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LONG TERM CARE RESTRUCTURING IN NEW YORK STATE: A CONSUMER PERSPECTIVE

LTCCC LONG TERM CARE COMMUNITY COALITION

Working to improve long term care through research, education & advocacy

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EXECUTIVE SUMMARY:

The long term care system in New York State serves a population that is diverse in terms of health care needs as well as personal needs and desires. In addition, it provides a wide range of services in different settings, from around the clock care in nursing homes to personal care and assistance in an individual's private home or community. From a consumer perspective, however, though the system serves many people, it does not serve many of them well.

While there are many good nursing homes in New York, generally speaking they are understaffed and outmoded, providing substandard care and a quality of life that is institutional and dehumanizing for both the residents and direct care workers. In addition, despite the long-acknowledged fact that consumers strongly prefer to receive long term care (LTC) services outside of nursing homes (and have the legal right to receive care in the least restrictive setting possible for them as individuals), nursing homes continue to be over-used and over-populated by residents who don't want to be there and who could safely be cared for elsewhere if such an opportunity was available to them.

Home and community-based services are an attractive idea for most consumers but systemic complexity and problems with access are basic issues that prevent many consumers from availing themselves of these options. In addition to these basic, threshold issues, there are crucial issues relating to: (1) monitoring and oversight (e.g., how can the state ensure good care and consumer safety behind the closed doors of an individual's home?), (2) programmatic efficiency (is a particular program a good use of government funding?) and (3) the extent to which a program is successful in achieving its stated goals and the fundamental goals of most consumer: to receive the care, assistance and environment necessary to enable one to achieve his or her highest practicable physical, social and emotional well-being (including the ability to retain and

maintain autonomy and self-direction). The third issue area is the central focus of this report.

The report endeavors to provide a context for assessing the LTC system as a whole from a consumer perspective and present ideas and recommendations on how restructuring should be tailored to best meet the needs of consumers. Two resources are used as a basis for identifying major consumer priorities and preferences and for assessing LTC programs and restructuring proposals: (1) the Long Term Care Community Coalition's white paper on the future of long term care in New York, which identified a number of fundamental principles for the long term care system and (2) the results of a survey of long term care ombudsmen and consumers across New York State, conducted for this report. While financing is, of course, a crucial issue, the report does not focus on financial issues *per se*; the relative "efficiency" of home and community based vs. institutional services continues to be debated and will, undoubtedly, be an area of further study by scholars and economists for many years to come. The goal of this paper is to present a consumer perspective on programs and options that are plausible within the present financing context.

Based on the principals identified in LTCCC's earlier white paper – which center on the need to focus on and empower the three people at the heart of the LTC system, the consumer, the formal caregiver and the informal caregiver – survey participants were asked to evaluate whether the LTC programs that they are familiar with are meeting the white paper principals. Their responses are discussed in terms of the different residential and community based programs and their overall thoughts about the challenges facing the system. While many of the responses confirmed well-acknowledged issues, like the systems overreliance on a "medical model" and lack of sufficient trained direct care workers, a number of participants made "out-of-the-box" recommendations such as "making nursing homes without walls the norm instead of

institutionalizing a population we should revere" and "[Governor] Patterson appoints a NYS Contractor/Builder with a heart for the needy. No politics."

Understanding the consumer as a whole and tailoring care to each individual's needs and preferences is one of the principles from LTCCC's white paper on the future of long term care in New York State and, as the survey results revealed, consumer representatives from across the state believe this to be one of the most important principles. Thus, the discussion on LTC program evaluation is premised on the idea that the government should assess whether or not all of consumer needs (medical as well as emotional and social) are being met.

However, because the monitoring and evaluations currently being done may not be sufficient or reliable in this respect, it is difficult to determine the extent to which long term care programs are achieving their goals or standards, particularly the goals and standards that relate to issues concerning consumer self-direction, psycho-social well-being or access to committed and skilled care givers. While the state is responsible, under the auspices of the federal government, for monitoring and oversight of programs that are funded through Medicaid and/or Medicare, the focus of these efforts tends to deemphasize non-medical issues. Though it varies somewhat from state to state, our findings indicate that, on a national basis, there seems to be little evaluation of outcomes for most programs, particularly for home and community based services (HCBS). While the ultimate goals for community based programs are to provide care in a setting that maximizes the individual's level of functioning and quality of life, little is known about how well these goals are being met.

The final section looks at the experience of New York State in terms of the principal priorities for consumers (and the challenges to achieving them): the need to appropriately and accurately assess the consumer's needs and desires; the need to overcome access issues; the need for sufficient direct care workers who have the appropriate training and supports to do their jobs well; and the

need for meaningful consumer direction and control. Selected initiatives undertaken by other states that could be instructive for New York are discussed for each issue and recommendations for the state as it moves forward are presented.

CONSUMER PROFILE 1: HILDA SIEGEL

Hilda was born in New York City and currently lives in a nursing home in Nesconset, New York. She celebrated her 99th birthday in December 2008. Her children threw her a big party at a restaurant not far from her nursing home, which was attended by family and friends, including her many grandchildren and great grandchildren.

She came to live in the nursing home after she broke the femur bone in her leg last April. She can walk with a walker and help from an aide and needs assistance with things like dressing and showering.

Hilda finds living in the nursing home very difficult. She misses her privacy. The food is bland and not what she is accustomed to, so she often just has cheese sandwiches for lunch and even dinner. She told us that some of the aides are wonderful and caring, but others are rude and impatient. "Many times I have to wait an hour or more for an aide to assist me to the bathroom."

> "There are not enough aides for the number of residents…. The worst part is waiting for an aide when you need someone to help."

Neither the care she is receiving nor the place where she is receiving it enable Hilda to live her life to the fullest: "I am able to walk with a walker but because I need someone with me I only walk a few minutes 3 times a week. The recreation staff is very good. They keep us busy with bingo and other activities. The rest of the hours are empty. The worst part is waiting for an aide when you need someone to help."

INTRODUCTION

The long term care system in New York State and across the nation serves a population that is diverse in many significant ways: long term care (LTC) consumers have a wide range of health care needs; represent the full gamut of cultures, communities and age brackets; and have as diverse personal needs and desires as the population that does not need long term care. At the same time, the LTC system has evolved over the years to provide a wide range of services in different settings, from nursing homes to personal care and assistance in an individual's private home. Unfortunately, the complexity of the LTC system is not so much a response to the diverse needs, desires and abilities of the people it serves; rather, it is largely a result of different political and financial exigencies that occurred over the years. As a result, though the system serves many people, it does not serve many of them well.[1]

The purpose of this report is to provide a context for assessing the LTC system as a whole from a consumer perspective and to provide recommendations to stakeholders and policymakers for ways in which restructuring efforts can be tailored to best meet the needs of consumers. While there are some nursing homes that provide good care and quality of life for their residents, generally speaking nursing homes are understaffed and outmoded, providing sub-standard care and a quality of life that is institutional and dehumanizing for both the residents and direct care workers. Few nursing homes have implemented culture change or other efforts that promote resident directed

[1] An assessment of the history of the long term care system is beyond the scope of this policy brief. For a good and succinct discussion, see *Improving the Quality of Long Term Care* from the Institute of Medicine (www.iom.edu/Object.File/Master/4/136/LTC8pagerFINAL.pdf).

and resident centered care. The vast majority has staffing well below recognized standards. Direct care staff turnover rates continue to be astronomical. In addition, despite the long-acknowledged fact that consumers strongly prefer to receive LTC services outside of nursing homes (and have the legal right to receive care in the least restrictive setting possible for them as individuals), nursing homes continue to be over-used and over-populated by residents who don't want to be there and could safely be cared for elsewhere if such an opportunity was available to them.

"…though the system serves many people, it does not serve many of them well."

Similarly, though other residential care settings like adult homes and assisted living are supposed to provide a better (more home-like and self-directing) environment than a traditional nursing home, they are often only marginally better. These options are generally for individuals who need or desire to receive their care in a residential setting but do not need around the clock care. They encompass a variety of housing types, levels of service and payment options. For many years in New York, there has been a wide disparity between facilities that were licensed and those that were not, as well as between private pay and publicly funded facilities. The Assisted Living Reform Law of 2004 was supposed to address these issues, but its implementation has been slow in coming.[2]

Almost 50% of New York State's Medicaid long term care spending budget is spent on non-institutional care, which includes home health services, personal care services, case management, hospice, home and community-based care for the functionally disabled elderly, and services provided under home and

[2] As of May 2009 there are two lawsuits pending seeking to overturn the assisted living regulations promulgated as a result of the 2004 law. *See* LTCCC's assisted living information website, http://www.assisted-living411.org/, for more information on the state law and on these two lawsuits, filed by two groups of providers and provider associations.

community-based services waivers. While these home and community-based services are most attractive to consumers, systemic complexities and problems with access are threshold issues that prevent many consumers from availing themselves of these options. Beyond these threshold issues are other issues that are also critical, including: (1) monitoring and oversight, (2) programmatic efficiency (is a particular program a good use of government funding, which in many cases is a fixed amount) and (3) the extent to which a program is successful in achieving its stated goals and those of every consumer: to provide the care, assistance and environment necessary to enable the individual to achieve his or her highest practicable physical, social and emotional well-being (including the ability to retain and maintain autonomy and self-direction). This third issue area is the central focus of the present report.

BACKGROUND

New York State has been discussing long term care reform for a number of years. Reform is needed for a number of reasons:

- New York's long term care (LTC) system is comprehensive but complicated, with overlap among programs and services. There is a lack of consistency in how, when and where people with similar levels of needs are served;
- Policymakers and consumers have increasingly recognized that the state needs to make more progress in its compliance with the U.S. Supreme Court's *Olmstead* decision,[3] which held that states must provide care in the least restrictive setting possible for the individuals receiving care;
- The projected growth among New York's elderly population will create increased demand for LTC services[4]:
  - It is expected that the population of New Yorkers age 65 years and older will increase by 30.4% from 2000 to 2020;
  - Most will be cared for at home, signifying a change from traditional LTC settings and greater dependence on family and friends (both of which will change the system's dynamics);
  - A study by the U.S. Department of Health and Human Services indicates that people who reach age 65 will likely have a 40% chance of entering a nursing home.

[3] *Olmstead v. L.C.,* 1 19 S. Ct. 2176 (1999).

[4] Long Term Care in New York State, Presentation to LTC Restructuring Advisory Group, December 18, 2007.

- New York and the nation will experience a decline in the amount of potential caregivers over time;
- The state is under considerable pressure to maintain or reduce LTC spending and get the biggest "bang for the buck" from money spent.
  - By 2030 total Medicaid LTC expenditures for residents aged 65 and older are projected to increase over $5 billion or 45%;
  - New York spends nearly $8 billion for an array of home and community based programs and services and over $6 billion for skilled nursing facilities; [5]
  - Nursing homes can cost more than twice as much as home-based care, making the latter a potentially attractive option from a fiscal viewpoint.

Distribution of Medicaid Spending on Long Term Care, FY2007[6]

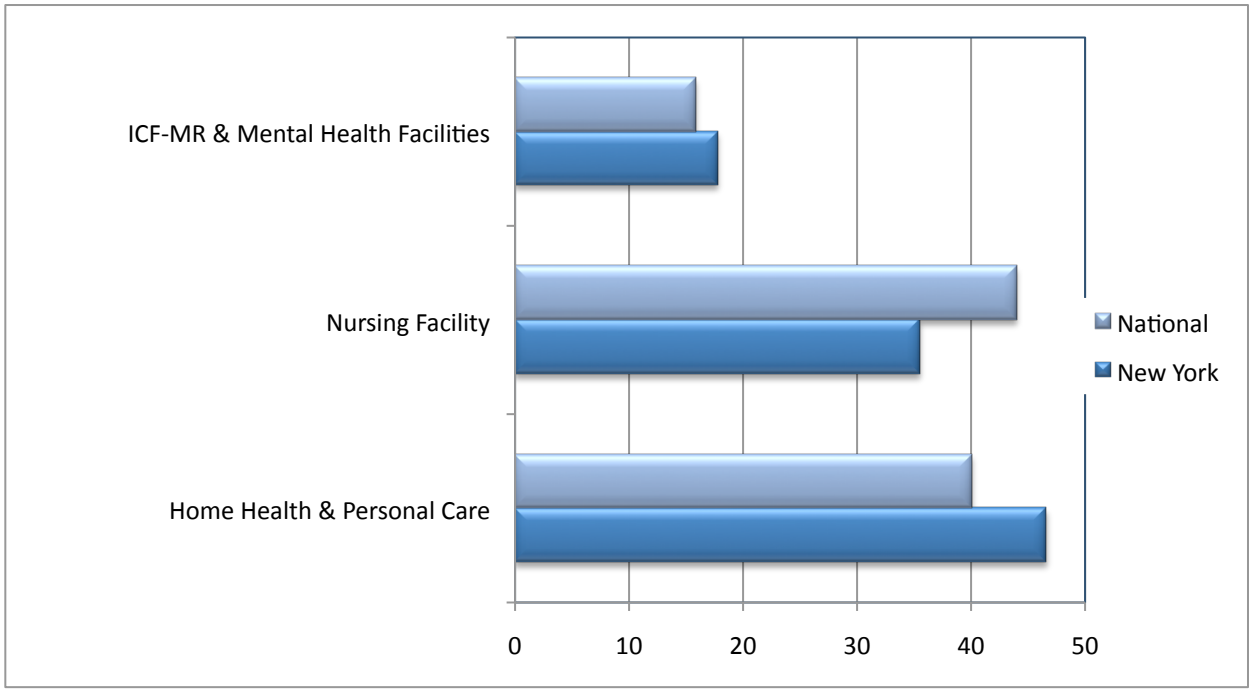

Figure 1

[5] *See* The Henry J. Kaiser Family Foundation, Individual State Profiles at www.statehealthfacts.org.

