

DEVELOPING A NEW AND BETTER LONG TERM CARE SYSTEM IN NY STATE

A white paper for the new
administration & state leadership
to facilitate implementation of
policies that better meet the future
needs and preferences of all our
citizens

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Developing a New and Better Long Term Care System In New York State: Introduction

Now is the Time to Propose a Better Long Term Care System

The election of 2006 signified a crossroads for New York State, with the advent of a new governor for the first time in twelve years. The new governor, along with the administrative leadership he selects, will have the opportunity to develop long term care policies that meet the future needs and preferences of all our citizens. The authority that comes with a new administration and the fresh systemic, philosophic and financial undertakings Governor Spitzer proposes will create opportunities for numerous populations and formidable momentum for reforming the design of Long Term Care. We see the election of Eliot Spitzer as the launching point for developing a new way of thinking about long term care policy in New York State.

The Long Term Care Community Coalition (LTCCC)¹, which has been dedicated to improving long term care in New York State for close to 25 years, respectfully presents this white paper with the hope that it will be a useful resource when considering what changes must take place to, as the new Governor has said, “redesign our health care system to reward the right kind of care.”

New York State’s Aging and Disabled Population

Similar to the rest of the nation, New York State’s population is aging. By 2025 the 60

¹ LTCCC, formerly the Nursing Home Community Coalition of New York State, is a coalition consisting of over two dozen consumer, citizen and professional organization which join together to improve long term care for consumers in all settings.

and older population of New York will increase 40 percent, from approximately 3.1 million to 4.4 million. The number of people 85 and older will grow steadily from approximately 275,000 in 1995 to over 390,000 in 2025 – an increase of 41 percent. The needs of our aging population will increase the demand on long term care services both in and out of the home. Studies show that more than 40 percent of people 85 years of age and older have lost the ability to perform one or more of the activities of daily living (ADLs), such as bathing and dressing. And, although loss of cognitive function, including Alzheimer’s Disease, affects less than 5% of those over age 65, the prevalence increases dramatically with age. One-third of those over age 85 have dementia.² Roughly one-fourth have a mental disorder.³ In 2005, 11.4 percent of working age adults had a disability (the prevalence rate). The highest prevalence rate was people with physical disabilities.⁴ More than two-thirds of low-income people with disabilities (SSI beneficiaries) report having fair to poor health and more than 75 percent need assistance with activities of daily living.⁵ The needs for long-term care in these populations will remain constant.

Our Current Long Term Care System: Need for Change

Our current system is in trouble and in need of reform. It is fragmented in terms of regulations and services, with four different long term care systems under the direction of four different state agencies: Office of Mental Health (OMH), Office of Aging

² Project 2015: The Future of Aging in New York State: <http://www.aging.state.ny.us>.

³ Laura Osinoff, testimony, “2004-2008 Statewide Comprehensive Plan for Mental Health Services,” May 19, 2004.

⁴ Cornell University, “2005 Disability Status Reports.”

⁵ Sharon K. Long, PhD.; Theresa A. Coughlin, MPH; and Stephanie J. Kendall, “Access to Care Among Disabled Adults on Medicaid,” Health Care Financing Review, Summer 2002.

(SOFA), Department of Health (DOH) and Office of Mental Retardation and Developmental Disabilities (OMRDD). New York has a serious lack of housing for those who want to remain in the community as they receive care; problems with workforce capacity and a lack of an effective workforce policy: we don't make good use of the workforce we do have in terms of training and preparing them for their roles, nor do we provide them with opportunities for career advancement.

Our White Paper

Because the central purpose of the long term care system is to provide care for New York's citizens, for this white paper we set out to identify the needs and preferences of New York's diverse population, focusing on those most likely to use long term care services (the frail elderly and the disabled), while paying particular attention to communities that are too often under-considered in health care policy development (due to factors such as race, language barriers, and mental illness).

In order to do this, we surveyed consumer groups across New York State and convened an advisory committee of experts representing diverse communities and expertise which contributed to the ideas outlined in this paper (see the last page for more information on the advisory committee). Our advisory committee meetings were focused on helping you develop a long term care system which truly fulfills its fundamental purpose: to provide quality and humane care to New Yorkers who need long term care, its consumers. In addition, we consulted with a number of our coalition members (consumer, civic and professional organizations across the state) and conducted research on activities and trends across the country.

This paper begins by outlining our vision: that the process of empowering the consumers of long term care (helping them take control of the factors that determine

their health and their lives and have the power to make decisions and choices) as well as empowering their formal and informal caregivers, is central to transforming the LTC system for the better. Following the outline, we present some fundamental principles that should be recognized when shaping the current and future of systems of long term care.

The heart of this paper is a presentation and discussion of recommendations on how we can utilize this vision to shape a system that adheres to our fundamental principles. We then address the need to protect New Yorkers who are now receiving long term care while necessary reforms are enacted, to make sure that quality of care is maintained and improved as we enact necessary reforms. The paper concludes with an assessment of current initiatives being discussed at the state level to see whether they can help or hinder making our vision a reality.

Our Vision of Consumer Centered Planning

The policy of long term care that we envision requires the state to facilitate the development of individualized care or service plans that give power to the central participants in the process: the consumer, the informal caregiver, and the formal caregiver. Though they are at the heart of the system they often have the least power.

By changing this focus, our goal is to enable consumers to receive care in the settings they need and want and make sure that there are adequate options in terms of both settings and services.

