IMPROVING THE OPTION

Consumers' Perspectives on New York State's Managed Long Term Care Demonstration Project

Nursing Home Community Coalition of New York State (NHCC)
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ACKNOWLEDGEMENTS

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EXECUTIVE SUMMARY

Managed long-term care provides significant opportunities to improve care for frail and chronically ill senior citizens and people with disabilities, but it carries with it important obligations. Protecting the health and well-being of program participants who are often frail, functionally disabled, and vulnerable must be the primary consideration of its implementation. The demonstration projects must recognize that the lives of most people needing long-term care services revolve around the health care and support services they receive, because their quality of life — and often their very ability to function at all — depends on these services.

If implemented carefully, thoughtfully, and with appropriate respect for the dignity and autonomy of the patient, New York State's managed long-term care demonstration projects can improve care through development of coordinated services, more efficient use of resources, increased emphasis on preventive and community-based care, and strict provider accountability for quality. Although there are potential problems with managed long-term care, the Nursing Home Community Coalition of New York State, a coalition of consumer, civic and professional groups, makes the following recommendations in the belief that the advice and experience of consumers and their advocates will improve quality, ease the transition to managed long-term care for patients and their families and designated representatives, and hasten the move to a more rational long-term care system.

The demonstration projects must recognize that the lives of most people needing long-term care services revolve around the health care and support services they receive.

We offer the following general principles, to be taken as a whole, to guide the state:

- The categories of eligible participants must be broad and inclusive.
- Consumer protections, educational programs, and ombuds services must be in place.
- Consumers and their advocates must be involved in the development of regulations and the approval of plans.
- Quality concerns must be paramount over cost containment.
- Mechanisms must be developed for continuous and meaningful public participation in monitoring and evaluating the quality of services.
- The authorized plans are demonstration projects. In order to determine if they can eventually be used as on-going models, the state must conduct adequate evaluations.
- The state must be responsible for holding the demonstration projects accountable for their actions and deficiencies, and must use a range of methods for ensuring compliance with standards.

We specifically urge the following actions be taken. These recommendations are presented as one package.

ELIGIBILITY, ENROLLMENT, AND DISENROLLMENT

To accurately gauge the feasibility of managed long-term care, the Department of Health must:

- Set the Medicare and Medicaid capitation rates at adequate levels, and risk-adjust them by case-mix.
- Allow plans to operate only after the funding streams of Medicaid and Medicare are both fully capitated and merged.
- Require that a broad cross-section of patients with varied conditions and care needs are enrolled and allowed to remain in the plans, especially those persons who:
  a) are not yet eligible for Medicaid-covered institutional care.
  b) at the time of application, require acute medical care services for a reasonably extended period of time, especially if the need for acute care results from a lack of adequate or appropriate long-term care.
  c) are cognitively competent or have a person acting on their behalf, yet have legitimate disagreements over proposed changes in a care plan.
  d) are cognitively competent or have a person acting on their behalf, yet disagree with a plan about issues of personal risk in remaining at home or in the community.
  e) do not have family members or others available as informal caregivers even if they are cognitively impaired.
  f) exhibit "abusive" behaviors symptomatic of their condition or disease.

APPROPRIATE CARE AND PROVIDER CAPACITY

To assure quality of care, the Department of Health must require plans to:

- Demonstrate their ability to provide or arrange for all the primary, acute, home and community-based care, institutional/nursing home care, and ancillary services necessary for the eligible populations.
- Offer a wide and varied selection of nursing homes.
- Offer options to use out-of-plan specialty providers and nursing homes when appropriate.
- Allow patients to continue with existing provider relationships for 60 days upon enrollment and 90 days once enrolled, and allow these providers the opportunity to join the plan's network.
- Define and specify "care management" standards and processes. All care managers must be professionals with training in geriatrics and/or disabilities and/or experience working with such populations.

CONSUMER RIGHTS

To protect plan enrollees, the state's program must:

- Allow enrollees to remain living as independently as possible in the community, and to choose among different models of long-term care including consumer-directed personal assistance.
- Assure that a thorough and vigorous education program is conducted for all enrollees and their families, proxies, and designated representatives.

- Require that all enrollee written materials be in detail, in large print, in plain English, and in other languages and formats as warranted/needed.
- Allow enrollees to retroactively disenroll based on misunderstandings at the time of enrollment.
- Establish the first day of the month following notification from the enrollee to the plans as the effective date for disenrollment.
- Mandate that enrollees and/or their designated representatives be active participants in care planning, and that they have the right to refuse to participate in a plan's activities and programs.
- Fully fund an independent, non-profit, statewide ombuds program which will a) help resolve enrollee complaints, grievances and appeals, b) assist individuals in navigating plans and accessing services, c) help enrollees understand their rights and responsibilities, d) collect, analyze, and report on data submitted by plans and other sources, and e) develop and promote related public policy recommendations.
- Require all grievance and appeals processes to be swift and simple.
- Allow complaints to be submitted both orally and in writing by either the enrollee or any other person who wishes to make a complaint on the enrollee's behalf, including designated representatives.
- Require that all plans and the Department of Health offer 24-hour toll-free telephone with TTD/TTY access, to be answered by a trained staff person.
- Require that all plan services continue and remain available to an enrollee during any internal or external grievance, appeal, or fair hearing process.
- Require each plan to offer an open forum such as an "Enrollees Council", run by members with the assistance of an independent ombudsperson or agency.