[6] *Ibid*. (Data Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on data from Centers for Medicare and Medicaid Services-64 reports, March 2009).

THE MEDICAID LONG TERM CARE SYSTEM IN NEW YORK STATE

The Medicaid program is the driving force behind long term care policy because it pays for a substantial percentage of long term care services and encompasses a vast array of services. There are 12 main Medicaid funded long term care programs in New York State. They can be divided into two principal categories: residential programs and community-based programs. Although a greater percentage of beneficiaries are enrolled in community-based programs, residential programs account for a larger portion of Medicaid spending. In 2007, for instance, Medicaid spent at total of 12.3 billion dollars on long term care; 53% of this was spent on residential programs and 47% went towards community based programs.[7]

"…both the quality and quantity of care are unevenly distributed."

The Medicaid long term care system is complex. Beyond the residential v. community-based division, it can be viewed as being made up of four different categories of programs: (1) Mandatory programs (known as entitlement programs, which every eligible individual is guaranteed access to); (2) Optional programs (consisting of services that the state is not required to provide, but if it chooses to provide them, it must do so for all eligible individuals); (3) Waiver programs (that have limited availability and strict eligibility criteria); and (4) Managed care programs. Most beneficiaries (80%) in New York State are enrolled in entitlement programs and consequently 86% of Medicaid long term care spending goes towards entitlement programs.

Direct care (such as assistance with meal preparation, bathing, feeding and mobility) is provided to beneficiaries in all of the programs. Coordination of care and skilled nursing, however, are not offered to all beneficiaries; they are only

[7] Alene Hokenstad, Meghan Shineman and Roger Auerbach, *An Overview of Medicaid Long Term Care Programs in New York*, Medicaid Institute at United Hospital Fund (2009). Henceforth, "UHFNY Study."

offered through certain programs. Having different programs allows beneficiaries to have more options. However, challenges with effective oversight (due to the multiplicity of providers and the various locations in which services are provided, as well as the different standards for direct care workers across the different programs) may have potential negative consequences[8] for individuals, as does service fragmentation: people may not be receiving all the services and care that they need. Instead they are often forced to choose a program that may not necessarily complement their desires or adequately meet their needs because that is all that is available to them. In sum, both the quality and quantity of care are unevenly distributed.

[8] *Ibid*.

CONSUMER PREFERENCES AND PRIORITIES FOR LONG TERM CARE

Though it is axiomatic to say that there are as many different preferences and priorities when it comes to long term care as there are long term care consumers, there are certain preferences and priorities that are virtually universal. Consumers who can live at home safely and have support, generally prefer to stay at home rather than going to a residential setting. Whether at home or in a nursing home, assisted living or other setting, the vast majority of people want to retain as much autonomy and self-direction as they are capable of. It is hard to imagine that there are any consumers that don't want to be treated with dignity and provided with the services they need to achieve their highest practicable physical, social and emotional well being.

This report uses two principal resources as a basis for identifying major consumer priorities and preferences and for assessing current LTC programs and restructuring proposals: (1) LTCCC's white paper on the future of long term care in New York, which identified a number of fundamental principles for the long term care system and (2) the results of a survey of long term care ombudsmen and consumers across New York State, conducted for this report.

LTCCC'S WHITE PAPER ON LONG TERM CARE

In 2006, the Long Term Care Community Coalition (LTCCC) published a white paper, *Developing a New and Better Long Term Care System in NY State*.[9] This white paper 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

[9] The white paper is available at: www.ltccc.org/publications/documents/WhitePaperFinal-corrected.pdf.

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 areas of expertise that contributed to the ideas outlined in the paper. Our advisory committee meetings were focused on helping to develop a long term care system which truly fulfills its fundamental purpose: to provide quality and compassionate 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.

The resulting paper presents numerous recommendations on how to improve the long term care system, based on the principle of empowering the consumer as well as his or her informal and formal caregivers. It presents a number of "guiding principles" for building a better LTC system:

- 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, in fact, highly institutional. 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.
- The present system must be improved as 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.
- 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.

SURVEY OF LTC CONSUMER REPRESENTATIVES

In the Fall of 2008 we conducted a survey of organizations from across the state that represent or work with long term care consumers to find out how they think the long term care programs that they are familiar with are functioning. The survey was designed to reflect the main concerns and priorities identified in LTCCC's white paper on the future of long term care (discussed above). It asked respondents to consider whether each of the main long term care programs in the state (from institutional care such as nursing homes to community-based care) meet the specific principles identified in our white paper. In addition, it asked respondents to evaluate the programs in terms of how well they function, meet the needs of consumers and permit consumers to be in the least restrictive

setting possible. Respondents were then asked to state possible obstacles to success and how to overcome them.

The survey was distributed to all of the local long term care ombudsman programs across New York, as well as consumer referral & counseling services and professional caregiver representatives (of care workers, not provider businesses) from across New York. As a result, the survey participants reflected a range of consumer stakeholders: the elderly, non-elderly disabled, people with AIDS/HIV, and people with mental health and/or cognitive disabilities. A total of fifty two (52) representatives participated in the survey (of 120 survey invitations sent out). This is a 43 percent response rate. Two-thirds (67.3%) of the participants were long term care ombudsmen, just under eight percent (7.7%) were long term care consumer groups and the remaining 25 percent represented referral and counselling services, disability advocacy, independent living centers, palliative care services and other advocacy/civic organizations.

A majority of the participants represented the elderly (73.1%), while 15.4% identified the non-elderly disabled as their constituency. Other constituencies represented among respondents included: dementia (5.8%), mentally ill (3.8%), people with AIDS and those with traumatic brain injury (1.9% each). The remaining participants (7.7%) represented the general population.

Foundational Questions

Ten years after the U.S. Supreme Court ruled that every consumer has the right to receive care in the least restrictive setting possible for them as individuals, a striking two-thirds of respondents (68.6%) reported that their constituents who need long term care are not able to access care in the least restrictive setting. As Figure 1 shows, the biggest reason cited for this is lack of knowledge by consumers and their loved ones about the services available to them. Approximately three quarters of the respondents (74.5%) felt that services were out there, but that the need for them exceeds their availability. For almost forty

percent (39.2%), basic lack of services was a barrier to their constituencies accessing care in the least restrictive setting possible.

Interestingly, one third of the respondents chose to write in about additional barriers beyond those listed in this question. A number of these related to housing issues, in particular the lack of affordable housing for LTC consumers in the community and problems with adult homes and assisted living, such as:

2. What are the obstacles (if any) to getting care in the least restrictive setting possible for your constituency? [Please check all that apply.]

	Response Percent	Response Count
Services are generally not available.	39.2%	20
Some services are available, but the need is greater than the availability.	74.5%	38
There is inadequate transportation for consumers to get to services (or for services to come to them).	47.1%	24
Lack of knowledge among consumers and loved ones about available services.	**80.4%**	**41**
Services are not culturally competent for some people who need them (e.g., there are people with language or cultural barriers that prevent them from accessing what is available).	31.4%	16
view Other (please specify).	33.3%	17
	answered question	51
	skipped question	1

Figure 2

- "Residents in Adult Homes are 'warehoused' with almost no help to better their living standards."
- "Once in a long-term care setting there are many roadblocks to getting the resident into a less restrictive setting - mostly the fear that the resident may injure him or herself. … Part of the problem is also money and lack of home care and assisted living environments."

Several respondents identified caregiver issues:

- "The lack of certified home health aides prohibit providing the 24-hour care most clients would require if in a community based setting (their own home)."

- "Can't always trust the care provider coming into the home."
- "The lack of trained, dementia specific workforce as caregivers. …[A]lthough there are some services available in less restrictive settings, it depends upon where you live in NY State, i.e., more is available downstate."

Financial issues were also a dominant theme, in particular the lack of services for those who cannot pay privately. One participant pointed to the need for more legal and lay advocacy to ensure and protect consumers' rights to care in less restrictive settings.

When asked about long term care system performance on a range of important criteria, from consumer choice to delivering "a bang for the buck," respondents' reactions varied significantly:

1. Please tell us how much you agree or disagree with the following statements about the long term care system.

	Strongly Agree	Moderately Agree	Moderately Disagree	Completely Disagree	Response Count
Provides the services that consumers need and want.	11.5% (6)	**48.1% (25)**	28.8% (15)	11.5% (6)	52
Enables people to get care in the setting they would prefer.	13.5% (7)	28.8% (15)	**34.6% (18)**	23.1% (12)	52
Delivers "a bang for the buck."	11.5% (6)	17.3% (9)	**40.4% (21)**	30.8% (16)	52
Provides access to long term care in the least restrictive setting possible for the individual.	15.4% (8)	26.9% (14)	**32.7% (17)**	25.0% (13)	52
Is easy for people to navigate.	11.5% (6)	17.3% (9)	32.7% (17)	**38.5% (20)**	52
Provides mechanisms to ensure that consumers are well informed.	13.7% (7)	23.5% (12)	**41.2% (21)**	21.6% (11)	51
Gives consumers choices about their care.	18.0% (9)	**28.0% (14)**	26.0% (13)	**28.0% (14)**	50
				answered question	**52**
				skipped question	**0**

Figure 3

A majority of respondents moderately or strongly agreed that the LTC system provides the services that consumers need and want. However, as the chart above indicates, a majority of respondents either moderately or completely disagreed that the LTC system was achieving any of the other goals listed. Delivering a "bang for the buck" and being easy to navigate were the two goals that respondents identified as being the least achieved by the current system (71.2% of respondents either completely or moderately disagreed with statements that the LTC system was accomplishing these goals).

The heart of the survey focused on the principles identified in LTCCC's white paper on the future of long term care, and how the reality of the system and specific programs within the system that participants are familiar with "measured up" against those principles.

1. Following are the eight principles identified in our white paper. Please rate them according to what you think their level of importance is.

	Very Important	Somewhat Important	Not Very Important	Response Count
The consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.	**94.0% (47)**	6.0% (3)	0.0% (0)	50
The consumer must have the primary role in directing his or her care when able.	**94.0% (47)**	6.0% (3)	0.0% (0)	50
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.	**98.0% (49)**	2.0% (1)	0.0% (0)	50
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.	**98.0% (49)**	2.0% (1)	0.0% (0)	50
Consumers must have adequate and appropriate options of where to receive services and by whom.	**92.0% (46)**	8.0% (4)	0.0% (0)	50
Consumers must have culturally competent long term care services.	**77.6% (38)**	22.4% (11)	0.0% (0)	49
Informal caregivers must be recognized as an important part of the long term care system.	**94.0% (47)**	6.0% (3)	0.0% (0)	50
Formal caregivers must be recognized for their central role in providing services.	**90.0% (45)**	10.0% (5)	0.0% (0)	50
Other (please tell us, in brief, if you believe there is an important long term care issue that is not identified here) view				9
			answered question	**50**
			skipped question	**2**

Figure 4

The first question on the white paper principles listed the principles and asked respondents to rate the importance of each. As Figure 3 shows, the overwhelming majority of respondents thought that each principle was very important. While it was expected that they would agree with the principles, this question was important to validate the findings of our white paper with the individuals who were taking this survey and also to give them a chance to consider the principles on their own before using them as a measure by which to judge the LTC programs that they are familiar with.