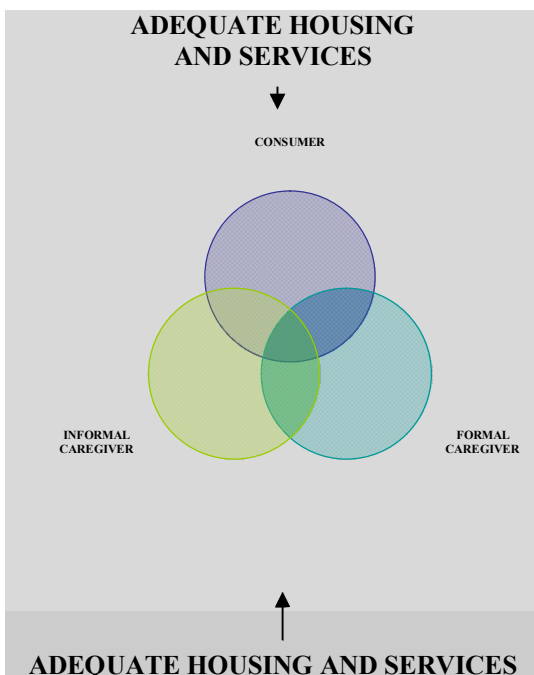
Success Through Individualized Care Planning

Long term care in New York State must be consumer, or person, centered. Each care or service plan must relate to an individual's medical and social needs as well as the

preferences of the individual and be developed with the individual to help him reach the goals he believes important and/or maintain his current functioning and lifestyle. This empowerment of consumers, who are too often disempowered by the long term care system, will encourage them to make decisions about their own lives and take control of their care. The needs of informal and formal caregivers, who are also systemically disempowered, often overlap with those of the consumer, but consumer choices must be the central focus of any long term care program. However, consumer needs and desires cannot be met without considering these other participants in the process. Informal caregivers have a considerable stake in the care of their loved ones, and their own lives are very much affected by the design of the system and the personal investment expected of them. Formal caregivers are also key; the day-to-day decisions they make, and their relationship with the individuals under their care, have a tremendous effect on consumers. A well developed consumer driven care or service plan must, whenever possible, be determined by an informed discussion between these parties.

GUIDING PRINCIPLES FOR BUILDING A BETTER LONG TERM CARE SYSTEM IN NYS

- The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care. Everyone involved should be empowered and valued though the consumer must have the primary role in directing his or her care when able.
- The system must also focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences. A consumer of long term care services is not simply a medical diagnosis; he is a whole human being made up of things he does well and things he can no longer do. The system must build on strengths as it deals with needs.
- Consumers must have the right to 'age in place' - remain in their own community if they become more dependent - with a decent quality of life until they can no longer do so safely or do not want to.
- While some adult homes meet the definition of community setting, many do not and are institutions. These adult homes should not be considered "remaining in one's own community."
- Housing options must be available for those who want to remain in their own community.
- Consumers must have adequate and appropriate options of where to receive services and by whom.



- Consumers must have culturally competent long term care services.
- Informal caregivers must be recognized as an important part of the long term care system. They keep their loved ones out of nursing homes, and they will contribute to the future success of home and community based services.
- Formal caregivers must be recognized for their central role in providing services. We cannot shape an effective long term care system without a well-equipped workforce to sustain it.
- The present system must be improved at the same time we move to a new system. We cannot abandon those who are now living in the current system as we move towards a new and better long term care system

Adequate numbers of housing options must be available.

RECOMMENDATIONS FOR BUILDING A BETTER SYSTEM OF LONG TERM CARE IN NYS

Empowering Consumers through Individualized Care or Service Planning

People who can make decisions over their lives and take control of their care tend to have better health outcomes. The best way to assure positive health and quality of life outcomes for consumers as we reshape the system of providing services, and the settings in which those services are obtained, is to identify needs and preferences on an individual basis. Everyone entering into long term care in the state of New York should have adequate access to available resources, and they should be assisted in establishing a plan which will help them to utilize their strengths and meet their goals, whether those goals are independence, community integration, or a level of care that suits their needs and

desires. Individuals cannot have satisfactory care unless there are adequate numbers of options in terms of housing and services.

Consumers Must Have Knowledge

In order to take control of their care, consumers must have the information necessary to make knowledgeable decisions. The state should:

- First consider how to guarantee seamless access to service options across all four long term care systems. One way might be to integrate the four long term care systems that are now operating in New York State. It is almost impossible for consumers to navigate these systems as they now stand. The “Single Point of Entry for Long Term Care” (POE) that is now being developed by New York State is a beginning. However, as noted in our later section dealing with current initiatives, the POE as it now stands perpetuates this fragmentation by focusing only on the elderly, ignoring the other long term care populations.

We must empower the most powerless in the long term care system.

- Develop consumer-friendly resources, specifically tailored to the needs of many diverse populations, to help those who are considering their scope of options. These resources must also give consumers the knowledge they need to navigate the long term care system, to think about their current and future long term care needs and preferences and to plan for their care.

Care or Service Planning Must be Redesigned

In order to meet our vision of consumer directed planning, the planning process needs to be redesigned. The state should consider:

- Making sure that there are adequate numbers of case (care) managers/social workers to help consumers analyze their needs and preferences as they develop a service plan. If there are not, the state should develop a plan to increase their numbers.
- A process that includes regular care management meetings with consumer, informal and formal caregivers to evaluate service plans.

Individualized care planning is crucial to the vision.

- How to facilitate meeting the preferences of those consumers who want to remain in their own home or community by developing plans to modify the environment, integrate the consumer into the community, create support services, meet transportation needs and develop

alternatives for the at-home consumer if formal caregiver does not show up or cannot come. New York's new Medicaid waiver gives the state flexibility to do this.