MARKETING

To protect plan applicants, the Department of Health must:

- Contract with an independent enrollment broker.
- Prohibit gifts and incentives to potential enrollees.
- Require that a plan's marketing program and materials be approved by the Department prior to implementation.
- Require a plan's marketing representatives to have knowledge of all state laws and rules governing the plan.
- Publish a guide on all plans, and a list of basic, important questions consumers should consider when choosing whether to enroll in a plan.

GENERAL REGULATION AND OVERSIGHT

To hold plans accountable, the Department of Health must:

- Define a very specific step-by-step process, *with consumer participation*, for the development and approval of managed long-term care plans.
- Assure that members of the state's Managed Long-Term Care Advisory Council be immediately appointed and that the Council begins to meet to represent the community in the development of regulations and a

Request for Proposals (RFP) by the Department.

- Establish mechanisms for regular public participation and feedback to the Department of Health, including semi-annual public hearings at the various plan sites, and anonymous surveys of consumer satisfaction and problems.
- Conduct annual, unannounced inspections of each plan, including interviews with enrollees, their families and designated representatives, and individual clinicians.
- Aggressively monitor the plans, cite them for deficiencies when warranted, and use fines and sanctions.

DATA COLLECTION AND PROGRAM EVALUATION

In order to assess the results of its demonstration projects, the Department of Health must:

- Collect data on: plan marketing; enrollment, denial of enrollment, and disenrollment; access to care within the plan; enrollee satisfaction with quality of life and quality of care; patient and provider profiles; utilization of services; discharge dispositions; complaints, appeals, and grievances; health outcomes; requests for information; Enrollee Council reports, requests, and recommendations; and plans' financial reports.
- Review and approve all plan data collection systems and outcome criteria before plans begin data collection.

LEGISLATION

In order to make the state's managed long-term care program an overall success, we recommend that the Legislature:

- Require annual written reports to the Legislature by the Commissioner of Health on September 1st of each year.
- Provide funding to require the Department of Health to contract for an *independent* evaluation of its managed long-term care demonstration project program.
- Enact strong whistle-blower protections.
- Maintain the state's prohibition on publicly-traded corporations owning and operating nursing homes, and carefully monitor and evaluate the performance of for-profit managed long-term care demonstration projects.

Managed long-term care is an experiment in New York. It involves making changes in the lives of people who are frail, elderly, or disabled. The Nursing Home Community Coalition of New York State is committed to assuring that the state's managed long-term care demonstration program provides the best care possible. We are excited by the potential benefits of managed long-term care. We believe that the active involvement of consumer advocates will be critical to the success of reform efforts as the state moves forward into the new world of managed long-term care. Our shared efforts will result in better care and quality of life for all our state's elderly, chronically ill, and persons with disabilities.

INTRODUCTION

Long-term care — how to provide it and how to pay for it — is becoming a more and more important issue for policymakers, legislators, and regulators, with serious consequences for taxpayers, providers, and consumers. From now through 2010, America's over age-65 population is expected to increase 17 percent, from 33.5 million to 39.4 million people, and between 2010 to 2030 by 75% to 69 million people[1]. Since advanced age often brings increased illness and disability, these demographic changes mean that New York must start looking now at how to structure and finance long-term care services for the future.

During the early 1990s, New York State moved aggressively to control its health care costs by instituting Medicaid managed care demonstration projects. In 1997, the federal government granted the state a waiver permitting the mandatory enrollment of most Medicaid beneficiaries into managed care programs, with the exception of those eligible for both Medicaid and Medicare (referred to as "dual eligibles".) During the same period, the state also began a separate voluntary managed care demonstration program for this population. Contingent on waivers from the federal government, additional demonstration plans were authorized under a 1997 law to provide health and long-term care services for the dually-eligible population on a capitated basis (a set monthly rate per enrollee.)

This paper brings a consumer perspective to the policy issues surrounding managed long-term care.

Some claim that a capitated managed care model, where plans are given a payment for which they are expected to provide all necessary care, is both a way to provide coordinated, integrated long-term care, as well as a way to control the cost of care. Consumers are apprehensive about this model, especially for long-term care patients. Managed care has historically been a medically-oriented system for treating diseases and illnesses, but it has generally not adequately addressed costly, on-going, and chronic care for a person who might never recover completely, or a person in need of long-term care.