The following discussion focuses on how the survey participants rated the principal LTC programs in New York in terms of the white paper principles. To facilitate the discussion, it is broken up into two subsections: one addressing residential services and the other non-residential services. This discussion focuses on highlights and specific findings of interest in the survey. A copy of the full survey results (with the exception of comments that were handwritten) is included in an appendix to the report, available on our website, www.ltccc.org.

Survey Results for Residential Services

1. Consumer, informal caregiver and formal caregiver must all be involved in the process of planning for the consumer's care.

   A majority of those respondents with an opinion (answered "yes" or "no"), felt that nursing homes, ALPs (Medicaid Assisted Living Program) and assisted living residences met this principle, with assisted living having the highest percentage stating it met this principle. On the other hand a (slight) majority of respondents with an opinion felt that adult homes did not meet this principle. Given that this principle speaks to the core recommendation of the white paper – that the LTC system must move towards empowering the three central (and historically least empowered) people in the system: the consumer, the formal caregiver and the informal caregiver – it is clear that respondents felt

that adult homes have not been successful in achieving one of the essential goals of both: to provide LTC in an environment that allows for more autonomy and self-direction than in a traditional nursing home.

2. Consumer must have primary role in directing his or her care when able.

   The vast majority of respondents with an opinion (indicated yes or no) felt that adult homes, the ALP and assisted living all give the consumer the primary role in directing his or her care, while a small majority (52.4%) felt that nursing homes do not. This might have to do with the fact that nursing home residents are more frail and have more dementia; it is more challenging to create an environment where nursing home residents direct their own care.

3. 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.

   Fifty-seven percent of the respondents with an opinion felt that nursing homes do not meet this criterion, while being equally divided between yes and no for adult homes. The ALP fared better with a strong majority believing that the ALP and assisted living meeting this principle.

4. 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.

   The respondents were almost equally divided on whether any of the residential programs met this criterion, with a slight majority stating that they did meet the principle. Unsurprisingly, the slightest majority was for nursing homes, which are generally the least connected to an individual's community in the residential care settings.

5. Consumers must have culturally competent long term care services.

   The respondents with an opinion strongly believed that only assisted living met this principle.

6. Formal caregivers must be recognized for their central role in providing services *and* Informal caregivers must be recognized as an important part of the long term care system.

   Two of the white paper principles speak to the importance of the role of formal caregivers and informal caregivers. In terms of all of the residential settings, a majority of respondents indicated that, overall, the settings were meeting these principles (the two exceptions were the recognition of informal caregivers in adult homes, for which responses were evenly divided, and the ALP, where only one third believed it had met this principle). Since numerous studies have shown that care providers, especially direct care workers, tend to be undervalued in the system, this result is surprising. However, because the survey respondents were all consumer oriented, the results here might indicate a disconnect between consumers and those that work with them and caregivers.

Survey Results for Non-Residential LTC Services

Taken as a whole, the results for non-residential services provide some interesting insights into the respondents' impressions of the full range of programs. With the exception of the Lombardi Program/Long Term Home Health Care, the non-residential programs were perceived as being largely successful in meeting the white paper principles, except for the one involving cultural competency. Only the Consumer Directed Care Program and the EISEP program had a majority of those with an opinion responding they met this principle.

Combining the responses for all of the principles, as shown in the chart at right (Figure 4), a large majority of respondents indicated that these programs were meeting the principles (the "Yes" columns).

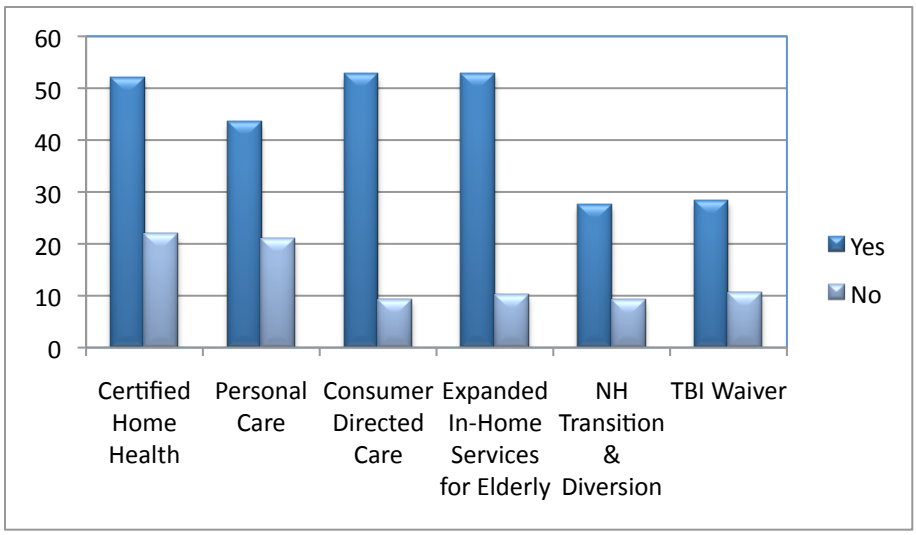

Figure 5

On the other hand, for the Lombardi Program, the responses were very mixed. While only a maximum of nine respondents gave an opinion on this program, most of them felt that the program was meeting the principles relating to formal and informal caregivers and for recognizing the right of the consumer to age in place. However, only one-third of respondents agreed that it was meeting the principle "Consumers must have adequate and appropriate options of where to receive services and by whom." For the non-residential programs in general, there was a greater lack of knowledge among those taking the survey. In particular, for the Medicaid Waiver Community-Based Programs (the TBI Waiver, the Lombardi Program and the Nursing Home Transition and Diversion Waiver), a majority of survey takers indicated that they did not know whether or not the program was meeting any of the white paper principles.

"focus on understanding the whole person, both physically and psychologically…"

Survey Conclusion

The last part of the survey focused on identifying and overcoming challenges.

Ranking of the LTC Principles: Survey participants were asked to once again review the principles of our white paper on the future of long term care, and rate which one they felt was most important. The number one choice (25%) was that the system should "focus on understanding the whole person, both physically and psychologically, and offer care tailored to each individual's strengths, needs and preferences." This was followed (at 20.5% vote each) by the need for consumers to be able to age in place and the concept that the consumer must have the primary role in directing his or her care, when able.

The Biggest Challenges: Participants were then asked to tell us the biggest challenges to realizing the principles. There were a number of reoccurring themes in their answers: lack of money or appropriate funding streams was often cited, as were inadequate workforce, inadequate availability of services (especially community based services) and lack of knowledge among consumers of available services. This question engendered a great deal of interest among respondents: of those that responded to the question (approximately 80% of the survey pool) close to 90% wrote in two challenges and almost three-quarters (71.8%) posited three challenges. In addition to the frequently cited issues (discussed above), there were a number of thoughtful and thought-provoking responses, such as:

- "not working with the consumer to identify their needs;"
- the system presenting too much of a "medical model;"
- "continuing paternalism;" and
- lack of holistic care.

Recommendations from Survey Participants: Lastly, the survey asked "What would you recommend as a systemic change to overcome the challenges you listed?" Here, too, the response rate was quite high and there were several recurring themes: increase resources for (and availability of) home and community-based services, implement staffing standards for all residential care settings; increase services in rural areas; and augment training for direct care staff in residential settings. As with the previous questions, this one also elicited many thoughtful and thought-provoking ideas:

"Truly embrace concept of person-centered care and choice."

- instill pride in staff;
- "improved monitoring of care providers sent into the home;"
- "upgrading old facilities (the physical plant as well as equipment);"
- "[Governor] Patterson appoints a NYS Contractor/Builder with a heart for the needy. No politics;"
- "making nursing homes without walls the norm instead of institutionalizing a population we should revere;"
- "Fund housing subsidies as part of the LTC system;" and
- "Improved information for the caregiver and or the consumer (if applicable), to understand their options."

CONSUMER PROFILE 2: WOODROW WILSON

Woodrow was born in Macon, Georgia. He now resides in an adult home in Yonkers, New York. He came to live in the home as a result of post-polio syndrome and advancing age. He is not happy to be there.

"I don't feel that the owner cares one bit for the residents of this home, and I also feel that most of the staff is unqualified for the positions they presently have," Woodrow said. He noted that things like recreation and food "could be much better" but "most importantly" he would like the chance to resume independent living. He made it clear that life in the adult home was a dehumanizing experience for him: "I would prefer if there was more personal care and thought given to the individual. Also, there should be qualified and

"…it could be worse; I could be in a ditch during a rainstorm."

independent workers (i.e., case managers, etc…) who assist in finding independent care instead of treating residents like prisoners or soulless objects…. I believe that the staff can and should be trained (and perhaps certified) a whole lot better than they are now. A licensed nurse or caregiver is a whole different type of person and worker, and can give better care than someone who came in off the street and is poorly trained…."

OVERVIEW OF MEDICAID LONG TERM CARE PROGRAMS IN NEW YORK STATE

RESIDENTIAL PROGRAMS:

There are two residential Medicaid-funded programs: nursing homes and the Medicaid Assisted Living Program (ALP). In 2007 approximately 81,000 or 33% of long term care beneficiaries were enrolled in residential programs in New York State. The total annual Medicaid expenditure for these programs was 6.6 billion dollars in 2007.[10] Following is a synopsis of the residential programs, including costs and positive and negative aspects of the programs for consumers. See the section, Long Term Care Program Evaluation and Assessment, for a discussion of how these programs have been assessed in terms of whether they meet consumer needs.

Nursing Homes:[11]

- Mandatory program.
- To be eligible, an individual must meet medical requirements for 24-hour care and supervision.
- Provides 24-hour care, meals and lodging, direct care (assistance with bathing, meal preparation, etc…), nursing supervision, social services, therapies (physical, occupational and speech) preventative care and dental services as needed or prescribed by a doctor.
- Reimbursed by risk adjusted capitated payments (Providers paid a monthly pre-determined amount and they receive more money for high risk consumers).
- In 2007, the program received 6.5 billion dollars from Medicaid and had 79,000 enrollees.

[10] Unless otherwise noted, the enrollment and spending data for this report were obtained from the UHFNY Study.

[11] See the DOH website for information about nursing homes, found at: http://www.health.state.ny.us/facilities/nursing/.

- Monitored by site inspections (conducted by the NY State Department of Health, DOH).
- Issues for Consumers: The purpose of the program is to provide a safe environment with supervised nursing and care. By law[12], nursing homes must honor and respect resident rights such as dignity, quality of care, freedom of choice and freedom to participate in activities of their choice. However, study after study has indicated that nursing homes consistently fail to meet this legal standard on a widespread basis. Nursing homes are notoriously institutional settings, often providing sub-standard care. Though a number of homes have made strides over the years to meet standards for both care and quality of life (such as many of those that are involved in the culture change movement), they are a small minority. Unfortunately for the consumer, access to culture change or resident-centered homes is rare, though nursing home care is often the only available option for long term care. This is especially true in rural areas of the state.

Medicaid Assisted Living Program (ALP): [13]

- Optional program.
- To be eligible, individual must require nursing home level of care but be able to be cared for safely in an adult home or enriched housing setting.

[12] Title 42 of Federal Regulations, Part 483, Requirements for States and Long Term Care Facilities (42CFR483) (available at http://www.access.gpo.gov/nara/cfr/waisidx_01/42cfr483_01.html). *See* also LTCCC's report, *Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them* (available at http://www.ltccc.org/publications/documents/Using_Law_and_Regulation_to_Protect_Nursing_Home_Residents_Updated_sept82006.doc).

[13] *See* the *New York State Medicaid Program Assisted Living Program (ALP) Manual* available at http://www.emedny.org/ProviderManuals/AssistedLiving/PDFS/ALP_Policy_Section.pdf. For more information about the laws and regulations, see NYCRR Title 18, Section 494.4, available on the DOH website, www.nyhealth.gov.

- Provides lodging and meals, direct care services, nursing services and therapies (physical, speech and occupational), and case management.
- Reimbursed by daily risk adjusted capitated payments.
- In 2007, the program received 79 million dollars from Medicaid and had 2,767 enrollees.
- Monitored by DOH.
- Issues for Consumers: The purpose of the program is to allow individuals who qualify for nursing home placement to live in a less institutionalized setting. However, many of the adult homes housing ALP programs are themselves very institutional settings, lacking privacy and opportunities for individual self-direction and autonomy. Therefore, to a large extent, the program is not fulfilling its purpose.

COMMUNITY BASED PROGRAMS:

Approximately two thirds of New York State's long term care beneficiaries (166,000 people in 2007) are enrolled in a community-based program.[14] The different programs, the services they provide, their positive aspects and points of concern for the consumer are discussed below. See the following section, Long Term Care Program Evaluation and Assessment, for discussion of how these programs have been assessed as to whether they meet consumer needs.