However, as we discuss in more detail in a later section, as it now stands it hinders the implementation of our vision because it ignores the needs of specific populations and it ignores the mental health needs of all populations.

- The concept that placement in an institution such as a nursing home or some adult homes should be considered the setting of last resort unless the consumer decides that his/her social and medical needs can only be met in an institution. The Managed Long-Term Care Program has the potential to help us realize our vision. If implemented carefully, thoughtfully, and with appropriate respect for the dignity and autonomy of the patient, New York State's managed long-term care plans can improve care.

Housing and Service Options for Consumers to Choose From Must Be Provided

In order for the planning to be meaningful, consumers must have adequate numbers of housing and service options to choose from. In order to do this, the state needs to:

- Conduct a housing needs assessment which includes an estimate of how many people are waiting for housing as well as how many people now in institutions such as nursing homes or some adult homes can and want to move to a non-institutional setting.
- Conduct an assessment of service needs.
- Focus on housing preservation by giving incentives to help preserve existing housing. Encourage incentives and innovative funding streams to develop accessible

housing (see, i.e., “Housing First Ideas” and AARP’s affordable assisted living report.)⁶

- Provide both *more* housing options – private homes, scattered sites and congregate housing in the consumer’s own community – and housing with *appropriate designs* and models which:
 - Are accessible with a focus on accident prevention;
 - Make activities of daily living (ADL) and health care help in the home available;
 - Make help with medication available;
 - Limit size of housing;
 - Encourage integrated housing in scattered settings;
 - Make end-of-life services available;
 - Make housing permanent if the consumer can and wants to remain;
 - Make housing available in all communities;
 - Utilize new technology to make housing safe and accessible;
 - Encourage consumer independence and autonomy;
 - Discourage “institutional” models such as many adult homes which are large, provide little privacy and are run as institutions; and
 - Encourage public/private partnerships to facilitate the expansion and design of housing and home and community based service options. (see, i.e., “New York State Coalition for Adult Home Reform.”)³

New York’s System of Long Term Care Must be Culturally Competent

New York’s long term care consumers are very diverse. Consumers can not be empowered unless the system itself understands the culture from which they come. In order to do this, the state must:

- Consider where and how different cultures get their information as it conducts outreach;
- Mandate that the language of the consumer be used by professionals where services are provided by using qualified interpreters; when that is not possible, ensure access to translation services;
- Consider how to engage people of different cultures;
- Consider how to assess the health care needs of people of different cultures;
- Encourage a culturally competent workforce through culture training and increasing awareness of specific cultural needs;
- Increase the numbers of linguistically and culturally competent professionals by encouraging diversity of different cultures, ethnic and racial backgrounds, in supervisory, governance and management roles;
- Encourage communication between consumers, workforce and informal caregivers in terms of different cultures; and
- Make sure that long term care policy reflects the needs of future immigrants.

Policies must meet the needs and preferences of our citizens.

⁶ See References & Resources at the end of this paper for all mentioned references.

“Aging in Place” and Remaining in Community Must Be Encouraged

In order to help consumers who want to remain in their own home and be integrated into their community with a decent quality of life, the state needs to:

- Develop supports for consumers to remain integrated:
- Develop quality mental health and health services to be given in the home or in a community setting;
- Reform the present para-transit system by dealing with its problems: it is often demeaning and has excessive wait times; the drivers lack knowledge and involvement with their clients; it is often lacking in adequate safety procedures; and it has numerous dispatching and scheduling problems;
- Encourage flexibility in the workplace by urging providers to develop schedules for some workers to arrive late, or early, depending on consumer, formal and informal caregiver needs and by encouraging workers and consumers to vary different times of service;
- Giving priority in scheduling to consumers who need to get out for a job or other event;
- Consider problems of isolation:
 - Develop more outreach programs for people who may be isolated at home;
 - Develop more home-based services to help ready consumers to go out and get services in the community;
 - Develop ways to bring people and community into any long term care setting to combat isolation; and,
 - Develop meaningful community activities for consumers of long term care.
- Prepare the community for integration of long term care

consumers by assessing both physical and attitudinal barriers and developing ways to overcome them; and

- Develop ways to use technology to improve accessibility and health outcomes.

The Financial Aspect of the System Must be Redesigned

In order to meet the vision of empowering consumers and encouraging “aging-in,” housing and services budgets should be separate, unless the particular situation necessitates that they be combined. . Thus, a consumer should not be forced to choose supportive housing - a service that bundles housing and care - risking eviction if he wants to change care providers. In addition, a consumer choosing to remain in his own home should be able to receive funds to help pay the rent and avoid institutionalization. Consumers must also be given housing and service provider options to choose from. It is important, however, that provider rates are appropriate, revisited on a regular basis and that worker wages and benefits are evaluated annually. Disability rates of payment should be developed in order for payment to be based and based upon the complexity of consumer’s long term care needs.

Empowering and Increasing a Well-Trained Workforce – Formal Caregivers

When there are adequate numbers of formal caregivers and they are given the knowledge needed to make decisions and impact the lives of the consumers under their care, they become interested parties with an investment in the success of both the individual consumer and the caregivers themselves. Well-trained and empowered formal caregivers are key to the process because they, along with caseworkers and other professionals encourage practical decision-making when implementing on-going service plans and often know the

consumer best. We can support and further the impact of these workers, and improve the system as a whole.