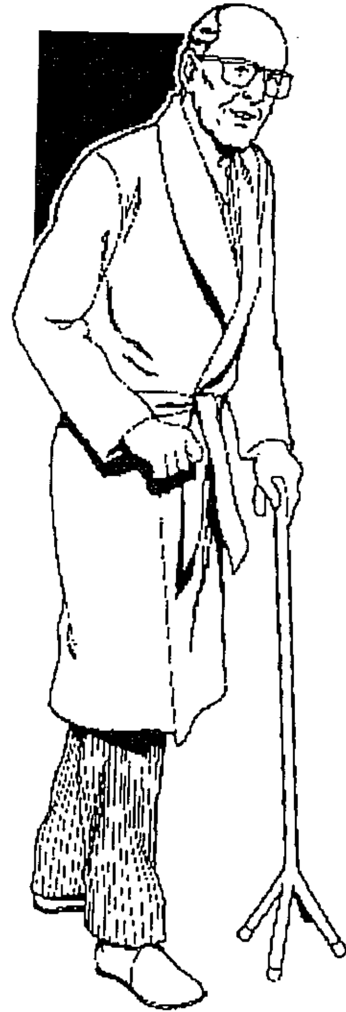
This paper brings a consumer perspective to the policy issues surrounding managed long-term care. It represents the views of the Nursing Home Community Coalition of New York State (NHCC) and the work of its Committee on Managed Long-Term Care. (See Appendix A for a list of its members.) NHCC is a statewide coalition of 30 consumer, civic, and professional organizations concerned about long-term and nursing home care. We look forward to meeting with New York State officials and others to discuss the ideas contained in this paper.

1 *Siegel, Jacob. "Aging in the 21st Century." National Aging Information Center, May 31, 1996.*

TWO ANECDOTES:

THE REALITY OF MANAGED LONG-TERM CARE:

BILL is a 73-year old man who enrolled in a managed long-term care plan in 1997. After one year of hospitalization and rehabilitation for a stroke and chronic emphysema, his doctor mentioned the plan as a way for him to live semi-independently and avoid going into a nursing home. Bill jumped at the chance. For him, the promise of managed long-term care has been a reality. He says, "What's really great about it is that I can live on my own." He has also been able to get a motorized wheelchair, a device the plan was able to get for him which would not have been covered under a traditional long-term care program.



LEN is a 70-year old man who's been enrolled in a managed long-term care plan since 1993 when he was discharged after hospitalization for a blood clot. Len has had numerous problems getting consistent care for infected root canals and for severe back pain resulting from sciatica and degenerative arthritis. He complains that he has not been able to continue with certain chiropractors and dentists he liked within his plan's network because the plan would not continue to adequately reimburse them or imposed limits on the number of treatments. He still suffers from serious back pain, and has lost two teeth.

THE POTENTIAL BENEFITS:

CONSUMER HOPES FOR MANAGED LONG-TERM CARE

- *Coordinated services* — A properly designed and implemented managed long-term care plan can create a system which integrates and coordinates all services and payments under one program. An integrated plan could provide "one-stop shopping" for consumers with many and varied needs. It can properly connect them with services they need, relieve them of the administrative hassles of applying for different services or delivery settings, and assure a medical "home" even when individual providers may change.

- *Emphasis on preventive and community-based care* — Managed long-term care can better emphasize preventive and community-based care as a way to minimize the need for costly acute and institutional care. This results in access to services especially critical to prevent or delay further illness and disability.

- *Savings for improved patient care* — For providers, there are currently separate payment systems for particular services delivered in particular settings. A Medicare-Medicaid integrated program could be administratively efficient, saving dollars for care. For government and providers, an integrated plan can eliminate incentives to cost-shift between Medicaid and Medicare, a dynamic which can adversely affect patient care and create onerous administrative burdens.

- *Flexibility of resource utilization* — Managed long-term care can provide the flexibility to use resources to provide a broader array of services based on a person's actual needs rather than in a rigidly proscribed manner. Cost-effective services not covered by traditional payers could be provided so that benefits are structured around a person's need for health, supportive, and social services. Such services could allow enrollees to live independently in the community.

Managed long-term care can provide flexibility to use resources to provide services based on needs.

- *Decreased costs* — Managed long-term care can help lower costs. By allowing providers to use reimbursement in creative and innovative ways, *some* costs may eventually be reduced. For example, using reimbursement to adapt a person's apartment to his/her disabilities may allow the person to remain living at home more independently, in a less restrictive — *and less costly* — environment than a nursing home. This approach also enhances enrollees' self-respect and dignity, and minimizes their perception of being "dependent" on society.

- *Accountability* — Managed long-term care programs can create two points of accountability for quality care: the entity which operates the plan, and the state which oversees it. With one plan responsible for providing and coordinating all care, patient care outcomes may be more easily assessed and tracked, and corrective actions taken.

THE POTENTIAL PROBLEMS:

CONSUMER CONCERNS ABOUT MANAGED LONG-TERM CARE

CAPITATED PAYMENTS

At the heart of consumers' concerns about managed care is the issue of capitated payments. As the need for long-term care services grows, the state and providers may be encouraged to pursue policies primarily focused on cost containment rather than on cost-effective care. Therefore, we raise the following concerns:

- *Limits on care and quality* — Comprehensive, chronic care is expensive. Capitated managed long-term care could become nothing more than an effort to control Medicaid costs through low capitation rates. If reimbursement is not adequate, providers will not be able to give needed services, or they may be tempted to reduce services to offset losses or increase profits. Whichever motive, quality may be compromised because of the incentives to keep costs down.

At the heart of consumers' concerns about managed care is the issue of capitated payments.