Traditional Care programs (PC or Home Attendant Program in NYC): [15]

- Optional program.
- To be eligible, individual must need assistance with at least one activity of daily living and must have physician's order sent to Local Department of Social Services (LDSS). A social and nursing assessment will then be arranged.

[14] UHFNY Study.
[15] See DOH website: http://www.nyhealth.gov/health_care/medicaid/program/longterm/pcs.htm.

- Provides direct care, with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) such as housekeeping, meal preparation, bathing and toileting or household chores (depending on the type of care needed, care is provided by home health aides, home attendants, personal attendants or certified nursing aides, hired and trained by a certified or licensed home care or nursing agency).
- Reimbursed by fee-for-service (providers paid for the number of visits or hours they provide).
- In 2007, the program received 2.2 billion dollars from Medicaid and had 57,000 enrollees (28,000 required nursing home level of care).
- Monitored by DOH.
- Issues for Consumers: The purpose of the program is to provide assistance to consumers with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) in their own home so they can remain in their home if they so wish. Access to this program, however, is not evenly distributed throughout the state. Due to lack of resources and home care workers, access is particularly limited in rural areas. In addition, although nursing home level of care is not an eligibility requirement for this program and skilled nursing is not provided, a study conducted by the United Hospital Fund revealed that two-thirds of personal care consumers had a comparable level of need to consumers in nursing homes. The level of need of consumers enrolled in this program may be higher than the range of assistance that this program can provide. In short, many consumers may not be receiving appropriate care.[16]

[16] UHFNY Study.

Consumer directed personal assistance programs:[17]

- Optional program.
- To be eligible, individual must need assistance with ADLs, have medical needs and have physician's order sent to LDSS, who will arrange for social and nursing assessment.
- Provides direct care or skilled nursing care to chronically ill or physically disabled individuals (care provided by home attendant, home health aide or a nurse, who are independent contractors).
- Consumers have flexibility in choosing their caregivers within certain parameters (see below).
- Recipients must be able and willing to make informed choices regarding the management of the services they receive, or have a legal guardian or designated relative or other adult able and willing to help make informed choices.
- The consumer or designee must also be responsible for recruiting, hiring, training, supervising and terminating caregivers, and must arrange for back-up coverage when necessary, arrange and coordinate other services; and keep payroll records.
- Reimbursed by fee-for-service.
- In 2007, the program received 300 million dollars from Medicaid and had 7,000 enrollees.
- Issues for Consumers: This program is different than the traditional Personal Care Program, in that it provides nursing services and gives power to the consumer by permitting him or her to recruit, choose and train the caregiver. Although the consumer is given this power, he or she must be capable of directing his or her own care or have a legal guardian, family member or another person willing and able to direct the consumer's care assist them. Applicants must state how they will

[17] http://www.health.state.ny.us/health_care/medicaid/program/longterm/cdpap.htm.

maintain their care if the aide is sick or on vacation, since there is no agency involvement. This responsibility may limit who can access the program (but allowing a guardian to direct the care allows consumers who cannot solve such problems to benefit from consumer directed care). Although consumers can choose their caregiver, there are some limitations. State regulations do not allow family members who have legal responsibility (spouses, parents, if the consumer is a minor) to become paid caregivers. Other relatives can become caregivers but they cannot reside with the consumer, unless the consumer requires full time care. In addition, not all counties provide this program and, in those that do, most LDSS does not inform consumers or family members of this option.[18]

Medical Adult Day Health Care (ADHC):[19]

- Optional program.
- To be eligible, consumers must be eligible for nursing home placement and have a physician's order for the daytime services. An interdisciplinary team of medical professionals then assesses the consumer's needs.
- Provides transportation, nursing, physical, occupational or speech therapy, nutritional and psychological assessments, rehabilitation and medical social services if nursing home level of care eligible (in New York State, most of these services are provided by nursing homes).
- Reimbursed by daily non-risk adjusted capitated payments per person.
- In 2007, the program received 300 million dollars from Medicaid and had 13,000 enrollees.

[18] Valerie J. Bogart, *Consumer Directed Assistance Program Offers Greater Autonomy To Recipients of Home Care*, New York State Bar Association Journal, Vol. 75, No. 1 (2003). Available at: http://onlineresources.wnylc.net/healthcare/docs/CDPAPBogartarticle.pdf.

[19] *See* DOH website http://www.health.state.ny.us/health_care/medicaid/program/longterm/addc.htm.

- The DOH is responsible for monitoring quality of care and standards for staff and admission assessments.
- Issues for Consumers: These programs were designed to enable people to get healthcare, social services and supervision in their communities. This can be particularly valuable for individuals who cannot get these services in their home or who desire a more social setting in their community. It can also help avoid nursing home or residential placement. On the negative side, some consumers may not like the concept of being an adult in "day care" or leaving their homes to receive services.[20] In addition, there is limited access to this program in many parts of the New York State, particularly in rural counties.[21]

Certified Home Health Agency (CHHA) services:[22]

- Mandatory program.
- To be eligible, individual must have referral from physicians or hospital discharge planners. Alternatively, consumers can contact visiting nurse providers.
- Provides part time, intermittent and long term health care and support services (including certain occupational, speech or physical therapy, arranging for medical supplies and equipment, care from home health aides or nursing aides).
- In some cases, Licensed Home Care Service Agencies contract with CHHAs (and LDSS) to provide services.[23]
- Reimbursed by fee for service.
- In 2007, the program received 1.3 billion dollars from Medicaid and had 41,000 enrollees.
- Monitored by DOH.

[20] http://www.longtermcarelink.net/eldercare/adult_day_care.htm.
[21] *See* report by New York State ADHC council, available at http://www.aahsa.org/article.aspx?id=6398.
[22] *See* DOH website. www.health.state.ny.us/health_care/medicaid/program/longterm/chhas.htm.
[23] Licensed home care agencies provide home care workers.

- Issues for Consumers: This program allows individuals to stay in their homes and receive ongoing care. However, similar to the situation with nursing homes, the monitoring by DOH may not be a reliable means of ensuring quality. In addition, there is limited access to this program in rural areas due to lack of resources, thus, although it is a mandatory program, access is not guaranteed.

Long Term Home Health Care Program (LTHHCP, also known as the Lombardi Program):[24]

- Waiver program.
- To be eligible, individual must be medically eligible for placement in a nursing home, but care costs cannot exceed 75% of the nursing home costs in the individual's county. Individuals apply for this program through the LDSS, or through a hospital discharge planner, but the county determines eligibility and LDSS authorizes services.
- Provides case management (by RNs), as well as direct care, skilled nursing services, speech, occupational, physical and respiratory therapy and dietary and medical social services. (No preventative services offered).
- Reimbursed by fee-for-service payments.
- In 2007, the program received 700 million dollars from Medicaid and had 24,000 enrollees.
- LDSS is responsible for assessing services and DOH surveys providers.
- Issues for Consumers: This program was designed to provide consumers with the opportunity to receive coordinated care without having to be placed in a nursing home. Its main goals are to prevent institutionalization or enable those who are institutionalized to return to the community and to reduce the costs associated with hospitalization

[24] *See* DOH website http://www.health.state.ny.us/health_care/medicaid/program/longterm/lthhc.htm.

due to case management and monitoring the consumer.[25] Although this program allows consumers to age in place, which is important, there are limitations on who can actually take advantage of this program. For example, if a consumer's care costs are too high, they may be discharged from the program and have to go into a nursing home. In addition, concerns have been raised that there are not adequate options of where consumers can receive these services, and the consumer does not have a primary role in directing his or her care.[26]

Medicaid Managed Long Term Care Program (MMLTC):[27]

- Provides mandatory and optional Medicaid services.
- To be eligible, individual must be eligible for placement in a nursing home and be able to stay safely at home at the time of joining the plan. The program can be accessed through a referral plan from a physician, another health care provider or through the LDSS, who verifies the appropriateness of the enrollment.
- Provides a wide range of services, including: care management, home care services, preventative care services, medical equipment, social day care, adult day health care and therapy and arrangements for nursing home care (but does not pay for nursing home care).
- Reimbursed by monthly non-risk adjusted capitated payments for Medicaid services.

[25] *Long Term Home Health Care Reference Manual*, available on the DOH website at http://www.health.state.ny.us/health_care/medicaid/reference/lthhcp/.
[26] *See* appendix for survey results.
[27] *See* DOH website http://www.health.state.ny.us/health_care/medicaid/program/longterm/mltc.htm and for more information on managed care, *see* http://www.health.state.ny.us/health_care/managed_care/mltc/aboutmltc.htm and *New York State's Consumer Guide to Managed Long-Term Care* available at: http://www.health.state.ny.us/health_care/managed_care/mltc/pdf/mltc_consumer_guide_08.pdf.

- In 2007, the program received 700 million dollars from Medicaid and had 20,000 enrollees.
- Monitored on an ongoing basis by performance reviews by the DOH.
- Issues for Consumers: Managed long term care was developed to fully integrate care and to meet this goal, it encompasses care coordination of services not covered under the plan such as Medicare services. It was also developed as a way to prevent people who need nursing home care from having to go to a nursing home and a way to keep costs down through capitation. However, the payments are not risk adjusted, which gives plans an incentive to "cherry pick" individuals with low care needs. In addition, since the plan only includes Medicaid services, it has less incentive to prevent acute care needs, which are paid for by Medicare. Consumers must also choose from a network of service providers for all covered services. There is also uneven access to managed care depending on region, since it and managed care in general are not available in all counties at this time.

Program for All-Inclusive Care for the Elderly (PACE):[28]

- Provides optional and mandatory Medicaid Services and Medicare primary and acute care services.
- To be eligible, individual must be nursing home level of care eligible and able to stay safely at home at the time of joining the plan (LDSS has responsibility of determining eligibility, enrollment and disenrollment).
- Provides services, determined by a team of doctors (including geriatricians), nurses and other health professionals. Offers social and medical services in adult day health centers, referral services, home

[28] *See New York State Managed Long Term Care Interim Report* to the governor and legislature available on DOH website, http://www.health.state.ny.us/health_care/managed_care/mltc/pdf/mltc_inter_rep.pdf.

care services, care management and acute care. PACE becomes consumer's only source of care and services.

- Reimbursed by monthly non-risk adjusted capitated payments from Medicaid and risk adjusted capitated monthly payments from Medicare. If an individual is not dually eligible, he or she must make up the difference in the costs.
- In 2007, the program received 100 million dollars from Medicaid and had 3,000 enrollees.
- Monitored on an ongoing basis by DOH.
- Issues for Consumers: By including Medicare and Medicaid services, these plans have more incentives to prevent both institutionalization for long term care needs as well as to prevent acute care problems. However, here too, the payments are not risk adjusted, therefore the same concerns listed above for MLTCPs (such as incentive to cherry pick clients) are an issue. Although PACE covers consumers' acute care needs, consumers are limited to a predetermined network of providers for all Medicare and Medicaid covered services. This limits consumer choice. In addition, access to this program is limited.[29]

Medicaid Advantage Plus: [30]

- Provides optional and mandatory Medicaid services and Medicare primary and acute care services. (A new program that began enrolling individuals in 2008).
- To be eligible, must be covered by Medicare and Medicaid and cannot be in a residential health care facility. Enroll with LDSS.
- Provides Medicare and Medicaid services (in some cases, there are co-pays), such as, inpatient hospital care as well as physician visits

[29] Pamela Nadash, "Two Models of Managed Long Term Care: Comparing PACE with Medicaid-only Plan", *The Gerontologist*, Vol. 44 (2004).
[30] www.health.state.ny.us/health_care/managed_care/docs/madv04_06.pdf.

(including substance abuse rehabilitation centers), nursing home care, home health services, podiatry services, chiropractor visits, ambulance services, vision care, dental and transportation services.

- Reimbursed by non risk adjusted capitated monthly payments from Medicaid and risk adjusted capitated monthly payments from Medicare.
- As of January 2009 had 408 enrollees.
- Monitored by DOH.
- Issues for Consumers: This is a new program that was also implemented to streamline costs, but unlike PACE and MMLTC, consumers must be dually eligible (Medicaid and Medicare). Because this is a new program, there is not much information about how well this program is meeting its goals or consumer goals. In terms of consumer choice, as is the case with all managed care, consumers are limited to a predetermined network of providers. In addition, there are restrictions on the services offered. For example, nursing home care is provided but only covered for 100 days per benefit period. Access is not yet available in all counties.[31]

Traumatic Brain Injury (TBI) Waiver program:[32]

- Waiver program.
- To be eligible, must be nursing home level of care eligible and be diagnosed with a TBI (or a related condition).
- Provides 11 Medicaid-funded services to assist participants to live in community-based settings and achieve maximum independence; these services are used in combination with existing Medicaid services.