We cannot have an effective system without a workforce to sustain it.

Need to Develop and Maintain Workforce Capacity

In order to do this, the state should:

- Collect data annually on:
 - Shortages in different parts of the state;
 - Retention and turnover rates;
 - Barriers to work in long term care; and
 - Reasons why potential workers want to work in long term care.
- Encourage a better screening system for employers, making sure potential workers understand the responsibilities and opportunities of the position.
- Develop roles for and encourage older adults to join the workforce; and
- Redirect HCRA funds to go to providers who can demonstrate they can retain workers and that workers are a major part of the service. Projects must demonstrate successful outcomes and ability to be replicated. Funds could be used to fund:
 - Adult learner training;
 - Supervision training;
 - Career ladders;
 - Empowering staff through decision-making roles;
 - Helping staff to access other benefits to ensure full-time work such as child care, housing, Medicaid, etc.
- Consider loan forgiveness.
- Increase wages and benefits to make sure workers have a living wage.

- Encourage better training for supervisors.
- Help workers who are transitioning to other long term care settings.
- Consider the use of the “universal” worker.
- Remove barriers to getting formal caregivers from other countries.
- Consider how we can assure that workers can get the supports they might need at the congregate setting place they work – it should not be too expensive for workers to get the care they need at the place they have given care.

Need to Improve Training

In order to do this, the state needs to:

- Develop training on consumer directed care.
- Encourage improvements in professional education, especially concerning:
 - Consumer or person directed care;
 - Mental health needs;
 - Communication with consumers and informal caregivers;
 - Cultural competency; Alzheimer/dementia care; and
 - Other specific conditions and diseases that are prevalent in the long term care population.
- Encourage the use of technology (i.e., telemedicine) in areas where there are demonstrated shortages, access to care has been compromised or in situations where outcomes with technology have been shown to improve outcomes. Such technology must aid and complement workers, not replace them.

Empowering Informal Caregivers

Seventy-five percent of all long term care in New York State is provided by informal caregivers – unpaid family members, friends or neighbors who provide full or part time care. In 1999 the estimated value of these caregivers was \$197 billion (see: Arno, 1999). These caregivers permit us to expand non-institutional services. Without informal caregivers willing to keep their loved ones at home, the Medicaid budget would be even higher than it is - informal caregivers keep their loved ones out of expensive nursing homes (Mittleman's work indicates that nursing home can be deferred up to 5 years with good family support). However, many informal caregivers feel financial stress as well as physical and psychological stress. Stress can be minimized by removing the feeling of powerlessness. This can be accomplished by making caregivers an integral part of the decision-making process (especially for consumers who cannot make decisions for themselves), helping them to be prepared for the caregiver role, be informed, giving them financial assistance and teaching them how to negotiate for services. Studies suggest that relatively low-cost supportive services for family caregivers can not only reduce the stress experienced by family caregivers, but can result in delayed nursing home placement for the person needing care. Empowering those who care for consumers will help them plan and make important decisions for their future, because their futures are intertwined.

Understand the Needs of Informal Caregivers

In order to empower informal caregivers the state should:

- Develop a tool to assess the needs and desires of informal caregivers throughout the state.

Unpaid caregivers help keep loved ones at home.

Meet the Needs of Informal Caregivers

In order to help informal caregivers deal with the stress of taking care of their loved ones the state should:

- Develop, based upon assessed needs, resources to meet those needs such as:
 - Support groups;
 - Information they can access on different health conditions needing long term care;
 - Readily accessible counseling for caregiver and family with strong crisis intervention;
 - Access to respite care; and
 - Information on how to balance the needs and choices of the informal caregiver with those of the consumer.

Financially Support Informal Caregivers

In order to help informal caregivers deal with financial stresses and continue in their role, the state must:

- Developing a method of including informal caregivers in the long term care budget;
- Develop a tax credit program; and
- Change SSI rules so that housing costs paid by informal caregivers are not deducted from the payment.

PROTECTING CONSUMERS IN THE PRESENT LONG TERM CARE SYSTEM AS WE DEVELOP THE NEW SYSTEM

As we consider what the state long term care system should become over the next few years, we must not abandon those consumers in the present system.

State Monitoring of the Long Term Care Must be Improved

In order to do this:

- OMH must take responsibility for the mental health needs of people who need long term care;
- Funds must be increased to long term care regulatory agencies to hire more trained and experienced inspectors and supervisors; and
- The state should implement recommendations from LTCCC's two reports on the nursing home survey system: "Nursing Home Oversight in NYS: A Regional Assessment," and "Nursing Home Residents at Risk: Failure of the NYS Nursing Home Survey and Complaint Systems."
- Increase consumer participation in state inspection and monitoring programs.

We cannot abandon those who currently reside in nursing homes or other institutions or who otherwise depend on long term care.

The Delivery of Long Term Care Must be Improved

Long term care providers must be encouraged to consider the consumer or person directed system. In order to do this, the state should:

- Encourage "culture change" projects that have support from management with grants that are open to all stakeholders, demonstrate meaningful outcomes and have an ability to be sustained; and

To the greatest extent possible, fines collected from long term care providers should be put into an account to be used only for improving long term care; (See LTCCC's 2006 report, "How Federal

Civil Monetary Penalties and State CMPs/Fines Can Support Good Care for Nursing Home Residents," for recommendations on how to use these funds.).

CURRENT STATE INITIATIVES: WILL THEY MOVE US TOWARDS OUR GOALS?

There are several ongoing and new initiatives which, depending on how they are carried out, can help or hinder our ability to achieve this vision. Following is a brief overview and assessment of the current initiatives.