- *Inadequate provider capacity or poor quality providers* — Qualified providers may not be willing to participate in a plan's network if the reimbursement rates offered by plans are not adequate. Inadequate rates may also mean that the latest technology may not be made available, or that individual providers may not be willing or able to spend the necessary time with a participant.

- *Lack of access to plans* — Costs for certain populations requiring intensive medical or custodial care (e.g., Alzheimer's patients), expensive medications, specialty equipment, or periods of intensive skilled therapies could easily exceed a capitated rate. Plans may refuse to enroll such people or, if they are allowed to enroll, may not give them necessary care or may encourage them to disenroll.

- *Limits on outside specialty care* — Access to specialists outside a plan's network, when necessary, may be curtailed to reduce costs. The long-term care population may need this access because they have complex health conditions, and a plan may not always include appropriate specialists within its network of providers.

- *Incentives toward institutional care* — Consumers may be put in nursing homes against their will, even when not medically appropriate, if home and community-based care becomes too expensive relative to institutional care.

CONSUMER CHOICE

Despite its increasing prevalence, managed care is a new idea for most people. Such programs are complicated and difficult to understand, as experience with the state's Medicaid managed care program demonstrates. Consumers must contend with marketing fraud and abuse as well as grievance and appeals procedures that can be problematic and complex for younger and healthier consumers, much less those who are seriously ill, disabled, or cognitively impaired. Once enrolled in a managed long-term care plan, consumers may not understand that they have certain legal rights, or know how to recognize when those rights are being violated or denied. Consumer education and the understanding of limits, rights, and appeals is crucial.

Despite its increasing prevalence, managed care is a new idea for most people. Such programs are complicated and difficult to understand.

Enrollees' ability to disenroll if dissatisfied with the care they are receiving within a plan may also be constrained. Disenrolling from a managed long-term care plan involves making dramatic, far-reaching, and difficult decisions. There must be an adequate process for people to disenroll who are dissatisfied, and the process must work for people who are significantly disabled, frail, or cognitively impaired. Similarly, there must be adequate procedures and processes (e.g., fair hearings) around issues of involuntary disenrollment.

Reliance on a managed care model may result in the following adverse consequences for consumers:

- *Limits on choices of providers* — At the heart of managed long-term care is the fact that enrollees may be limited to the individual clinicians affiliated with a plan's network. Enrollees may not like these limitations, may not like or develop a good relationship with the particular practitioners offered, or may feel they cannot receive care from an appropriate type of provider.

- *Disruption in on-going care* — Once restricted to the providers in a given plan's network, new enrollees may have to sever existing provider relationships. Persons in need of long-term care often require a great deal of complex care, and want and need providers who know them and their health history, and with whom they feel comfortable.

- *Loss of consumer control* — The role of the "care manager" is very powerful in managed long-term care. Enrollees and their family members may not be allowed to identify their own needs and direct how best to meet them. The care manager or care team may make decisions based on cost to the plan rather than the patient's needs, or unilaterally make decisions on issues of abusive behavioral symptoms that can otherwise be resolved together with the enrollee or designated representative.

- *Limits on nursing homes* — Access to nursing homes may be limited because a plan may only contract with a few homes. Unless seeking short-term, subacute or rehabilitative care, entering a nursing home is different than simply selecting another medical service; one is actually choosing a "home", and it is often the last move a person will make. Enrollees may not be able to make choices related to proximity to their community or loved ones, kind of food served, religious background, languages spoken, and other considerations of personal and daily life.

- *Emphasis on the "medical model"* — Historically, managed care has focused on providing primary and acute care services to a young and relatively healthy population. Managed care does not have much experience serving long-term care populations, who require extensive and intensive supportive and social services just as much, if not more, than health care. Will managed long-term care models be able to provide such services? The potential of an emphasis on the medical model will not serve the needs of this population, and indeed, a lack of appropriate emphasis on non-medical services may actually worsen their medical conditions.

RECOMMENDATIONS

In 1997, New York State enacted a new law (Chapter 59, Sections 81-88) authorizing up to 24 new capitated long-term care demonstration projects to be set up by provider organizations and networks, with five to be sponsored by commercial HMOs.

We urge the Department of Health and the Legislature to implement the following recommendations to make sure that the potential benefits of managed long-term care become a reality and the potential problems are avoided.

ACCESS TO PLANS: ELIGIBILITY, ENROLLMENT AND DISENROLLMENT

The demonstration projects must be available to all populations needing long-term care. If plans can exclude individuals with the highest needs and the most complicated conditions, the state risks creating a program which works for "easier" populations, and then presuming it works for all others. We therefore urge the Department of Health to:

- Set the Medicare and Medicaid capitation rates at adequate levels, and risk-adjust them by a case-mix variable which includes social and personal factors and support service needs, as well as medical factors. If this step is not taken, plans may try to limit enrollment of those people whose care needs are more costly or, if they do enroll them, may not provide all the care needed.

Demonstration projects must be available to all populations needing long-term care.

