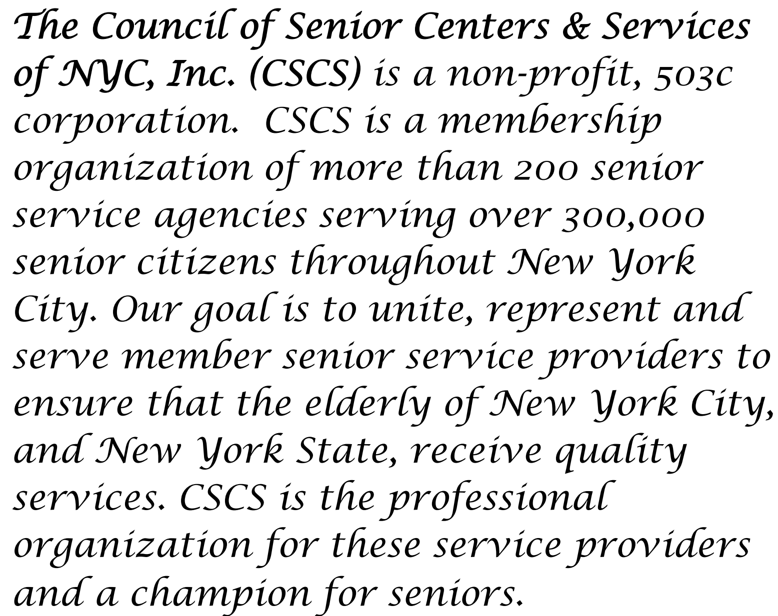
Council of Senior Centers & Services of NYC

No Time to Wait: The Case for Long Term Care Reform

Recommendations for Modernizing Long Term Care in New York

[January 2009]



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CSCS

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January 2009

Dear Colleague,

Council of Senior Centers and Services of New York City, Inc. (CSCS) is pleased to present this groundbreaking policy paper on creating a community-based long term care system in New York State, "No Time to Wait: The Case for Long Term Care Reform."

For 30 years, CSCS has advocated for cost-effective, humane ways in which the elderly can remain in their homes and communities. We can point with pride to our 200 member agencies that provide community-based services to 300,000 older New Yorkers in neighborhoods throughout New York City. CSCS and its members are vital assets available to the state in developing a user-friendly, community-based long term care system. We are grateful to Neal Lane, former director of the NYS Office for the Aging, for his insights into this issue and the paper he wrote that makes the case that there is "no time to wait." Special thanks to co-author Bobbie Sackman and copy editor Anne Perzeszty for their work in bringing the paper to publication.

Why is there no time to wait? The reasons are many and varied: unique demographic developments of increased numbers of New Yorkers living longer, senior preference to age in place and the needs of the vast majority of elderly who are not Medicaid eligible.

Family caregivers work hard to support their loved ones to keep them at home. In the coming years, a growing number of New Yorkers will grow old in the community, not in nursing homes. This fact gives rise to challenges such as how to provide both preventive and ongoing services to older adults in a way that balances cost and the need to be sensitive to individual needs.

CSCS believes that moving into a community-based long term care system must be done in a thoughtful, planned way and that the process needs to begin now because there is *no time to wait*. There is no time to wait because it is about all of us.

Please join us in planning for the future of aging in New York.

Sincerely,

Igal Jellinek	William J. Dionne
Exective Director	CSCS Board President

EXECUTIVE SUMMARY

As people face frailty, it is one of those self-evident truths that they prefer to live in their own residences and receive support in their homes. It is, simply, what we would all want for ourselves. We want to stay connected to the community in which we live. When we do need help we want to have support in the least intrusive and least costly way. Remaining home and, to the degree possible, in control of one's life, is good for us and it is good for the payer. This basic human condition, the need to control one's world, to live as independently as possible is "at the heart of human rights in old age (Hawkins, 1999)."

There is a confluence of skyrocketing growth in numbers of older adults age 75+ and minority older adults occurs at the same time that we will be seeing dramatic declines in the number of workers and caregivers per older adult. On the near horizon, the aging of the baby boomers is reaching maturity. We have:

- Dramatic increases in the old, old, half of which require direct support.
- Rapid rates of growth of minority older adults who have lower incomes and are beset with a higher incidence of frailty than the general population.
- With lower birth rates, we are witnessing a shrinking workforce and fewer caregivers.
- NYS has an outflow of well and wealthy older adults and an influx of frail and poor older adults.
- The boomers will begin to confront serious disability within the next five years.
- The boomers' retirement income will be less likely to be based on fixed pensions and they will be more subject to fluctuations in the economy.