New York Commission on Health Care Facilities in the 21st Century

The Commission was created by Governor Pataki in conjunction with the state legislature to assess hospital and nursing home capacity in New York State and make recommendations for "right-sizing" (i.e., down-sizing) hospitals and nursing homes. Because the Commission was created "to undertake a rational, independent review of health care capacity and resources in New York State and to ensure that the regional and local supply of hospital and nursing home facilities is best configured to appropriately respond to community needs for high-quality, affordable and accessible care, with meaningful efficiencies in delivery and financing that promote infrastructure stability," it would seem that this initiative will aid in meeting our vision. However, the way their goals are being carried out seems to contradict a number of our guiding principles.

The Commission, though neither elected by nor accountable to the public, was given formidable powers: under the law establishing it, its "recommendations" go into effect unless the governor and legislature take affirmative steps within a

short time period to stop them. From the perspective of New York's citizens, and the goals discussed above of creating a long term care system that allows for person directed care in a consumer preferred setting, there are a number of things to be concerned about in the Commission's activities and the powers granted to it by Governor Pataki and the state legislature:

- It seems as if the Commission will recommend downsizing before adequate alternatives are determined to be in place for those who need a nursing home level of care. Though our goal of enabling people to get care outside of nursing homes is, on its face, compatible with the goal of reducing nursing home size, it is crucial that a strong system be in place to enable consumers to get care outside of nursing homes before nursing homes are down sized. This will require an investment in community-based services, including housing;
- There is a concern that the recommendations of the Commission could inadvertently result in the loss of essential mental health and substance abuse services. Mental illness and behavioral symptoms are major reasons why individuals end up in nursing homes. Such critical services must be preserved or alternatives must be found.
- Many stakeholders were not included; any decision to downsize nursing home capacity must be done with the broad based input from diverse stakeholders – including citizens, consumers, providers and experts – not by a top down panel such as this Commission;
- Commission members seem to be interested only in discussing capacity; other issues such as how to meet the long term care needs of our citizens with the capacity we will have must also be discussed, or it will seem that the over-riding

- priorities are to produce financial savings, not better outcomes for New Yorkers who need care; and
- The Commission performed only cursory examination of nursing home issues (focusing mostly on hospitals), citing only one data source on nursing homes which was not up to date. According to one of the regional commission members, there was not a lot of time or resources spent on nursing home issues and “to me it did not seem like the right way to deal with long term care.”

In November we issued an open letter to the Commission leadership and state leaders detailing our serious concerns about the Commission's activities and the power given to it by former governor Pataki. This letter is available on our nursing home information Website, www.nursinghome411.org. As that letter notes, the Commission's findings and recommendations can be useful to improving long term care in NY State, but only if they are considered with other perspectives in a more balanced and broad-based approach.

Current initiatives must be analyzed to see if they meet the vision.

New York's New Medicaid Waiver Implementing the Federal-State Health Reform Partnership (F-SHRP)

This new waiver, in effect October 1, 2006 through September 30, 2011, provides both opportunities and challenges for New York's new leadership.

- The waiver explicitly relies on the state implementing the recommendations of the Commission on Healthcare Facilities which is both troublesome and astounding, considering those

recommendations were not yet made when the waiver was granted and the problems discussed above. However, the waiver does provide the new governor with resources and flexibility to overcome current systemic biases that result in lack of consumer choice and empowerment, over institutionalization, and other problems identified in this White Paper and other reports. It will be crucial, however, to ensure that long term care consumers are able to access the services they need as systemic changes are implemented and thereafter, and that there are true opportunities for all consumers to have choices and options that meet their personal health and psycho-social needs, and that both formal and informal caregivers are not unduly burdened in the process. As written, the waiver ignores the needs of specific populations and it ignores the mental health needs of all populations.

Single Point of Entry for Long Term Care

The state's plan for development of a single point of entry (POE) for long term care is already underway. This initiative would seem to be perfect for meeting our goal of empowering consumers and their informal caregivers by giving them the information they need to make informed choices and have seamless access to all care options. It can also be a step toward integrating the four long term care systems in New York. Yet, this initiative may be limited in its reach because of the following:

- It continues one of the major problems with our long term care system – fragmentation – by focusing only on the elderly and by being structured locally rather than regionally or state wide;
- It is unclear whether the POE will be culturally competent to work

effectively with people having not only different needs, but different ages, cultures, races, languages and sexuality;

- It has not made adequate provision to help people with mental illnesses except those with serious and persistent mental illness;
- It is also unclear whether the system, when developed to the point of including an assessment function, will have the ability to help consumers access the care they need in the settings they prefer, and not act as a funnel, sending individuals for care that meets the capacity of the system more than their needs as individuals;
- If counties administer the POE and pay for the services, it is possible that there may be a conflict of interest when determining the level of services required by an individual.

Our research on POE programs across the country (contained in our report, *Single Point of Entry for Long Term Care and Olmstead: An Introduction and National Perspective for Policy Makers, Consumers and Advocacy Organizations*) indicates that a POE can be a valuable component of a system that moves us toward our vision of long term care. The POEs that have been successful in this regard are those that are structured in a way that allows for cultural competence and sensitivity to diverse consumers, helps them to understand appropriate options and facilitates their accessing of those options. A critical element to ensuring these goals is the inclusion of well-trained staff to assist consumers.