[31] *See* contract available on DOH website http://www.health.state.ny.us/health_care/managed_care/docs/madv04_06.pdf.
[32] *See* DOH website http://www.health.state.ny.us/health_care/medicaid/program/longterm/tbi.htm.

- Services include care coordination to promote independence and prevent nursing home placement. In conjunction with the consumer, a service coordinator develops a care plan that meets consumers' needs and goals. DOH assists eligible individuals by subsidizing housing in order to create affordable housing options.
- In 2007, the program received 100 million dollars from Medicaid and had 2,000 enrollees.
- Providers are monitored by Regional Resource Development Specialists (RRDS) who are contracted by the DOH.
- Issues for Consumers: This program was developed as a strategy to prevent the need for nursing home placement. Consumers are provided with a choice, however, if they prefer to live in a community or a facility. Housing subsidies are available for those in need and who wish to remain in the community but resources are limited and they are provided on a first come first served basis. Many people with TBI are thus still relegated to institutions.[33]

Nursing Home Transition and Diversion Waiver (NHTD):[34]

- Waiver program.
- To be eligible, consumers must have proof of physical disabilities (letter from LDSS or physician required), need nursing home level of care and are able to live in the community.
- Assists consumers to transition from nursing home to community or can be used in order for the consumer to avoid nursing home placement.
- A service coordinator develops a specialized needs based service plan (services include assistive technology, counseling, one time services to help individuals transition back into the community and set

[33] *See* the profile of Terry Lawrence featured in this report. Terry had a TBI as a result of an accident and has had to go to another state to get adequate care.
[34] http://www.health.state.ny.us/facilities/long_term_care/waiver/nhtd_manual/index.htm.

up living arrangements, home delivered meals, internal or external adaptations to the home).

- The services have different fee restrictions and approval processes. Reimbursements are on a fee-for-service basis.
- Monitored by the Regional Resource Development Centers (RRDC) and Regional Resource Development Specialists (RRDS), who are contracted by the DOH.
- Issues for Consumers: This waiver program was developed with the philosophy that consumers of long term care have the right to control and manage their care and the services are provided based on the consumer's needs and goals. The care is consumer directed, which provides for the empowerment and self-direction that LTC consumers overwhelmingly seek to retain. However, because this is a waiver program, access is very limited. Most areas of the state do not have appropriate community-based services to provide for those individuals who are capable of transitioning and would want to. This includes a lack of appropriate and affordable housing options.

CONSUMER PROFILE 3: SYLVIA GOLDBERG

Sylvia was born in Warsaw, Poland. In her lifetime she has lived in the New York area, where she raised two daughters with her husband Sol. Most of her older adult life was spent in south Florida. After her two sisters died, while she was living in Florida, Sylvia suffered two back fractures and felt that she should return to New York to be closer to her daughters in case she needs their help. She currently resides in an assisted living facility in the Bronx.

Overall, Sylvia is unhappy with her situation. She is not so much dissatisfied with the health care services available in her assisted living – she does not require long term health care service. Rather, she finds that her quality of life is diminished. A loss of independence and feeling of uselessness are two of the biggest issues that she mentioned to us. This appears to directly contradict the fundamental purposes of assisted living: to provide a high quality of life and autonomy for individuals who don't have a need for a nursing home level of care but want the safety and services that assisted living can provide.

LONG TERM CARE PROGRAM EVALUATION & ASSESSMENT

Long term care consumers generally have a multitude of needs, as a result of both the multidimensional conditions that often result in the need for LTC and the multifaceted nature of all individuals, including those who depend on LTC services. Long term care programs, therefore, cannot focus solely on treating a specific ailment or condition. The individual receiving care has psychosocial needs that go beyond his or her medical issues that must also be recognized. For example, individuals receiving care in a residential setting are not just there to receive physical or nursing therapies, the facility is their home.[35] Individuals enrolled in the Traditional Personal Care Program may rely on home attendants to prepare their meals, bathe and toilet them, but their psychosocial needs also need to be met. They may not have relatives or friends to help them out and they may be missing personal relationships in their lives. They might feel a lack of control and self-direction that is exacerbated by the way their care is given.

> "Outside of nursing homes, little is known about the quality of care or outcomes of services provided by medically oriented home health agencies, and even less about the quality of social service oriented home-and community-based services."
>
> - Institute of Medicine, *Improving the Quality of Long-Term Care*, P. 6 (2001).

Understanding the consumer as a whole and tailoring care to each individual's needs and preferences is one of the principles from LTCCC's white paper on the future of long term care in New York State and, as the survey results revealed, consumer representatives from

[35] Institute of Medicine, *Improving the Quality of Care in Nursing Homes*, National Academy Press, p. 47, available at http://www.nap.edu/catalog.php?record_id=646 (1986). Hereinafter, the "IOM Nursing Home Report."

across the State believe this to be one of the most important principles.[36] Long term care program evaluations should assess whether or not all of consumer needs (medical, mental health & social) are being addressed. Because evaluations and assessments generally focus only on medical needs it is hard to determine how well long term care programs are achieving their goals or standards, particularly those that relate to qualitative issues, such as consumer self-direction, psycho-social well-being or access to committed and skilled care givers. While the state is responsible, under the auspices of the federal government, for monitoring and oversight of programs that are funded through Medicaid and/or Medicare, as indicated above these efforts tend to deemphasize non-medical outcomes.[37] Though it varies somewhat from state to state, on the whole there appears to be little evaluation of non-medical outcomes for most programs nationally, particularly those providing home and community based services (HCBS). For instance, the essential goals for community-based programs are to maintain or improve both the individual's level of physical functioning and quality of life. But little is known about how well these goals (the latter one particularly) are being met.[38] [39]

This section begins with a brief review of programmatic monitoring and assessment. It then presents overviews of several of the LTC programs that

[36] *See* appendix for full survey results, available on the Access to Care page of our website, http://www.ltccc.org/key/AccessToLongTermCare.shtml.

[37] While the merits and shortcomings of the oversight and surveillance system are beyond the scope of this paper, it is worth noting that the right to receive care in the least restrictive setting possible for the individual, and to be cared for in a way that enables people to achieve their highest practicable physical, mental and emotional well-being, are recognized in federal law. *See* LTCCC's nursing home website, www.nursinghome411.org, and the Resource section at the end of this paper for more information.

[38] Charlene Harrington, Terence Ng, Stephen H. Kaye, Robert Newcomer, *Home and Community Based Services: Public Policies to Improve Access, Costs and Quality*, University of California, San Francisco (2009).

[39] Institute of Medicine, *Improving the Quality of Long Term Care*, National Academy Press, available at http://www.nap.edu/catalog.php?record_id=9611 (2001). Hereinafter the "IOM Long Term Care Report."

provide a range of experiences in terms of their goals and different approaches to monitoring and evaluation.

STATE PROGRAM MONITORING:

In New York State, a division of the Department of Health (DOH), the Office of Long Term Care, is responsible for monitoring most of the Medicaid funded long term care programs and the Office of Health Insurance Programs is responsible for the Managed Long Term Care (MLTC) programs. Quality of care is evaluated mainly by site inspections.[40] Nursing homes are surveyed every 9 to 15 months and Certified Home Health Care Agencies (CHHAs) are surveyed every three years by DOH.[41]

EVALUATION OF CHHAS:

The quality performance of CHHAs is measured using a tool called the Outcome Assessment Information Set (OASIS). OASIS "was designed primarily to produce data that could be used in assessing the outcomes of care provided in the home setting, not as a comprehensive assessment instrument for use in planning patient care…"[42] Data from different home health agencies are collected and posted on the CMS website (www.medicare.gov) in order to allow consumers to compare providers.[43] Evaluation criteria include patient outcomes (defined as a change in condition or a lack of change during a specific timeframe of care). [44] CMS is currently undertaking an enhancement of OASIS, called OASIS C, which has been in development since 2005. It was finalized in early 2009 and, as of this writing, approval from the Office of Management and Budget is pending. According to the agency's filing in the Federal Register,

[40] UHFNY Study.
[41] Charlene Harrington, Terence Ng, Stephen H. Kaye, Robert Newcomer, *Home and Community Based Services: Public Policies to Improve Access, Costs and Quality*, University of California, San Francisco (2009).
[42] IOM Long-Term Care Report, p.120.
[43] *See* the CMS website at http://www.cms.hhs.gov/HomeHealthQualityInits/.
[44] *See* the CMS website at http://www.cms.hhs.gov/HomeHealthQualityInits/10_HHQIQualityMeasures.asp#TopOfPage.

> "The revision of the OASIS instrument is an opportunity to consider various components of quality care and how patients might be better served as they (and information about them and their care) move among health care settings. For this reason, the OASIS C includes process items that support measurement of evidence-based practices across the post-acute care spectrum that have been shown to prevent exacerbation of serious conditions, can improve care received by individual patients, and can provide guidance to agencies on how to improve care…."[45]

The CHHAs also have to follow federal training standards for direct care workers. Other HCBS do not.[46]

Only 43% of those surveyed by LTCCC agreed that CHHAs focus on consumer's physical and psychological needs and provide care that is tailored to each individual.[47] In addition, the direct care staff turnover rate is approximately 40-50 percent in New York State, which raises concerns regarding the quality of care being afforded to consumers, including:

1. The consumer may not be receiving consistent care.
2. Each caregiver may have a different style that the consumer is not used to and may not like.
3. The high turnover rate suggests dissatisfaction amongst the direct care workforce. If direct care workers are dissatisfied in their jobs, this will likely be reflected in the care they provide.

[45] Federal Register, Vol. 74, No. 44, March 9, 2009 at 10050.
[46] Charlene Harrington, Terence Ng, Stephen H. Kaye, Robert Newcomer, *Home and Community Based Services: Public Policies to Improve Access, Costs and Quality.* University of California, San Francisco (2009).
[47] *See* survey results in appendix, available at www.ltccc.org/key/AccessToLongTermCare.shtml.

EVALUATION OF NURSING HOMES:

Quality of care and resident life are evaluated in nursing homes by site inspections conducted by the State, under the auspices of CMS. Information gathered from these inspections, as well as staffing and quality data is made available to consumers on CMS' Nursing Home Compare website[48] and on New York State's Nursing Home Profile website.[49] It is important to note that because the quality data and staffing data listed on the website are largely self-reported by individual facilities to the federal government, there are questions as to their accuracy. The state also assesses nursing home performance through complaints that have been filed by residents, family members, ombudsmen and facility personnel with DOH. Although the survey process includes speaking with residents and family members, little formal evaluation has been conducted of how effective this requirement is. In addition, the survey and complaint system itself has long been identified as having problems relating to its ability to accurately and effectively identify problems.[50]

The Institute of Medicine (IOM) conducted an important study on nursing homes in 1986 that revealed a variety of problems and exposed surveys as being unreliable and lacking in validity in a number of important ways.[51] Although the study is two decades old, unfortunately for consumers, many of these problems persist. Poor providers are still operating and residents still suffer from conditions such as malnutrition, pressure sores, urinary incontinence and pain, not to mention lack of dignity and dehumanizing conditions.[52]

According to IOM, the survey process should be more outcome oriented and consumer centered to measure performance properly. Following are some of

[48] *See* the CMS website at http://www.medicare.gov/.
[49] *See* DOH website at http://nursinghomes.nyhealth.gov/.
[50] *See* LTCCC's reports: *Nursing Home Oversight in New York State: A Regional Assessment* (2006) and *Nursing Home Residents at Risk: Failure of the NYS Nursing Home Survey and Complaint Systems* (2005).
[51] IOM Nursing Home Report.
[52] IOM Long Term Care Report.

the recommendations IOM made in 1986 to improve the survey process. They are still meaningful today:

- The DOH should "surprise" providers as much as possible.
- Frequency of the surveys should be based on the providers' quality of care history and major changes, such as new ownership or administration (in addition to the standard annual surveys).
- It is ineffective to spend equal time in poor performing and good performing nursing homes. Poor performers require more attention.
- Surveys should be centered on the residents and resident interviews, rather than self reported provider information.
- The care being provided to the residents should be scrutinized more thoroughly. Inspection of resident care reviews should be more fully incorporated in the survey process.
- There should be coordination and sharing of information between those responsible for reviewing the survey information and those who review the filed complaints.
- It is important to ensure that the facilities are safe and sanitary, but more focus is needed on resident centered and outcome assessments. Key indicators need to be developed to measure if the outcomes are appropriate or inappropriate.
- The federal government should put a greater effort into ensuring survey staff are properly trained and monitored.