- Allow plans to operate only when the funding streams of Medicaid and Medicare are both fully capitated and merged. If plans operate without having Medicaid and Medicare combined, the state will not obtain an accurate picture from its demonstration programs of the actual costs of a managed long-term care program. The state must seek waivers from the federal government to capitate payments to plans for Medicare-covered services. Without these waivers, plans will be capitated only for Medicaid-covered services. Only when plans are fully capitated for both Medicare and Medicaid will there be a possibility of adequate funding to provide the full array of services needed by disabled and chronically ill enrollees (i.e., those needing combinations of acute and long-term care services.)

  Once plans are fully capitated for both Medicare and Medicaid, they will then receive a combined rate for Medicare-covered and Medicaid-covered services. Plans with enrollees needing large amounts of long-term care services (covered by Medicaid) but needing low amounts of acute care (covered by Medicare) can then offset the costs of long-term care against their unused Medicare portion. However, if plans are capitated only for Medicaid, they will only be able to offset these losses by either refusing to enroll people needing a lot of long-term care, not providing them with the care they need once enrolled, or disenrolling them.

- Allow persons to enroll in plans who: a) are *not* yet eligible for Medicaid-covered institutional care (i.e., they have transferred personal financial assets within 3 years prior to application for Medicaid), but who *are* eligible for Medicaid-covered community-based care. Should the subsequent need for nursing home care arise, these people should be evaluated on a case-by-case basis as to whether they should be allowed to remain enrolled. If allowed to remain, the state should provide the additional funding if the individual does not have access to the transferred assets.

  b) at the time of application, require acute medical care services for a reasonable period of time, especially if the need for acute care resulted from a lack of adequate or appropriate long-term care. (This is only an issue if Medicaid and Medicare are not fully capitated and combined.)

- Require that plans maintain the enrollment of persons who have legitimate disagreements over proposed changes in a care plan. The state cannot allow the inappropriate use of enrollment and disenrollment to limit an enrollee's involvement in care planning.

- Limit the ability of plans to deny enrollment or to involuntarily disenroll persons who want to remain in the community based on a perception that they pose a danger to themselves or formal caregivers:

1) Cognitively-competent individuals who disagree with a plan about issues of personal risk in remaining at home or in the community and who understand the consequences of such actions must be allowed to make such decisions for themselves, and be allowed to enroll or remain enrolled in a plan.

2) Cognitively-impaired and cognitively-competent individuals must be able to enroll or remain enrolled in a plan even when family members or others are not available as informal caregivers, therefore creating a situation a plan may deem "unsafe". Instead, the plan must make it "safe" for the enrollee by providing alternative services such as 24-hour personal care, 7-day/week adult day care, or congregate housing.

3) Persons who exhibit "abusive" behaviors symptomatic of his/her condition or disease must be allowed to enroll or remain enrolled in a plan. Such behaviors which could be deemed dangerous to self or others by the plan must not be arbitrarily considered unsafe for the formal caregiver; instead the plan must adequately train staff to appropriately handle such situations.

APPROPRIATE CARE AND PROVIDER CAPACITY

In order to assure that enrollees receive the care they need in a timely and appropriate manner, the Department of Health must require that plans:

- Demonstrate their ability to provide or arrange for all the primary, acute, home and community-based care, institutional/nursing home care, and ancillary services necessary for the eligible populations.
- Define and specify "care management" standards and processes. All care managers must be professionals with training in geriatrics and/or disabilities and/or experience working with such populations.
- Offer a wide and varied selection of nursing homes, meeting the needs of diverse populations.
- Offer options to use out-of-plan specialty providers or nursing homes, when appropriate.
- Allow new enrollees to continue with existing provider relationships for 60 days. For current enrollees whose provider leaves the plan, allow such continuance for 90 days. (These provisions conform to New York's Managed Care Bill of Rights.)

CONSUMER RIGHTS

In order to assure that an enrollee's rights are provided and protected, the Legislature and/or the Department of Health must:

- Require plans to allow enrollees the right to remain living as independently as possible in the community, with appropriate medical and support services, even if the cost to the plan is higher than if the enrollee were placed in a nursing home. Also assure the right of enrollees to choose and direct their personal care services to meet their in-home long-term care needs (i.e., "consumer directed care.")

Require plans to allow enrollees to remain living as independently as possible in the community, with medical and support services.

- Assure that a thorough and vigorous education program is conducted both by the state and by plans for all enrollees and their families, proxies, and designated representatives informing them of all their options, rights, and responsibilities, including how to reach the State Department of Health. This effort should be conducted by the independent party selected for all marketing efforts (see section IV below.)

All enrollee written materials, including handbooks, lists of providers accepting new patients, attestations, and information on disenrollment must be in detail, in large print, in plain English and other languages, and in other formats such as Braille or audiotape as warranted/needed. All materials must be kept current.

- Allow enrollees to retroactively disenroll based on misunderstandings at time of enrollment concerning the basic nature of managed long-term care (e.g., limits on care options, services, and individual providers.)

- Establish the effective dates for voluntary disenrollment to be the first day of the month following notification from the enrollee to the plan.

- Mandate that enrollees and/or their designated representatives be an active participant in care planning. Enrollees must also be allowed the right to refuse to participate in any particular program provided or offered by the plan, and such refusal should not lead to involuntary disenrollment. Refusals shall be recorded with enrollee's signatures to avoid misunderstandings.