Long Term Care Compact

The proposed legislation for a long term care (LTC) Compact Subsidy gives chronically ill senior citizens the option of “investing” their assets towards the cost of their long term care. The Compact Subsidy

proposal essentially privatizes long term care for a portion of the population. It allows participants to choose from non-Medicaid or Medicaid providers of care. Under the current proposal, participants who take part in the Compact will pay upfront a “pledge” of either \$300,000 (the approximated cost of a 3-year long term care stay) or up to ½ their assets, whichever is less.

- Concerns about the Compact Subsidy relate to whether the mechanisms of the proposal will actually alleviate the fiscal burden on Medicaid. Will many participate in the Compact, given that most individuals do not know their estimated time in long term care? What will happen to those “left behind” (who must rely on the system)? What role does the Compact play in the planning aspect for heirs of seniors and younger people with disabilities? Does the proposal take away autonomy of seniors and the disabled by mandating them to “cash in” their assets, or does the proposal help seniors and younger people with disabilities take control of their long term care?
- Do we want to essentially privatize a substantial portion of long term care in this way? What is the impact of this type of privatization in terms of real costs and quality of care & choice for consumers? Long term care is critical for all elderly individuals and people with disabilities; does the Compact ensure care only to those who are financially well off while doing little to heighten the overall quality of care?
- Another concern is that many seniors and people with disabilities can receive long term care services at a lower cost when they employ people (including families, friends and neighbors) informally or “off the books” to administer care, rather

than having to use established LTC services, often at a higher price. If the existing care is already good for some consumers, the Compact may do little for them. For these people, it could mean that their asset pledge may not go as far as needed.

In order to achieve the vision outlined in this paper and overcome fiscal challenges, it is expected that the state will need to reexamine funding mechanisms for long term care. However, the Compact, as it is currently written, is fraught with many potential problems, as noted above. It is crucial that all consumers be protected and ensured equal access to care under any new financing plan developed.

***Olmstead* Activities**

The U.S. Supreme Court’s *Olmstead* decision requires states to administer their services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” In New York, the Most Integrated Setting Coordinating Council (MISCC) was established to explore and recommend ways to ensure New Yorkers with disabilities receive services in the most integrated settings appropriate to their individual needs. The Council, a statutorily established group, was charged with implementing the *Olmstead* Decision in New York State. Partially as a result of MISCC’s work, Governor Pataki signed the Nursing Facility Transition and Diversion law in November 2004. This bill authorizes the NY Department of Health to seek a new federal waiver under the Medicaid program to provide home and community-based services to individuals who may otherwise be cared for in a skilled nursing facility.

As the discussions (above) on Medicaid waivers indicate, New Yorkers have yet to realize much of the potential benefits of the *Olmstead* decision, which has been federal law for over seven years. Implementing the goals of our vision for long term care will

enable New York to meet its legal mandate under *Olmstead*.

Managed Long Term Care

The managed long-term care program has the potential of helping us realize our vision. It provides significant opportunities to improve care for frail and chronically ill senior citizens and people with disabilities, but it carries with it important obligations. The managed long term care programs must make clear that protecting the health and wellbeing of program participants who are often frail, functionally disabled, and vulnerable is the primary consideration of its implementation. The program 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. It must include services for all populations now being served by all the long term care agencies: Office of Mental Health, Office of Aging, Department of Health and Office of Mental Retardation.

If implemented carefully, thoughtfully, and with appropriate respect for the dignity and autonomy of the patient, New York State's managed long-term care plans 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. However, if these conditions are not present, the opportunity will be squandered. Please see "*IMPROVING THE OPTION: Consumers' Perspectives on New York State's Managed Long-Term Care Demonstration Program*," www.ltccc.org for more detailed information.

New York State's Interagency Geriatric Mental Health Planning Council

This council, established by the Geriatric Mental Health Act, brings together

representatives of the different state agencies, consumer organizations and others to address the mental health needs of aging New Yorkers. This initiative may help implement one of the important recommendations of our vision: the integration of the four long term care systems that are now operating in New York State.

Conclusion: A Holistic Approach to Care Is More Efficient

You are in a position to change the way New York delivers long term care to all its citizens. We know that there are a multiplicity of interests at work in determining the future of this system, and that is why our white paper provides some specific suggestions on how we believe current and future reform efforts should be framed. We hope that our fundamental principles provide you with guidelines on how to keep the consumer at the center of the process, no matter what shape the system takes. Long term care should holistically address the whole person; it should place him or her in a position of power when determining a course of action. Such a system is more likely to have positive outcomes and satisfied consumers. Effective systems and satisfied consumers are not mutually exclusive. A comprehensive approach, implementing the suggested recommendations above, can save money. For instance, bolstering nursing home staffing levels could decrease costly hospital utilization by residents and expensive worker turnover and injury compensation claims (See our 2004 policy brief, "LTCCC Urges NY State Leaders to Consider Costs of Poor Care," available on the publications page of our Website, www.ltccc.org). In addition, integrating our four long term care systems, facilitating empowerment

of consumers who decide to remain at home or in their own community, facilitating empowerment of and supporting informal caregivers (who already save Medicaid huge amounts of money), and facilitating empowerment and increasing a well-trained workforce will help us become more efficient.

Please feel free to contact us for any questions or comments.

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- This article focuses on the value of informal caregiving.

Andrew I Batavia. "Consumer direction, consumer choice, and the future of long-term care. " Journal of Disability Policy Studies 13.2 (2002): 67-73.

- This article discusses the growing trend toward consumer direction and consumer choice in long term care.

John Capitman, Mark Sciegaj. "A contextual approach for understanding individual autonomy in managed community long-term care. " The Gerontologist 35.4 (1995): 533.