In order to more effectively address the problem of nursing facilities being allowed to operate despite long-term and significant problems, CMS recently initiated the Special Focus Facility Program, which identifies facilities that have a long record of poor care and "yo-yo" compliance with regulations. These facilities are given focused attention with increased monitoring. They face closure if they do not institute systemic improvements. LTCCC and other

consumer organizations strongly supported this initiative. However, we were disappointed to learn that it only focuses on a very small minority of the nursing homes that have long term significant problems. Therefore its impact is, necessarily, quite limited.

EVALUATION OF THE NHTD WAIVER:

Monitoring of the NHTD (Nursing Home Transition and Diversion) waiver program is unique in the sense that DOH relies on other health specialists and organizations to monitor quality and regional needs. DOH contracts with Regional Resource Development Centers (RRDCs) which, according to DOH, are each "responsible for managing the waiver with an emphasis on ensuring participant choice, availability of waiver service providers, and cost effectiveness of waiver services within its contracted region." They are supposed to ensure that program participants can live as independently as possible and inform the DOH about regional needs and quality assurance improvements.[53] To help them meet their goals and provide monitoring, each RRDC must hire a registered nurse evaluator. Functioning, in a sense, above the RRDCs are Quality Management Specialists (QMSs) that DOH contracts with on a regional basis (three in NY State) to work specifically on quality issues. They are given access to all provider records relating to waiver activities and have the right to meet with participants (consumers) at any time (with the participant's consent). The QMS liaises with DOH, the RRDCs, nurse evaluators, and waiver participants to ensure quality through a variety of activities including: reporting on and monitoring incidents of abuse or neglect (including follow-up contacts with the participant and/or legal guardian to assure satisfaction with outcome of investigation) and providing ongoing quality monitoring (including annual participant satisfaction surveys). The DOH Waiver Management Staff (WMS) has the overall responsibility for overseeing quality of program services. In addition,

[53] *See* the NHTD Program Manual available at http://www.health.state.ny.us/facilities/long_term_care/waiver/nhtd_manual/index.htm.

there is a Quality Advisory Board that provides an ongoing (at least twice yearly) forum for data sharing. The Board is "designed to keep waiver participants, stakeholders, advocates and community representatives informed and involved in the process for change or improvement to the NHTD waiver program."[54]

Although there is an extensive and ongoing evaluation process for this program, there are still some concerns. The underlying philosophy of this program is to allow consumers to control and manage their own care, however, only twenty eight percent of LTCCC's survey respondents (out of those who knew) agreed that consumers have the primary role of directing their own care, when able to. Moreover, even though consumer needs are assessed in order to develop a care plan, only twenty seven percent of respondents agreed that the system understands the individual as a whole, taking into account his or her physical and psychosocial needs.[55] These results indicate that improvements in quality of care, from the consumer perspective, are necessary.

EVALUATION OF MANAGED LONG TERM CARE:

Quality of service in managed long term care programs is monitored through random site visits, complaint investigations and by the review of financial statements. Managed long term care programs are required to meet the same standards as HMOs. DOH's Division of Managed Care and the Division of Quality and Evaluation are responsible for ensuring that HMOs follow the set rules and regulations.[56] If individuals have a complaint, depending on the issue, they need to either file a grievance or an appeal.

[54] *Ibid*.
[55] *See* survey results in appendix.
[56] *See* the DOH website at www.health.state.ny.us/health_care/managed_care/providers/index.htm.

IPRO, the quality improvement organization for New York State[57] conducted a Medicaid Managed Long Term Care consumer satisfaction survey, in order to provide information to DOH regarding the value of these programs in terms of quality, access and response time for complaints. The survey compared beneficiaries enrolled in different health plans and they were grouped by plan model (PACE or partially capitated plans), age group, ethnicity and race. Over 4000 surveys were initially sent out but the findings are based on fewer participants (the response rate was 33.5%).[58]

Managed long term care plans appear to incorporate some consumer directed care and to positively influence consumers' quality of life. In particular, 75.9% of PACE respondents and 76.6% of partially capitated plan (MMLTC) respondents felt as though they were usually involved in decisions regarding their own care. In addition, 83.6% of PACE respondents and 83.7% of partially capitated plan respondents felt that their plan helped them manage their illness. Although this indicates that these programs have certain advantages, there is still room for improvement, particularly in the area of complaint resolution. Less than half of the respondents reported filing official grievances or appeals (43% of PACE enrollees and 37.3% of partially capitated plan enrollees), but out of those who did only 41.5% of partially capitated plan enrollees were satisfied with the response they received (those who were enrolled in PACE fared a little better with 48.8% satisfaction).[59] Although there is a system and process set up for complaints, unsatisfactory situations are not always dealt with. Managed care allows consumers to be a part of the planning process for their own care, but the large percentage of complaints that consumers felt were not satisfactorily

[57] QIOs (quality improvement organizations) provide information to the public on home health agency performance to help make consumers aware of provider performance and encourage providers to improve quality.
[58] *See* IPRO *Managed Long Term Care (MLTC) Plan Membership Satisfaction Survey Report* available at http://www.health.state.ny.us/health_care/managed_care/mltc/pdf/dmc_mltc_survey.pdf.
[59] *Id*.

resolved indicates that consumer needs and priorities may be under-recognized.

EVALUATIONS FROM OTHER STATES/CURRENT NATIONAL MULTI-YEAR PROJECT:

Though the importance of consumer directed and centered care is widely acknowledged, these values have not been well measured to date. As noted earlier, program assessments tend to focus on medical outcomes with little attention paid to psycho-social outcomes. Following are brief examples of some state efforts to measure consumer self-direction and satisfaction and an overview of a federal effort to holistically assess home and community based services.[60]

- Consumer direction studies
    1. Studies confirm that consumer direction leads to perceived consumer empowerment, better quality of life and consumer satisfaction. A study conducted in Arkansas demonstrated that 64% of consumers enrolled in consumer directed HCBS programs were very satisfied, compared to 47% of consumers enrolled in agency directed HCBS programs.[61]
    2. Similarly, it was found that Medicaid consumers in Washington State who were enrolled in consumer directed programs were more satisfied than consumers enrolled in agency directed programs.[62]
- Quality of care evaluations

[60] *See* the footnotes accompanying the discussion and the Reference section at the end of the report for more details.

[61] *See Reforming Long Term Care Services in New York State Center for Disability Rights Position Paper*, available at http://www.cdrnys.org/index.php?option=com_content&view=article&id=138:reforming-long-term-care-services-in-new-york-state-center-for-disability-rights-position-paper-&catid=17:blogs-recent&Itemid=24.

[62] *See* summary report from Meeting the Nation's Needs for Personal Assistance Services State of the Science Conference National Press Club, Washington, D.C. April 27, 2007 at http://pascenter.org/documents/SOS_Conf_Summary.pdf.

1. In Minnesota, nursing homes receive a report card based on quality of care indicators. The results are made public, with the hopes that nursing homes will aim for the high scores and good results, meaning their quality will be improved. In addition to state inspection results the report cards measure quality of care and resident satisfaction. Residents are interviewed in order to measure criteria such as, dignity, privacy, autonomy, security, comfort, etc… Efforts are made to ensure consistent data reporting and the results are risk adjusted, to control for resident characteristics that do not account for provider performance.[63]
2. Maine has developed quality indicators across HCBS programs. State officials explain that these indicators will allow for an assessment of the programs as well as measure program outcomes and consumer satisfaction.[64]

- Federal Project: the Measure Scan Project
    1. It is widely recognized that evaluation criteria need to be identified to measure the effectiveness of HCBS. Currently, the Agency for Healthcare Research and Quality (AHRQ, the lead federal agency charged with healthcare quality, efficiency, safety and effectiveness), is conducting the Measure Scan Project, a multi-year effort to identify and evaluate measures and instruments that could be used, or adapted for use, in assessing the quality of home and community-based services offered under state Medicaid programs and the patient outcomes associated with receiving HCBS under Medicaid.

[63] *See* LTCCC's report, *Modifying the Case-Mix Medicaid Nursing Home System to Encourage Quality, Access and Efficiency*, available at http://nursinghome411.org/documents/finalreportMar.pdf.
[64] E. Kassner, S. Reinhard, W. Fox-Grage, A. Houser and J. Accius, *A Balancing Act: State Long Term Care Reform*, P.73, AARP Public Policy Institute, available at http://www.aarp.org/research/longtermcare/programfunding/2008_10_ltc.html (2008).

2. According to the agency's website, AHRQ is working in consultation with stakeholders to: "Develop program performance indicators, client function indicators, and measures of client satisfaction… use these indicators and measures to assess HCBS and their associated outcomes and to assess each State's overall system of providing these services… [and make available to the public] any best practices identified and the results of a comparative analysis of system features for each State."[65]
3. This is part of a larger "Quality of Care Measures" effort mandated by Congress in the Deficit Reduction Act of 2005. The effort is expected to run through 2010.
4. The Measure Scan Project Team includes: the Centers for Medicare & Medicaid Services, the Administration on Aging as well as a number of outside experts and substantive reviewers.
5. A 23-member Technical Expert Panel has been assembled to advise the Project Team on the methodology for collecting measures and on the criteria for evaluating them.

[65] http://www.ahrq.gov/research/ltc/hcbs.htm.

CURRENT NY STATE PLANS & PROPOSALS: DO THEY MESH WITH CONSUMER GOALS?

Following is a brief review of three current proposals and plans relating to LTC restructuring that could be especially meaningful for consumers.

Nursing Home Value-Based Purchasing Demonstration

- NYS is one of four states across the country chosen by CMS for this demonstration program.
- Scheduled start: June 2009, three year duration.
- Major goal: determine if financial rewards to highly performing nursing homes and improving nursing homes (on a variety of criteria) result in fewer resident hospitalization (and, by inference, better resident outcomes).
- Issues for consumers: the demonstration is well-rounded in the criteria used to make awards, based on four "domains" - staffing, appropriate hospitalizations, MDS outcomes, and survey deficiencies. This is a significant improvement over typical pay for performance type initiatives, which often focus on single or very limited criteria. However, resident satisfaction and quality of life should be essential components of any so-called value based purchasing initiative. In addition, such programs should be integrated into nursing home reimbursement so that nursing homes are paid for meeting standards, not merely receiving bonuses for coming closer to the minimum standards that they are already being paid to achieve.[66]
- www.nhvbp.com.

[66] *See* LTCCC's report, *Modifying the Case-Mix Medicaid Nursing Home System to Encourage Quality, Access and Efficiency* (http://nursinghome411.org/ModifyingtheCase-MixMedicaidNursingHomeSystemtoEncourageQualityAccessandEfficiency.htm) (2009).

Downsize Nursing Homes by 6000 beds/Increase Medicaid Affordable Assisted Living Program (the "ALP Program")

- The NYS budget approved in Spring 2009 included a provision to downsize nursing home capacity across the state by 6000 beds over the next five years and increase the ALP program by 6000 beds.
- Issues for consumers: The general idea of this initiative – to lessen dependence on nursing home care and increase access to assisted living – is in line with consumer desire to access LTC in less restrictive and more home-like settings. However, the fatal flaw in this plan is that the ALP program, for the vast majority of participants, is not providing the type of environment or quality of life that are recognized aspects of assisted living. This is due to the fact that ALP "beds" are housed in adult homes, many of which are highly institutional settings. New York passed an assisted living law in 2004 that sets forth important minimum standards. From a consumer perspective, it is crucial that state-funded assisted living meet the basic standards recognized by the state.
- In April 2009, NYS Assemblyman Richard Gottfried introduced legislation that would apply the consumer protections of an "enhanced assisted living residence" (EALR) as described in the Assisted Living Law and basic assisted living requirements to new ALP beds and to all ALP beds over time.

Money Follows the Person Federal Rebalancing Demonstration Program

- In January 2007, CMS approved New York's application to participate in the Money Follows the Person Federal Rebalancing Demonstration Program (MFP) that will provide enhanced Federal Medical Assistance Percentage (FMAP) reimbursement for select services for one year to people who have resided in a nursing home for at least six months, were in receipt of Medicaid for at least one month prior to transitioning from the

nursing home and are transitioning into a qualified residence.

- Program goal: encourage deinstitutionalization efforts and "facilitate ongoing systems change that will assure that individuals have access to community-based services when they are in need of long term care (LTC) supports."[67]
- Issues for consumers: This addresses the major issue for consumers of getting care in the least restrictive setting possible. However, it does not address issues related to availability of either non-institutional services or appropriate and affordable housing options.