Create and fully fund an independent statewide Managed Long-Term Care Ombuds Program consistent with the model of the Managed Care Consumer Assistance Program proposed by the Legislature (A.7770/S.5329, 1997-1998). Its role will be to a) help resolve enrollee complaints, grievances, and appeals, b) assist individual enrollees in navigating plans and accessing appropriate and high quality health and long-term care services, and c) assure that enrollees understand their rights and responsibilities. The program should also collect, analyze, and report on a variety of quantitative and qualitative data submitted by plans and/or received from other sources, and develop and promote policy recommendations for improving services, health outcomes, and quality of life.

The Ombuds Program should be established and funded through state government agencies involved in managed long-term care, including the Office for the Aging and the Department of Insurance. It should be administered and coordinated in conjunction with any other government agency which may have a managed care ombuds program including the Department of Health and the Department of Insurance.

Create and fully fund an independent statewide Managed Long-Term Care Ombuds Program consistent with the model of the Managed Care Consumer Assistance Program.

Structurally, the Ombuds Program should consist of two levels of independent, contracted entities: a statewide Ombuds Advisory Council to oversee the program; and local/regional Ombuds Assistance Centers which will actually provide direct ombuds services as outlined above. Entities at both levels should be non-profit organizations, governed by a majority of enrollees, members of the public, or representatives from non-partisan organizations who have experience in long-term care services and advocacy, and should be free of any conflicts of interests with any long-term care payers or providers.

The Ombuds Advisory Council should a) recommend the awarding of contracts to the local/regional Ombuds Assistance Centers, b) collect, analyze, and report on quantitative and qualitative data submitted by the local/regional Centers and plans, c) develop recommendations for improvements in services, and d) promote public participation in debate of policy recommendations. The Ombuds Assistance Centers shall provide individual counselling, educational, and assistance services to enable enrollees to choose a plan and access services, shall asssist enrollees in pursuing grievances, complaints, and appeals, and shall submit quantitative and qualitative data and recommendations based on their records to the Ombuds Advisory Council.

- Require all grievance and appeals processes to be swift and simple, especially in situations where the health and functioning of the enrollee is significantly in jeopardy. In these cases, decisions and notifications must be expedited. All time period requirements must be in calendar days, not business days. There must be only *one* level of internal review required. A Medicaid "fair hearing" or Medicare appeal must be possible at any time without having to exhaust internal appeal procedures. Allow complaints to be submitted both orally and in writing by either the enrollee or any person who makes a complaint on the enrollee's behalf. Designated representatives must be allowed to act at any time on an enrollee's behalf for those persons not able to act for themselves because of illness, disability, or cognitive impairment, unless a competent enrollee refuses their participation.

- Require that all plans offer 24-hour, toll-free telephone and TTD/TTY access, and that all calls be answered by a trained staff person who is capable of responding to inquiries and requests for assistance and approvals for care/coverage. All plans must be able to fully communicate with persons with vision and hearing impairments, and in all languages used by at least 1% of the target population.

- Require the continuance and availability of all services during any internal or external grievance, appeal, or fair hearing process, and if a plan's decision should be upheld, until alternative arrangements or placements are made.

- Require each plan to offer an open forum known as an "enrollees' council" (similar to residents' councils in nursing homes) for participants to discuss their experiences among themselves and make recommendations. These councils must be organized and/or assisted by independent ombudspersons or agencies, not plan staff, and must meet at least quarterly. Plans must make participation possible for all enrollees by providing transportation and/or forms of telecommunication when necessary. The plan must respond formally in writing to all reports, requests and recommendations from the Council, and when possible, recommendations should be incorporated into the plan's policies and procedures.

MARKETING

In order to make sure applicants understand the meaning of enrolling in a managed long-term care plan, the Department of Health must:

- Contract with an enrollment broker, independent of the state and any plan, to assist consumers in choosing a plan.

- Prohibit gifts and incentives to potential enrollees.

- Require that a plan's marketing program be approved by the Department prior to implementation.

- Require that the plan's marketing representatives have a knowledge of all state laws and rules governing the plan.

- Publish annually a guide on all plans, similar to those on long-term care insurance currently published by the State Insurance Department.

- In consultation with consumers and their advocates, publish and make widely available, including on the internet, a list of basic, important questions consumers should consider when choosing whether to enroll in a plan.

GENERAL REGULATION, OVERSIGHT, AND ENFORCEMENT

The Department of Health must develop and enforce good, strong regulations to guide the implementation of managed long-term care demonstration projects. We urge the Department to take the following steps:

- Assure that members of the state's Managed Long-Term Care Advisory

Council, as defined in law (Chapter 59, Section 82(10) and New York Public Health Law Section 4403-f(10)), are immediately appointed and that the Council begins to meet. The architecture for plans is currently being developed by the Department without the participation of this body.

The Department of Health must develop and enforce good, strong regulations.

The Council's first tasks must be representing the community in the development of regulations and a Request for Proposals (RFP) by the Department, and developing a framework to evaluate the state's managed long-term care demonstration projects. It must also work with the Department to develop criteria to evaluate on an on-going basis whether plans are improving and effectively delivering service. All meetings of the Council must be open to the public, held regularly, and held around the state to provide access to all citizens.