We now know that emphasizing community-based consumer-centered care is not only good for consumers, it is also good for the payer. Rebalancing long term care (LTC) is not only about relying less on nursing home care and more on home care; it must be about a shift from a medical model of delivering care and more on home care. It must also be about a shift from a medical model of delivering care to persons at home to a balanced model of community-based care. Failure to modernize long term care will likely result in the collapse of Medicaid in New York State in the next five to eight years. Modernizing long term care will require leadership; it is now time for that leadership.

CSCS believes that the way forward in long term care is to:

- Place the values and philosophy of practice of the aging network at the center of modernizing long term care
- See state services as a coherent system and not disparate services
- Take a holistic view of the system of care that achieves positive customer and payer outcomes
- Value choice where the consumer understands all the available service options
- Provide for sufficient community-based services to be in place at the point that persons are returning from, or are no longer entering, the institutions
- Broaden consumer access to information beyond that provided by those who have a vested interest in what that consumer chooses

- Improve the critical transition between hospital and home which would have significant, positive implications for the hospital, for the payer, for the patient/consumer and for their caregivers

Housing and Transportation

Housing and transportation are essential underpinnings for remaining in the community as frailty occurs. As the state implements a community-based long term care system, policy and programs must reflect the financial challenges older New Yorkers face living on limited incomes in an increasingly expensive world. CSCS recommends:

- Establishing a task force to coordinate the development of affordable senior housing with services with either DHCR or HRA as the coordinating agency
- Adjust the New York Assisted Living Reform Act that will allow more nonprofit entities to develop assisted living by emphasizing community-based housing designed to meet a continuum of supportive housing needs with and without licensure
- Use tax credits and other fiscal mechanisms to expedite development of affordable housing
- Allow the use of paratransit and Medicaid funds for the purchase and operation of community-based agency vans
- The New York State agencies of Aging, Housing and DOH co-convening a task force which includes the relevant state and community stakeholders to define the key housing issues that promote, or inhibit, persons living with the greatest independence possible
- Designating a central coordinating government agency to expedite the development of affordable senior housing and assisted living
- The New York State agencies of Aging and Transportation co-convening a task force on transportation for older adults to create a strategic view for transportation

CSCS believes there are four areas critical to modernizing the New York State long term care system:

- A Strong Community-Based Service System
    - To achieve a consumer-centered system, a systems approach is essential. It is possible to defer or delay costly levels of care and defer or delay utilizing Medicaid as the principal payer.
    - As the state builds out a strong community-based care system, it is essential that New York strengthen its senior centers by creating a new senior center initiative.
    - Given that caregivers provide 80% of he care that frail, community-dwelling older adults receive, it would a prudent investment to support them at a level comparable to the federal investment.
- Organizing a Community-Based Point of Entry (POE) for Success
    - Further development of a continuum of non-medical community-based services will divert or delay non-Medicaid individuals from the Medicaid door. A community-based POE system holds promise to include both the community and the consumer.
- Long Term Care Restructuring Waiver
    - A long term care restructuring waiver is a vital strategy to move from a medical orientation in community-based care to a more efficient and effective balanced model of care that is consumer-centered. The goals and objectives of the original

long term care restructuring waiver give New York the best change for success. The current options being considered have abandoned the essential cost containment and quality of life strategies of intervening as early as possible and partnering with families, including non-traditional families such as in the LGBT community and other family networks.

- Personal Responsibility
    - New York State has strengthened the capacity for personal responsibility, giving individuals better information and better options for them to protect their future. Most notable has been the regulatory reforms in the state's long term care insurance market and the initiative to establish Long Term Care Insurance Resource Centers throughout the state. There is more work to be done to promote personal responsibility and CSCS urges the state to do so.

It is an undeniable reality that our current model for delivering long term care is unsustainable. There is no time to wait.

For further information, contact Bobbie Sackman, CSCS Director of Public Policy, at bsackman@cscs-ny.org.

What if. . .New York State could have a system that contains Medicaid costs, reduces demand for nursing home care and is responsive to the needs of seniors and their families? We believe it would make sense to invest in such a model.

CSCS Support for Long Term Care Reform

Introduction

As people face frailty, it is one of those self-evident truths that they prefer to live in their own residences and receive support in their homes. It is, simply, what we would all want for ourselves. We want to stay connected to the community in which we live. When we do need help we want to have support in the least intrusive and least costly way. Remaining home and, to the degree possible, in control of one's life, is good for us and it is good for the payer. This basic human condition, the need to control one's world, to live as independently as possible is "at the heart of human rights in old age (Hawkins, 1999)."

There is a confluence of skyrocketing growth in numbers of older adults age 75+ and minority older adults occurs at the same time that we will be seeing dramatic declines in the number of workers and caregivers per older adult. On the near horizon, the aging of the baby boomers is reaching maturity. We have:

- Dramatic increases in the old, old, half of which require direct support.
- Rapid rates of growth of minority older adults who have lower incomes and are beset with a higher incidence of frailty than the general population.
- With lower birth rates, we are witnessing a shrinking workforce and fewer caregivers.
- NYS has an outflow of well and wealthy older adults and an influx of frail and poor older adults.
- The boomers will begin to confront serious disability within the next five years.
- The boomers' retirement income will be less likely to be based on fixed pensions and they will be more subject to fluctuations in the economy.