[67] RFA Number #0903030430, New York State Department of Health, Office of Long Term Care, Division of Home and Community Based Services, Bureau of Medicaid Long Term Care Waivers (http://www.health.state.ny.us/funding/rfa/0903030430/0903030430.pdf). *See* the program announcement on CMS's website (http://www.cms.hhs.gov/NewFreedomInitiative/downloads/MFP_2007_Announcement.pdf) for more information.

CONSUMER PROFILE 4: TERRY LAWRENCE

Terry was born in Ellenville, NY and continues to make his home there with his wife Kim. However, he is currently residing in a nursing home because of an injury he suffered in an accident in October 2003, which resulted in traumatic brain injury. He is getting good care, but the facility is out of state. Being so far from home has caused him and his family tremendous suffering.

"You don't know the feeling I get every time they call and put Terry on the phone and all he wants to do is come home. It is heartbreaking," says Kim. Terry went to two different facilities in New York State, but neither was able to meet his needs. According to Kim, "The care Terry received at Northeast Center for Special Care and Charles Bishop Maclean Nursing Home was substandard.... I believe the so-called treatment at those facilities made his condition worse. He was chemically restrained at N.E. and left to wander alone in C.B.M. with the administration trying to have him committed to a psychiatric center…

Terry has been in a Massachusetts facility for two years now. I am very happy he is in a facility that truly cares about him and his rehabilitation, and [is] not just warehousing him. Terry has made amazing accomplishments and has a somewhat quality of life, whereas N.E. Center constantly told me and his family that he would never get any better. What kind of attitude is this for a so-called top notch TBI [traumatic brain injury] facility in the country?"

Kim told us that, as a life-long resident of New York, "I feel the state has let us down in providing support and care for Terry and his family. There are over 400 NY State residents who are warehoused out of state who need to come home also. Most of… [those] I have met have not had visits from family and friends because of the distance and expense to travel."

OVERCOMING CHALLENGES TO APPROPRIATE CARE IN APPROPRIATE SETTINGS: MAJOR ISSUES & RECOMMENDATIONS FOR OVERCOMING THEM

The systemic friction that exists between institutional and non institutional long term care is becoming more and more apparent in New York State and across the nation as the diversity of consumer needs, and the validity of the consumer's right to receive care from a system tailored to their needs (rather than vice versa), are more widely recognized. States have recognized and sought to address these issues in different ways. As a result, the ratio of residential versus Home and Community Based Services (HCBS), the types of HCBS available and the extent to which these services are available to consumers differ greatly from state to state.

As previous sections of this report have discussed, consumers want and are entitled to a choice of services but the resources necessary to provide adequate choice are often not available. Historically, institutional services have received more Medicaid financing, though in recent years states have focused on expanding HCBS.[68] From a consumer perspective, long term care funding needs to become more balanced and restructuring outcomes must include sufficient opportunities for consumer choice and direction. Mechanisms for determining service needs – both for individual consumers and for systemic policy implementation – must not only ensure that health care needs are safely met but also that consumers' legally-recognized rights to maintain autonomy, dignity and independence are fulfilled.

This section looks at the experience of New York State in terms of the principal priorities for consumers and challenges to achieving those priorities: the need to

[68] Enid Kassner, Susan Reinhard, Wendy Fox-Grage, Ari Houser and Jean Accius, *A Balancing Act: State Long Term Care Reform*, AARP Public Policy Institute, pp.6-9, available at assets.aarp.org/rgcenter/il/2008_10_ltc.pdf (2008).

appropriately and accurately assess the consumer's needs and desires; the need to overcome access issues; the need for sufficient direct care workers who have the appropriate training and supports to do their jobs; and the need for meaningful consumer direction and control. Selected initiatives undertaken by other states that could be instructive for New York are discussed for each issue and recommendations for the state as it moves forward are presented.

Measuring Consumers' Need and Desires

Issue: Many consumers of long term care enter the system after hospitalization. Upon their discharge, they are usually not given much choice regarding LTC programs or preferences of setting in which to receive care.[69] To be eligible for long term care services, consumers must demonstrate that they require assistance with direct care tasks, due to a functional, cognitive or medical impairment. Often, long term care consumers have a variety of needs and, although other eligibility indicators exist, programs often determine eligibility based on nursing home level of care. Each program uses a different assessment tool and consequently the definition of nursing home level of care is not consistent across programs.[70] The lack of a standard definition and of a uniform assessment tool to determine consumers' needs makes it difficult to determine if consumers are accessing the right program. According to a study conducted by the United Hospital Fund in 1995, two-thirds of personal care consumers in New York City had a level of needs that was equivalent to the level of needs of nursing home residents, in terms of functional and cognitive impairment.[71] It is thus unclear if consumers are accessing programs that are appropriate and tailored to their needs.

[69] Charlene Harrington, Terence Ng, Stephen H. Kaye, Robert Newcomer, *Home and Community Based Services: Public Policies to Improve Access, Costs and Quality,* P.5, University of California (2009).
[70] UHFNY Study.
[71] *Ibid*.

Potential Remedies: In order to ensure that long term care consumers are accessing appropriate care, it is fundamental that they are appropriately assessed, in terms of their needs and abilities, and that there is a connection between the assessment results and program eligibility. One potential solution is to have a uniform assessment tool for consumers and standardized eligibility criteria (based on consumer need and preferences) for each program. The NY State budget passed for 2009-10 includes $5 million for the creation of state-wide tool to evaluate an individual's care needs, determine program eligibility and generate care options for him or her. From a consumer perspective, there are both pluses and minuses to such a system. On the one hand, in addition to ensuring that a consumer's needs and desires are appropriately identified, a standardized instrument can save the consumer time and frustration that would accompany having to fill out a different form for different providers or for different programs that they access. Likewise, once a uniform tool is developed and implemented statewide, it has the potential to lead to a more efficient use of state resources. On the other hand, it is crucial that the tool is designed to provide enough flexibility so that it is truly suitable for all consumers and does not pigeonhole their needs and desires.

The experience in Iowa could be instructive on this issue. Iowa has developed new eligibility standards for nursing homes and HCBS. In order to qualify for nursing home care, an individual must require assistance with three or more activities of daily living (ADLs) or require a "safe and secure environment" due to chronic confusion or a mental illness. HCBS will be provided if an individual requires assistance with one to three ADLs, or if an individual suffers from confusion or a mental illness.[72] Consistent standards across the state, based on

[72] Donna Folkemer and Barbara Coleman, *Long-Term Care Reform: Legislative Efforts To Shift Care To The Community*, National Conference of State Legislatures, available at http://www.ncsl.org/programs/health/forum/longtermcarereform.htm (2006).

need requirements, helps ensure that consumers are accessing programs that are appropriate for their needs.

Vermont provides another example of categorizing consumer needs in a way that might be instructive for New York. In an attempt to equalize access to institutional and community based services and provide care based on level of care need, Vermont has fundamentally changed its long term care delivery system. Consumers have been divided into three categories of level of care needs, based on an independent living assessment. Given resource constraints, care can be prioritized by establishing which consumers require the most assistance. Those who have the highest needs are entitled to nursing home care or community based services. Consumers with high or moderate needs receive care based on available resources and funding. This new state waiver defines who is eligible for services based on their needs but it also has expanded who can receive services. Consumers with moderate needs represent consumers who were previously ineligible for services. They are now offered, based on availability of resources, case management services, adult day health care and assistance with direct care services in their homes. The state has decided to provide services earlier to enable individuals to remain independent for a longer period of time and decrease the amount of future disabilities. Some waiting lists exist for the high and moderate need population and it is not yet clear how appropriate this waiver is for other states, but Vermont has been successful in serving more consumers in community settings. The state has also found a way to determine who is eligible and for which services, based on the consumer's actual needs.[73]

[73] *See* Jeffrey S. Crowley and Molley O'Malley, *Vermont's Choice for Care Medicaid Long-Term Services Waiver: Progress and Challenges As the Program Concludes its Third Year*, The Henry J. Kaiser Family Foundation, available at http://www.kff.org/medicaid/upload/7838.pdf (2008).

Recommendations:

1. New York State should proceed, with caution, with its plans to implement a uniform assessment tool. We recommend that the tool be developed with input from diverse stakeholders, including the adult disabled, the elderly and caregivers and that experience with the tool be evaluated periodically to ensure that it adequately assesses the needs and desires of consumers in order to ensure that they are receiving appropriate care.
2. New York should assess the experiences in Vermont and Iowa in terms of how eligibility requirements for LTC programs might be adjusted in ways that better serve consumers and prevent unnecessary institutionalization. The issues of doing this efficiently (within funding available for LTC services) and prevent waiting lists and other access issues (which Vermont is known to have experienced) will be important considerations.

OVERCOMING BARRIERS TO ACCESS:

Issue: New York State is large and composed of many different counties, with varying population size and characteristics. Though the state has not regionally restricted any programs, not all counties have the same availability of resources.[74] This is problematic for consumers because providing care in the least restrictive setting is not always possible.[75]

There are twenty-six rural counties in New York State (according to CMS' definition) and providing home health services in these areas has proven to be very difficult since twenty-five of these counties are serviced by very few (one or

[74] UHFNY Study.
[75] Charlene Harrington, Terence Ng, Stephen H. Kaye, Robert Newcomer, *Home and Community Based Services: Public Policies to Improve Access, Costs and Quality*, P.5, University of California (2009).

two) Medicare certified agencies.[76] Consumers outside of New York City account for a much smaller proportion of enrolment in community programs, such as the Medicaid Managed Long Term Care program (MMLTC), and are more frequently serviced via institutional means.[77] When asked if New York State's long term care system enables consumers to get care in the setting they would prefer and if the system provides access to services in the least restrictive setting, most people who responded to our survey said it does not.[78] The paucity of community based options in some areas (in particular rural areas) is likely inhibiting progress throughout the state (including urban/metropolitan areas), because there is little political incentive in areas that have been shut out of community based services to increase the state's investment in these services.

Funding community based programs in rural areas of the state has proven difficult. Efforts were made to increase funding, beginning in 2000, but these were not made permanent. Congress authorized a 10 percent add-on for home health services in rural areas, as part of the Benefits Improvement and Protection Act. This add-on expired in 2003, was reinstated at 5 percent for a year by the Medicare Modernization Act and then again in 2006, as part of the Deficit Reduction Act. It expired January 1, 2007 and has not yet been renewed. Giving permanence to this payment mechanism could greatly improve the resources available in rural areas, as would more, overall balancing of Medicaid expenditures. [79]

Potential Remedy: Alaska is the largest and least densely populated state in America, but it is also one of the most balanced states in terms of its financial contributions to home and community based services. They have also tailored

[76] *See* the Home Care Association of NYS website at http://www.hca-nys.org/search.cfm?SearchType=Homecare.
[77] Charlene Harrington, Terence Ng, Stephen H. Kaye, Robert Newcomer, *Home and Community Based Services: Public Policies to Improve Access, Costs and Quality*, University of California (2009).
[78] *See* survey results in appendix.
[79] *See* the Home Care Association of NYS website at http://www.hca-nys.org/.

policies to improve long term care access in rural areas. The state created a rural long term care development program with grant money from the "Alaska Mental Health Trust Authority." The program provides consumers services such as the Personal Care Assistance Program, care coordination and adult day centers. In addition, the Robert Wood Johnson Foundation provided funding to the state in the form of their "Coming Home Grant." This enabled the state to create the Assisted Living Development program, in order to develop assisted living in rural areas. As of 2006, five apartment style affordable assisted living facilities have been completed. Alaska developed these programs with grant money, but their Medicaid expenditures are also evenly distributed between institutional services and HCBS.[80]

Recommendation: New York should take concrete steps towards the greater realization of community based services across the state by looking at the Coming Home grant programs in Alaska and other states, as well as other states' activities in developing affordable housing for consumers (including affordable assistive housing), and using these experiences as a basis for developing and implementing plans that respond to the unique challenges New York faces. The state's unique challenges – stemming from its diverse urban, suburban and rural areas; wide variations in both real estate costs and availability of direct care workers; and regional political rivalries – has resulted in an inability to make substantial progress in overcoming its over-reliance on institutional services. As the New York State Most Integrated Setting Coordinating Council and many other have noted,[81] consumers' desire for community based services is well established, as is the legal right to these services. The state should now look at what has worked in different environments – from the rural to the urban, assess

[80] Enid Kassner, Susan Reinhard, Wendy Fox-Grage, Ari Houser, Jean Accius, *A Balancing Act: State Long Term Care Reform*, Pp.37 and 98, AARP Public Policy Institute, available at http://www.aarp.org/research/longtermcare/programfunding/2008_10_ltc.html (2008).