- Immediately define a very specific step-by-step process, *with consumer participation*, for the development and approval of the plans, including a stringent readiness review and approval of marketing plans.

- Establish mechanisms for regular public participation and feedback to the Department, especially for plan applicants, enrollees, their families, and clinical staff. These mechanisms should include semi-annual public hearings at the various plan sites, held during evening and weekend hours, and attended by relevant Department personnel, legislators and their staff, and members of the Advisory Council. Relevant agency heads and/or program officers with authority, with members of the Advisory Council present, must be required to report on and answer questions about the development and operations of the demonstration projects.

- Conduct quarterly, anonymous surveys of participants and providers that assess issues of quality of care, enrollee/family/designated representative's satisfaction with quality of life and quality of care, and access to, availability of, and continuity of care. The Department, with the assistance of the Advisory Council, will need to develop new objective process and quality outcome measures to be measured by the plans and supplied annually to the Department.

- Aggressively monitor the plans, cite them for deficiencies when warranted, and use sanctions such as "directed plans of correction" (whereby the Department tells providers how to correct situations) and fines to enforce compliance.

- Conduct annual, unannounced inspections of each plan, including interviews with enrollees, families, individual clinicians and caregivers, during evenings, nights, and weekends. Substantial fines must be levied for serious violations which cause harm or have the potential to cause harm. Follow-up, on-site inspections must be made.

DATA COLLECTION AND EVALUATION

Since all of the plans authorized under the law are demonstration projects, the state must have adequate data to evaluate both the individual plans, and the state's managed long-term care program as a whole. Therefore, the Department of Health must:

- Require all plans to collect and submit data on: plan marketing; enrollment, denial of enrollment, voluntary and involuntary disenrollment; access to care within the plan; enrollee/family /designated representative's satisfaction with quality of life and quality of care; patient and provider profiles; utilization of services; discharge dispositions; complaints, appeals and grievances and resolutions; health outcomes; requests for information; enrollee council reports, requests, and recommendations; and how the plans actually spent their capitated payments.

- Review and approve all plan data collection systems and outcome criteria before plans begin data collection.

LEGISLATION

In order to make sure the state's managed long-term care program works to the advantage of applicants and enrollees, as well as the state, the Legislature must enact legislation which:

- Amends the current law to require annual written reports to the Legislature by the Commissioner of Health on September 1st of each year. This policy will allow legislation to correct problems to be developed and passed during the next regular Legislative session.

- Provides funding to require the Department of Health to contract for an independent evaluation of its managed long-term care demonstration projects because the state has a potential conflict of interest in its role as Medicaid payer. Both qualitative and quantitative studies must be required.

Require the Department of Health to contract for an independent evaluation.

- Enacts strong whistle-blower protections to encourage clinical and administrative staff to report quality, access, and professional practice problems without fear of retribution by plan operators.

- Maintains New York's prohibition on publicly-traded corporations owning and operating nursing homes, and carefully monitor and evaluate the performance of for-profit managed long-term care demonstration projects.

CONCLUSION

Managed long-term care is an experiment in New York which involves making substantial changes to the lives of the frail, elderly, chronically ill, or persons with disabilities who participate in the demonstration projects. The Nursing Home Community Coalition of New York State is committed to assuring that the state's managed long-term care program provides the best care possible for those New Yorkers who choose this option. Further, the Coalition believes that these demonstration projects offer the State models to be used in formulating a variety of statewide programs in continuing care to address both the social and medical needs of the rapidly expanding population of elderly and disabled residents.

We believe that the active involvement of consumer advocates will be critical to the success of the state's efforts to move forward into the new world of managed long-term care.

We hope that these demonstration projects result in better, consistently high-quality care provided in a manner which respects the dignity and autonomy of the participant. At the same time, we have some serious concerns about the implementation of the program and some of the inherent problems with managed care.

We cannot stress enough that if the state's focus is solely on cost reduction, its experiment will fail, both in terms of the care provided for participants and in terms of cost control. It is well established that bad or delayed care always costs more in the long run.

We believe that the active involvement of consumer advocates will be critical to the success of the state's efforts to move forward into the new world of managed long-term care. We offer these comments with the hope that our shared efforts will result in better care and quality of life for all our state's elderly and disabled residents.

If you have any questions or comments, please feel free to contact the Nursing Home Community Coalition at (212) 385-0355.

APPENDIX A:

SELECTED ANNOTATED BIBLIOGRAPHY

Alliance for Health Reform. *Managed Care and Vulnerable Americans: Adults with Disabilities* Washington, DC: Alliance for Health Reform, December 1997.

A pamphlet which examines caring for people with disabilities in managed care, and the challenges not yet fully explored by policymakers, private and public insurance plans, and people with disabilities.

Alliance for Health Reform. *Managed Care and Vulnerable Americans: Medicare and Medicaid Dual Eligibles.* Washington, DC: Alliance for Health Reform, March 1997.

A pamphlet which examines the issues involved in moving low-income seniors citizens and persons with disabilities into managed care, and how policymakers could resolve the issues to answer government's concerns and patients' care needs.

CASA Association of New York State. *Managed Long-Term Care and the Role of Government* Albany, New York: CASA Association of New York, October 1996.