- A framework for identifying community long-term care program and policy features that support or hinder client autonomy is proposed in this article. The issues of financing, organization and delivery of care that offers clients meaningful choices are addressed.

RoAnne Chaney. *Promoting Community Integration: Barriers and Best Practices from Seven State Recipients of Olmstead Planning Grants*. 2003. Center for Health Care Strategies, Inc. (CHCS).

- This report discusses that people with chronic illnesses or disabilities should not have to live in an institution or nursing home if they can live in the community with the right support.

Friedman, M. "Baby Boomers With Schizophrenia And Other Long-Term Psychiatric Disabilities: Prepare Now." Mental Health News: Fall, 2005.

- An op-ed on the key challenges and recommendations to meeting the needs of people with long-term psychiatric disabilities who are aging.

Friedman, M. "Mental Health Is Key To Restructuring Long-Term Care Reform." Mental Health News: Spring, 2005.

- An op-ed on the need to incorporate the mental health needs of older adults in the restructuring of the long-term care system and the challenges that must be confronted in order to do so.

Long Term Care Community Coalition. *Certified Nurse Aide Training "Model" Program*. 2002. New York: Long Term Care Community Coalition.

- This training program, developed by a committee of consumer and caregiver organizations, including the New York State Nurses' Association, addresses how to prepare nursing assistants to deliver safe, quality care.

Steven Henry Lopez. "Culture Change Management in Long-Term Care: A Shop-Floor View. " Politics & Society 34.1 (2006): 55-80.

- This article proposes that the right sort of managerial philosophy can transform nursing homes from impersonal institutions into safe, caring communities. Their research suggests that culture change depends on adequate staffing.

Nancy A Miller, Sarah Ramsland, Charlene Harrington. "Trends and issues in the Medicaid 1915(c) waiver program." Health Care Financing Review 1 Jul 1999: 139-160.

- Over the past 15 years, Medicaid 1915(c) home and community-based waivers have made a substantial contribution to states' efforts to transform their long term care systems from largely institutional to community-based systems. Emerging, as well as long-standing, policy issues related to the waiver program include concerns with access, variation in availability by disability group, state decisions related to the provision of community-based LTC, and evidence of effectiveness.

Mittelman, Mary S. et al. (2004). "Sustained Benefit of Supportive Intervention for Depressive Symptoms in Caregivers of Patients With Alzheimer's Disease." American Journal of Psychiatry, 161 (5), 850-856.

Mittelman, Mary S. et al. (2004). "Effects of a Caregiver Intervention on Negative Caregiver Appraisals of Behavior Problems in Patients With Alzheimer's Disease: Results of a Randomized Trial." Journal of Gerontology: Psychological Sciences, 59B (1), P27-P34.

- These studies of family support indicate nursing home admission can be deferred with good family support.

Richard J. Mollot, JD. *Nurse Aide Training in New York: An Overview of Programs and Their Regulation by the State, with Recommendations for Improvement*. 2003. New York: Long Term Care Community Coalition.

- This article examines the impact of training on care and quality of life for nursing home residents. Better training can also improve conditions for the aides themselves.

Richard J. Mollot, JD. *Single Point of Entry for Long Term Care and Olmstead: An Introduction and National Perspective for Policy Makers, Consumers and Advocacy Organizations*. 2005. New York: The Long Term Care Community Coalition.

- This is a study on POE and *Olmstead* implementation examines strengths and weaknesses of different state activities across the U.S. With an eye to how they relate to New York State's unique situation.

Laurie E Powers, Jo-Ann Sowers, George H S Singer. "A Cross-Disability Analysis of Person Directed, Long-Term Services." Journal of Disability Policy Studies 17.2 (2006): 66-76.

- This article presents a cross-disability review of the common elements of person directed services, describes three primary types of models (personal assistance services, brokered support, and cash and counseling), and summarizes the research evidence related to their efficacy.

Marilyn J Rantz, Karen Dorman Marek, Mary Zwygart-Stauffacher. "The future of long-term care for the chronically ill." Nursing Administration Quarterly 1 Oct. 2000: 51-58.

- Consumers want long-term care that addresses six areas of concern: community-based services, continuity, coordination, caring, convenience and cost. The authors discuss how consumers and consumer advocates, working cooperatively with health care leaders, could reinvent home health care, nursing home care and other long term services.

Cynthia Rudder, Ph.D., Richard J. Mollot, JD., and Martin Sobel. *Nursing Home Residents at Risk: Failure of the New York State Nursing Home Survey and Complaint Systems*. 2005. New York: The Long Term Care Community Coalition.

- This study examines the effectiveness of the New York State inspection and complaint systems.

Cynthia Rudder, Ph.D. and Meghan Shineman. *Nursing Home Oversight in New York State: A Regional Assessment*. 2006. New York: The Long Term Care Community Coalition.

- This report, a follow-up to LTCCC's 2005 national report, examines the effectiveness of each New York state regional office in ensuring resident safety and quality of life.

Cynthia Rudder, Ph.D. *What Makes for a Good Working Condition for Nursing Home Staff: What Do Direct Care Workers Have to Say?* 2003. New York: The Long Term Care Community Coalition.

- In New York State, the nursing home staffing crisis is being reported as the worst in decades. Although there are many reasons for the problem, working conditions is a major factor. This paper is a description of a study conducted to discover, from workers themselves, what makes for good working conditions. It includes a tool to measure worker satisfaction.