[81] *See*, for instance, *Addressing the Service and Support Needs of New Yorkers with Disabilities: Report of the Most Integrated Setting Coordinating Council* (http://www.omr.state.ny.us/MISCC/images/2006_annual_report.pdf).

the options available, and develop a state-wide plan for change. The experience in Alaska could be particularly instructive for overcoming persistent challenges in New York's rural areas. And, if the state overcomes the unevenness of access to community based services, there might be more political support statewide for greater investments in community based care.

ACCESS TO PROPERLY TRAINED STAFF:

Issue: Quality of care and resident satisfaction is largely contingent on professional caregivers committed to providing not only physical care but also to meeting the psychosocial needs of long term care consumers. It is also important that there are enough workers to provide home and community based services to the growing population in need of long term care.[82] Efforts must be made to increase awareness of the importance of comprehensive long term care and caregivers must be properly trained to provide it.

Potential Remedy: Florida established the Teaching Nursing Homes program in 2001 in order to forge relationships between medical schools, nursing homes and nursing schools. The program's goal is to provide an integrated, patient centered long term care system. It promotes education and research in long term care as well as best practices and endeavors to improve quality by linking academic teachings, organizations and advocacy groups to long term care. The philosophy is that better training and multidisciplinary awareness will promote and protect the interests of long term care consumers.[83] The Robert Wood Johnson Foundation funded a similar program in the 80s, with the following goals: to improve quality of care, improve staff training and increase the interest in geriatrics at nursing schools. Though that program did not have a substantial impact on the field at the time, and is not considered to have been a success, there are a number of ways in which it is thought to have influenced

[82] IOM Long Term Care Report.
[83] www.aspe.hhs.gov/daltcp/Reports/statenhE.htm.

subsequent developments in the field. For instance, nurse practitioners in nursing homes gather data on such factors as pressure sores and incontinence now using the methods developed by one of the leaders of the foundation's program evaluation team.[84]

Recommendation: Capacity building in the direct care work force is needed to address the shortage of workers. Given the high turnover rate among direct care workers (70% annually in nursing homes and estimated at 50% in home care)[85], more worker incentives are necessary as well. These incentives should address major issues such as working conditions (a persistent problem[86]), improving benefits and increasing wages. While the current financial crisis in New York and the nation poses significant challenges to increased investment, steps can and should be taken to address these issues. It is crucial that state policymakers consider the financial costs of high worker turnover when assessing the costs and benefits of proposed investments in the workforce. For instance, lowering turnover rates could provide a significant savings to the state (such as by reducing rates of hospitalization of consumers receiving inadequate care or injury rates of direct care workers). In addition, New York policymakers should consider how the LTC payment systems could be reformed to better encourage provider investment in direct care staff. Training and credentialing requirements for workers should be updated to both meet the needs and career goals of

[84] *See* the *Teaching Nursing Home Program*, by Ethan Bronner, available at: http://www.rwjf.org/pr/product.jsp?id=14835. *See*, also, the *Reforming Long Term Care Services in New York State Center for Disability Rights Position Paper*, available at http://www.cdrnys.org/index.php?option=com_content&view=article&id=99%3Areforming-long-term-care-services-in-new-york-state-center-for-disability-rights-position-paper&Itemid=49).

[85] National figures as noted by the Paraprofessional Healthcare Institute (http://phinational.org/issues/low-wage-work/).

[86] *See* LTCCC's reports: *Improving Working Conditions for Nursing Home Direct Care Staff,* available at http://www.ltccc.org/publications/documents/Finalreport104_000.doc (2004) and *What Makes for a Good Working Condition for Nursing Home Staff: What Do Direct Care Workers Have to Say?,* available at http://www.nhccnys.org/documents/WorkingConditionsBooklet_000.pdf (2003).

workers and the needs of consumers.[87] It is crucial that the consumer's psychosocial needs, not just physical needs, are met. As the Paraprofessional Healthcare Institute has noted, the state should "[d]esign worker registries and other resources to support both consumers and workers in home- and community-based services, and especially for those in consumer-directed programs."[88]

CONSUMER DIRECTION:

Issue: Consumer direction and consumer-centered care lie at the heart of restructuring issues, from a consumer perspective. Fundamentally, it is crucial for consumers to be involved in the planning process for their care and that this involvement and control continue while care is delivered. As studies have shown, consumer direction leads to positive outcomes in terms of quality of life, consumer satisfaction and feelings of empowerment.[89] Certain programs, such as the Consumer Directed Personal Care Program, involve the consumers in the planning of their care to a great extent, but most other programs do not. In addition, although the Consumer Directed Personal Care Program exists, consumers are not well informed about its existence. Lack of knowledge among consumers and their loved ones about services that are available is one of the

[87] *See* the following LTCCC publications for more information on nurse aide training issues: *Nurse Aide Training in New York: An Overview of Programs and Their Regulation by the State, with Recommendations for Improvement*, available at http://www.ltccc.org/papers/oversight.pdf (2003); *Certified Nurse Aide Training "Model" Program*, available at http://www.ltccc.org/publications/documents/ModelProgram.pdf (2002); and *Nurse Aide Training: Preparing for the Future, Proceedings of the February 4, 2002 Conference*, available at http://www.ltccc.org/papers/proceedings.htm (2002).

[88] As noted on the Paraprofessional Healthcare Institute's website, *Policy Solutions* (http://phinational.org/what-we-do/policy-solutions/).

[89] http://www.cdrnys.org/index.php?option=com_content&view=article&id=138:reforming-long-term-care-services-in-new-york-state-center-for-disability-rights-position-paper-&catid=17:blogs-recent&Itemid=24.

biggest obstacles to making New York State's long term care system truly responsive to the needs of the citizens that it serves.[90]

Potential Remedy: Consumer direction is a national issue in long term care. Its importance is increasingly recognized and many states have been introducing more consumer choice and direction into their long term care systems. For example, Wisconsin has a program called "Family Care" (FC).[91] It is a capitated managed care program that provides both acute and long-term care services. Under this program, all eligible individuals are entitled to home and community based services in those counties where it exists.[92] This program incorporates consumer choice, because "money follows the person" to whatever setting the individual needs and wants.[93]

In addition, the program was developed with consumer input: more than half of the members of Wisconsin Council on Long Term Care, which advises the state, are program participants or their representatives. The council is also working with the state to develop training manuals for Family Care.[94] Two governmental organizations manage the program: Resource Centers, which provide a single entry point for information, advice and access to a wide range of community

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[90] *See* survey results at www.ltccc.org.

[91] The official state website page with information on the program is http://dhs.wisconsin.gov/ltcare/.

[92] Though the CMS website states that there are no waiting lists for these services, the Wisconsin Department of Health Services website indicates otherwise, stating:

> In his February 2006 State of the State speech, Governor Doyle announced plans to expand Family Care statewide and eliminate waiting lists for community-based long-term care programs during the next five years. While Wisconsin has been a national leader in offering community-based alternatives to nursing home care, about 11,500 people are on waitlists for community care statewide.

(http://dhs.wisconsin.gov/ltcare/generalinfo/WhatisFC.htm).

[93] *State Perspectives on Emerging Medicaid Long-Term Care Policies and Practices,* National Association of State Medicaid Directors (2007).

[94] S. Crisp, S. Eiken, K. Gerst and D. Justice, *Promising Practices in Long Term Care Systems Reform: Wisconsin Family Care*, *Prepared for:* U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Disabled and Elderly Health Programs Division, Medstat (2003).

resources to consumers and Care Management Organizations (CMO), which manage the Family Care benefit and provides enrollees with choices about the types of long term supports they receive and the settings in which they are provided.[95] Although this program provides consumer choice and self-direction, services must be provided as cost effectively as possible and through a pre determined provider network, thus limiting choice.[96]

Recommendation: New York State incorporates some self directed services into their long term care system, though it is limited. The state should take steps to implement consumer direction more widely.

1. One way this could be done is by educating those responsible for long term care placements (like service coordinators, nursing home discharge planners and hospital social workers) about the benefits of consumer direction, the consumer's right to self-direction whenever possible and how they can provide consumers with the option of self directed care.[97]
2. Similarly, state quality assurance staff and state ombudsmen should have augmented, ongoing training on consumer directed and centered care in all of the settings that they work in. These education and training efforts should be premised on the understanding that every consumer is entitled to self-direction and to receive the level of care necessary to maintain their highest practicable physical, social and emotional well-being. The new CMS guidelines for nursing home surveyors,[98] which focus on resident

[95] *Id*.
[96] *Family Care Independent Assessment: An Evaluation of Access, Quality and Cost Effectiveness For Calendar Year 2003 - 2004*, APS Healthcare, Inc., (2005).
[97] *See Reforming Long Term Care Services in New York State Center for Disability Rights Position Paper*, available at: http://www.cdrnys.org/index.php?option=com_content&view=article&id=138:reforming-long-term-care-services-in-new-york-state-center-for-disability-rights-position-paper-&catid=17:blogs-recent&Itemid=24.
[98] *Issuance of Revisions to Interpretive Guidance at Several Tags, as Part of Appendix PP, SOM*, Centers for Medicare and Medicaid Services. According to the CMS website, "This revision will be implemented June 17, 2009. At that time, a final copy of this new guidance will be available at http://www.cms.hhs.gov/Transmittals/ and ultimately incorporated into Appendix PP of the State

quality of life and dignity and provide specific illustrative examples on how facilities should be fostering resident self-direction, will be an excellent starting point in this regard if they are properly incorporated into the survey process.

3. As our survey results suggest, lack of knowledge about community based programs among consumers and their families, the waiver programs in particular, indicates that much needs to be done to inform them about the range of options available so that they can achieve better access. The Money Follows the Person Demonstration that the state is now embarking on (discussed earlier) could be a good step forward in making this a reality and, if so, instructive for future efforts.

Operations Manual."

RESOURCES

Following are selected resources for further information on the issues discussed in this report. In addition, the "Access to Care" page on our website, www.ltccc.org, has a copy of the survey conducted for this report and other information related to long term care access and restructuring.

SELECTED REPORTS AND DATA RESOURCES

State Perspectives on Emerging Medicaid Long-Term Care Policies and Practices, National Association of State Medicaid Directors (http://www.nasmd.org/resources/docs/LongTermCareRpt1007.pdf) (2007).

Money Follows the Person and Balancing Long-Term Care Systems: State Examples, Prepared for: U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Disabled and Elderly Health Programs Division, Medstat (2003).

A Balancing Act: State Long Term Care Reform, AARP Policy Institute (http://assets.aarp.org/rgcenter/il/2008_10_ltc.pdf) (2008).

Do Non-institutional Long-Term Care Services Reduce Medicaid Spending?, Health Affairs, Volume 28, Number 1263 (www.allhealth.org/SCANforum/Mar9Docs/NoninstitutionalLongTermCareServices.pdf) (Jan/Feb 2009).

Medicaid and Long-Term Care Services and Supports, Kaiser Commission on Medicaid Facts (http://www.kff.org/medicaid/upload/2186_06.pdf) (Feb 2009).

Medicaid Long Term Care: New York Compared to 18 Other States, New York Health Policy Research Center (http://www.rockinst.org/pdf/health_care/2009-02-19-LTC_Interim_Report_final.pdf) (2009).

An Overview of Medicaid Long-Term Care Programs in New York, Medicaid Institute at United Hospital Fund (www.uhfnyc.org) (2009).

Improving the Quality of Long-Term Care, Institute of Medicine (http://www.nap.edu/catalog.php?record_id=646) (2001).

Improving Quality Care in Nursing Homes, Institute of Medicine (http://www.nap.edu/catalog.php?record_id=646) (1986).

Consumer Directed Assistance Program Offers Greater Autonomy to Recipients of Home Care, New York State Bar Association Journal, Volume 75, Number 1 (http://onlineresources.wnylc.net/healthcare/docs/CDPAPBogartarticle.pdf) (2003).

SELECTED WEBSITES

The Agency for Health Care Research & Quality (http://www.ahrq.gov/)

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.

AARP Public Policy Institute (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/)

The Commonwealth Fund is foundation dedicated to improving healthcare. Their website presents reports and studies on a variety of issues relating to healthcare system improvement, including materials on innovative state practices, health system data and performance profiles.

The Robert Wood Johnson Foundation (www.rwjf.org)

The mission of the Robert Wood Johnson Foundation is to improve the health and health care of all Americans. The website presents numerous reports and resources on a range of healthcare policy issues, including nursing home culture change, affordable assisted living, patient-centered care and workforce issues.

National Resource Center for Participant-Directed Services (www.participantdirection.org)

The resource center was launched in April 2009 to provide technical assistance, training, research, and policy analysis to states and other organizations with the goal of improving the lives of people of all ages with all types of disabilities who want to maintain their independence and freedom to direct their own services and supports.

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