An analysis of managed care in the long-term care system, and the role of state and local government.

Center for Vulnerable Populations. *A Framework for the Development of Managed Care Contracting Specifications for Dually Eligible Adults.* Portland, Maine: Center for Vulnerable Populations, November 1996.

A self-described framework or platform for states to use in constructing their own state-specific managed care program designs and contracting specifications for dually-eligible persons.

Dallek, Geraldine; Perkins, Jane; and Schlosberg, Claudia. *A Guide to Meeting the Needs of People with Chronic and Disabilities Conditions in Medicaid Managed Care.* Washington, DC: Families USA Foundation and the National Health Law Program, January 1998.

An analysis of how states are responding to the concerns of vulnerable Medicaid-eligible populations for comprehensive care and support services in managed care; also includes information on states' motivations, the potential improvements for beneficiaries under well-designed programs, the types of programs being established, the potential perils for states and beneficiaries, and how advocates can be involved in planning, implementation, monitoring, and enforcement.

Demel, Beth. *Systemic Problems with Medicare HMOs: Case Studies from the Medicare Rights Center HMO Hotline.* New York: Medicare Rights Center, September 1998.

An analysis of cases handled by the Center's National HMO Appeals Hotline during its first six months of operation.

Fish-Parcham, Cheryl. *A Guide to Marketing and Enrollment in Medicaid Managed Care.* Washington, DC: Families USA Foundation, June 1997.

An analysis of the kinds of marketing and enrollment problems in Medicaid managed care, the ways that states have addressed such problems, and strategies for community advocates.

Fish-Parcham, Cheryl; Perkins, Jane; and Rivera, Lourdes. *A Guide to Complaints, Grievances, and Hearings Under Medicaid Managed Care.* Washington, DC: Families USA Foundation and the National Health Law Program, January 1998.

Explanations of the different aspects of federal and state laws and regulations that can help ensure due process for Medicaid beneficiaries, how managed care changes them, and policymakers' concerns; also includes examples of the mistakes made by some states and how they have been addressed, ideal procedures, significant steps some states have taken, and ways advocates can intervene.

Gallin Lynch, Lisa. *A Guide to Access to Providers in Medicaid Managed Care.* Washington, DC: Families USA Foundation, April 1998.

A review of what can happen when Medicaid managed care enrollees have inadequate access to providers, and what states are doing to assure adequate provider networks; also examines the language of contracts between plans and state agencies, selected state policies and applicable federal requirements, and steps that advocates can take to improve access.

Minnesota Department of Human Services. *Long Term Care Options Project: Acute and Long Term Care Integration for Medicare/Medicaid Dual Eligibles.* St. Paul, Minnesota: Minnesota Department of Human Services, April 1995.

A summary of Minnesota's demonstration and waiver proposal submitted to the U.S. Health Care Financing Administration.

Molnar, Chris; Soffel, Denise; and Brandes, Wendy. *Knowledge Gap: What Medicaid Beneficiaries Understand — And What They Don't— - About Managed Care.* New York: Community Service Society of New York, December 1996.

A report based on interviews with Medicaid beneficiaries in New York City; findings focused on use of services, and knowledge and experience with managed care plans.

New York State Department of Health. *Description of Managed Long Term Care Plans in New York State.* Albany, New York: New York State Department of Health, Office of Continuing Care, May 1998.

An overview of managed long-term care programs, proposed, in-development, and operational, in New York State.

New York State Office for the Aging. *Managed Care Approaches in Long Term and Integrated Care* Albany, New York: March 1996.

A short monograph focusing on issues of access, case management, and home, community-based, residential and integrated care; part of a larger series.

Saucier, Paul. *Public Managed Care for Older Persons and Persons with Disabilities: Major Issues and Selected Initiatives.* Portland, Maine: Center for Vulnerable Populations, November 1995.

An analysis of the major policy and program issues which have emerged from the debate over the impact of managed care on older persons and persons with disabilities, and the limited research on these issues; also includes selected descriptions of state initiatives.

Swirsky, Lisa and Dallek, Gerri. *Monitoring Medicare HMOs: A Guide to Collecting and Interpreting Available Data* Washington, DC: Families USA Foundation, May 1998.

An analysis of how groups which advise Medicare beneficiaries work with clients so as to help them be able to obtain and analyze information and make informed choices when considering a managed care plan.

Thompson, Deborah. AConsumer Issues in Dually Eligible Waivers. Cambridge, Massachusetts: Alzheimer's Disease and Related Disorders Association of Eastern Massachusetts, Inc., 1997.

An outline distributed as part of a presentation at a conference sponsored by the Eastern Paralyzed Veterans Association in New York City, August 1997.

APPENDIX B:

ORGANIZATIONAL MEMBERS OF THE COMMITTEE ON MANAGED LONG-TERM CARE

Alzheimer's Association, New York City chapter

Coalition of Insitutionalized Aged and Disabled

Disabled in Action of Metropolitan New York

Friends and Relatives of the Institutionalized Aged

National Association of Social Workers/New York State

New York City Department of Aging

New York Statewide Senior Action Council

State Communities Aid Association

Women's City Club of New York

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