We now know that emphasizing community-based consumer-centered care is not only good for consumers, it is also good for the payer. Rebalancing long term care (LTC) is not only about relying less on nursing home care and more on home care; it must be about a shift from a medical model of delivering care and more **on a balanced model of community-based** care **inclusive of a broad array of non-medical services**. Failure to modernize long term care will likely result in the collapse of Medicaid in New York State in the next five to eight years. Modernizing long term care will require leadership; it is now time for that leadership.

CSCS believes that the way forward in long term care is to:

- Place the values and philosophy of practice of the aging network at the center of modernizing long term care

- See state services as a coherent system and not disparate services
- Take a holistic view of the system of care that achieves positive customer and payer outcomes
- Value choice where the consumer understands all the available service options
- Provide for sufficient community-based services to be in place at the point that persons are returning from, or are no longer entering, the institutions
- Broaden consumer access to information beyond that provided by those who have a vested interest in what that consumer chooses
- Improve the critical transition between hospital and home which would have significant, positive implications for the hospital, for the payer, for the patient/consumer and for their caregivers

Community-Based Services in LTC Reform

According to the report issued by the Commission on Health Care Facilities, in the 21st Century there is a likely correlation between increasing community-based services and a reduction in demand for nursing home beds. The report cites: "For example, in Michigan, an expansion of waiver services was followed by a 7% drop in nursing home bed-days in three years. A 1996 Lewin Group study found that while Medicaid nursing home spending increased 140% nationwide from 1980-1994, Washington State's increased by 121%, Colorado's by 92%, and 69% in Oregon, all three of which were states that expanded non-institutional services." The obvious conclusion from the report is New York State relies too heavily on nursing homes in our long term care system and we can positively affect Medicaid costs by shifting to a greater emphasis on community-based long term care.

Balanced Community-Based Care

The needs of persons living with impairment are, nearly always, both medical and non-medical in nature. However, on a daily basis, for the vast majority these needs are predominately non-medical. For most of their day, frail persons are likely to need support with things such as meals; transferring (e.g.,from bed to chair); maintaining a clean, comfortable environment; bathing; transportation to doctor's appointments, socialization, etc. and related social service supports. For the majority of frail individuals, skilled nursing care and other health care services are needed only intermittently.

Affordable housing with or without supportive services is also key to community-based care. Rebalancing long term care (LTC) is not only about relying less on nursing home care and more on home care. It also must be about a shift from a medical model of delivering care to persons at home to a balanced model of community-based care. The delivery of care should be more closely aligned with what the consumers' daily needs are, which are in most cases non-medical services with health care as adjunct services and quality of life considerations. Doctors' orders and nursing assessments make sense in delivering needed health care. They do not make sense for delivering non-medical support. A system that is driven by a medical model, whether or not in home care, **or** in a nursing home, is expensive and predisposed to the limiting of a person's self

determination. On the other hand, a continuum of community-based services that includes senior centers, meals-on-wheels, transportation, mental health and socialization can deliver a wide range of services that contain costs while protecting an individual's self-determination.

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For more information, see CSCS's report *Growing Old in New York City: The Age Revolution* at www.cscs-ny.org/files/policydocuments06/GrowingOld_FEB2006.pdf

In the mid 1990s a comparison of consumers served by New York State's Expanded In-home Services for the Elderly Program (EISEP) social model approach to long-term care was made with their counterparts served in the Medicaid program. The comparison showed EISEP consumers used dramatically less publicly supported service than did the Medicaid consumers. This comparison looked at similar consumers, all over 65 and had generally comparable functional deficits.

…the EISEP customer cost the government approximately one-fifth that of the Medicaid consumer…AND SHOWS THE IMPORTANCE OF THE POWER OF CASE

Both the EISEP and the Medicaid consumers required similar amounts of care per week (22 hours/units for EISEP consumers and 25 hours for Medicaid consumers). One of the most important findings was the power of providing case management that built partnerships with and supported the family along with others who are providing non-paid support to the frail person. More than one-half of all the care received by the EISEP consumer was from informal caregivers while less than 1% of the care needed by the Medicaid consumer was from informal caregivers. The study also showed that a portion of a frail person's care could be met by lower cost social services, primarily meals, social adult day care and transportation. Through partnering with the family and utilizing non-medical community supports where appropriate, the overall result was that the EISEP customer cost the government approximately 20% or one-fifth that of the Medicaid consumer.

