xi Section 24 of the managed care Model Contract requires Managed Care Plans to comply with Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973. Each is required to have an ADA Compliance Plan concerning accessibility "at the Contractor's program sites, including both Participating Provider sites and Contractor facilities intended for use by Enrollees." These Compliance Plans must show which provider sites are and are not accessible as well as establish reasonable alternative access where a site may not be accessible. Each such plan must be filed with and approved by the NYS Department of Health. Managed Care Plans are advised that one method for fulfilling some of these responsibilities is to evaluate the degree of accessibility among providers within its network.

xii The statutory establishment of the program (*See Appendix*) and the list of services to be provided have been adopted and adapted from Wisconsin statutes (Sections 16.009 (2) (p) 1. to 5 and 46.281 (1n)(e)) as well as guidance to managed care organizations found here: http://www.dhs.wisconsin.gov/dsl_info/infomemos/DLTC/CY2010/IMemo2010_07.pdf

xiii ibid.

xiv See note xi.

xv Wisconsin's guidance on cooperation states that plans "shall cooperate with any advocate selected by a client" with this definition: *"1.To provide any information related to the client's eligibility, entitlement, cost sharing, care planning, care management, services or service providers to the extent that the information is pertinent to matters in which the client has requested the advocate's assistance. 2.To assure that a client who requests assistance from an advocate is not subject to any form of retribution for doing so."* *See:* http://www.dhs.wisconsin.gov/dsl_info/infomemos/DLTC/CY2010/IMemo2010_07.pdf