Dorie Seavey, Ph.D., Steven L. Dawson and Carol Rodat. *Addressing New York City's Care Gap*. 2005. New York City: Paraprofessional Healthcare Institute.

- In this issue paper, the current state of New York City's labor market for home and community-based direct-care workers is reviewed and projected future conditions are projected.

David Barton Smith. *Reinventing Care: Assisted Living in New York City*. 2003. Nashville: Vanderbilt University Press.

- Smith's study draws on twenty-five years of research, including hundreds of

interviews and visits to representative facilities. He provides a succinct overview of how care is presently organized for New York's aging population and traces the history of the system up to the present. Among the key issues he addresses are the role of market forces and government regulation, the impact of class differences on access to quality care, and the ways in which perceptions of community affect the creation and management of assisted living programs.

Kimberly A. Steinhagen and Michael B. Friedman, LMSW. *The New York State Service System for Older Adults with Mental Health Needs*. 2006. New York: The Geriatric Mental Health Alliance of New York.

- This glossary explains terms used within the New York State Service System for Older Adults with Mental Health Needs.

Denise A Tyler, Victoria A Parker, Ryann L Engle, Gary H Brandeis, et al. "An Exploration of Job Design in Long-Term Care Facilities and its Effects on Nursing Employee Satisfaction." *Health Care Management Review* 31.2 (2006): 137-144.

- This study used quantitative and qualitative methods to examine the design of nursing jobs in long-term care facilities and the effect of job design on employee satisfaction.

Jennifer L Wolff, Judith D Kasper. "Caregivers of Frail Elders: Updating a National Profile." *The Gerontologist* 46.3 (2006): 344-356.

- This is a profile of family caregivers.

SELECTED WEBSITES

The Agency for Health Care Research & Quality

<http://www.ahrq.gov/research/longtrm1.htm>

As the lead federal agency charged with supporting and conducting health services research, the Agency for Health Care Policy and Research (AHRQ) undertakes and funds studies on long-term care.

This link provides a summary of: use, cost, and financing; access and quality of care; organization and delivery of care; consumer and caregiver behavior; special populations; data development and methodology. These sections include important selected findings and provide bibliographies, as well as a complete listing of long term-care research conducted and funded by AHCPR since 1990.

AARP (formerly American Association of Retired Persons)

www.aarp.org/research/longtermcare

AARP Policy & Research features authoritative information on issues affecting the 50+ population. This collection of research publications, speeches, legal briefs and opinion pieces seeks to provide deeper insight and fresh perspectives to opinion leaders, scholars and other professional audiences.

Center for Health Care Strategies

http://www.chcs.org/publications3960/publications_show.htm?doc_id=213770

The Center (CHCS) is a national non-profit organization devoted to improving the quality of health services for beneficiaries served by publicly financed care, especially those with chronic illnesses and disabilities.

Center for Personal Assistance Services

www.pascenter.org

The Center provides a range of information and data on long term care. For each state, including New York, the PAS Center has data on consumers, workers, and costs as well as information on *Olmstead* plans and lawsuits and other state-specific resources.

The Commonwealth Fund

http://www.cmwf.org/topics/topics.htm?attrib_id=11989

The Fund is a private foundation that aims to promote a high performing health care system that achieves better access, improved quality, and greater efficiency, particularly for society's most vulnerable. The above link is to an issue brief, "In Pursuit of Long-Term Care: Ensuring Access, Coverage, Quality." It discusses providing accessible, affordable, and high-quality long-term care services to an aging population as a growing challenge to long-term care providers. It also addresses concerns include how to provide an adequate mix of institutional care and home and community-based services and how to monitor the quality of services delivered in these settings.

Geriatric Mental Health Alliance of New York

<http://www.mhawestchester.org/advocates/geriatrichome.asp>

The Alliance advocates for changes in mental health practice and policy that are needed to improve current mental health services for older adults and to develop an adequate response to the mental health needs of the elder boom generation.

The Henry J. Kaiser Family Foundation

<http://www.kff.org/medicaid/upload/7485.pdf>

The Kaiser Family Foundation is a non-profit, private operating foundation focusing on the major health care issues facing the nation.

The link above is to the report, "Beyond Cash and Counseling: An Inventory of Individual Budget-based Community Long-Term Care Programs" describes the evolution of beneficiary managed home and community based services since the original demonstration and provides an overview of state activity as of January 2006.

Long Term Care Community Coalition (LTCCC)

www.ltccc.org
LTCCC is a coalition of consumer, civic and professional organizations, and individuals from across New York State. Its mission is to improve care for long term care beneficiaries, particularly in New York State through research, education and advocacy. LTCCC offers a wide range of publications related to long term care issues.

New York State Coalition for Adult Home Reform (NYSCAHR)

www.scaany.org/initiatives/AdultHomeReform.php

NYSCAHR works to assure that people with psychiatric disabilities living in adult homes are not ignored. The publications at this link address adult home reform.

US Department of Health and Human Services: Assistant Secretary for Planning and Evaluation

<http://aspe.hhs.gov/daltcp/reports/ltework.htm>

ASPE is the principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development, and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis. *The link above is to a report to congress on the future supply of long term care workers and how that relates to the aging "baby boomer" population.*

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This white paper has been prepared by the Long Term Care Community Coalition (LTCCC) which is devoted to improving care for the elderly and disabled. We work to ensure that long term care consumers, who are often very vulnerable, are cared for safely and treated with dignity.

LTCCC strives to improve care for the elderly and disabled in all settings. We encourage & help people to speak out on their own, and provide a voice for those who are too frail to advocate for themselves.

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