TABLE 1 (From the NYSOFA Budget for SFY 2003-2004)
Comparison of Services Received by EISEP and MA Upstate Personal Care Clients

Services	EISEP Clients*	MA Personal Care Clients**
Formal Services	**10 hours/units**	**25 hours**
- Home care	5.5 hours	---
- Case management	0.5 hours	---
- Other aging services***	4.0 units	---
Informal Care	**12 hours**	(<1% receive ADL help)
TOTAL	**22 hours/units**	**25 hours**

* Clients receiving EISEP case management and in-home services, or EISEP case management only. NYSOFA, Aging Network Case Management Study (ANCM Study), 1995.

** Upstate MA Personal Care clients. NYSDSS, Upstate Database Report Personal Care Services, 1994.
***This includes services such as transportation, home delivered meals and social adult day care.
Note: Services do not include private pay or Medicare reimbursed care.

System of Care

Another problem exists in the current arrangement for supporting persons living with impairment in the community. We have a fragmented system and a system of "silos." This creates a complex environment for the consumer to try to navigate, one that is beyond all of us and, at times, even beyond the most experienced professional ("*When Experts Need Experts*;" New York Times; ll/10/05). Perhaps more importantly, we have a system where providers of care function and are accountable within but not across their "silos" of care. No one entity is responsible for the overall outcomes of the general system of care within the community or for the overall outcomes for the individual. Without taking a holistic view of the system of care, without a holistic view of an individual's care, positive outcomes are as much serendipitous as they are planned or managed.

HOUSING AND TRANSPORTATION: CORNERSTONES OF AGING IN PLACE

A community-based long-term care system must include affordable housing and accessible transportation. At the top of the list of concerns stated by older New Yorkers is affordable housing – whether you rent or own. Another major concern is accessible and affordable transportation – whether you live in mass transit rich New York City or in the suburbs or rural New York State. Housing and transportation are cornerstones of aging in place. As such, policy and programming and maximizing state resources around these services are major priorities for CSCS.

It is time to bring together housing, health care and social supportive services so that services work in tandem for seniors and their family caregivers. Funding silos and policies currently fragment services at best, and frequently haven't yet recognized the need to actively develop a continuum of services in the community as seniors age. A one-stop agency designed to facilitate the building of affordable senior housing and assisted living needs to be developed.

As stated in the CSCS 2006 statewide study on transportation that surveyed the operating costs of vans run by senior centers and other community-based senior service organizations, "The use of vehicles is the underpinning for many of the programs serving older adults in communities throughout New York State. Transportation services provided included: meal deliveries; transportation to and from senior centers and adult day programs; recreation trips; medical appointments; pharmacy; dialysis; bank, post office, Social Security, library, cemetery visits; voting and grocery shopping. A van is crucial in preventing unnecessary isolation of the elderly. An operational van can mean the difference between a homebound elderly person receiving a meal or not, a caregiver being able to ensure that their loved one attends day care, or an individual being able to make a doctor's or dentist's appointment." Without transportation, aging in place in one's home and community is often a lonely, isolating experience.

In this policy paper, which includes recommendations, CSCS puts forth a detailed list of the needs and possible solutions to meet the housing and transportation challenges as New York's aging population grows.

Financing Balanced Community-Based Care

Financing for non-medical services that support the independence of frail persons, or persons at risk of becoming frail, has not kept pace with the need for these services. This is particularly evident in funding for non-medical support services delivered by aging service providers in dramatic contrast to funding for medical model home care. Medicaid, the funding stream for medical model home care and nursing home care, is an entitlement program and, therefore, has the inherent capacity to grow as demand grows. Growth in Medicaid long-term care has significantly increased over the last decade. This is not the case in the essential non-medical service sector.

Prior to 2006, funding from the federal government via the Older Americans Act was flat for the preceding decade and that was true for state funding as well. The notable, but modest, exception was the federal funding of Title III-E, the National Family Caregiver Support Program, in 2001. The effect of this flat funding was the erosion of capacity as inflation took its toll on programming. On the state level, funding for services administered by the NY State Office for the Aging has remained relatively flat. The exception has been a $25 million infusion into the EISEP program over the past two years after a decade of insufficient increases.

CSCS conducted a survey of aging service programs in NYC released in 2005, *More With Less Is Impossible*. One hundred seventy five programs (mostly senior centers) responded. The survey revealed the following:

- Thirty nine percent (39%) of agencies reported cutting staff due to increased costs.
- Increased costs impact the services that agencies provide – 44% of those responding cut programs to meet increased costs.
- A majority of the respondents, 55%, met increased costs by cutting funds from another part of the budget such as staff and programs.

Allowing senior centers to wither is having a serious impact on our communities' capacity to support older adults

Allowing senior centers to wither is having a serious impact on our communities' capacities to support older adults remaining integrated in their communities. This is a painful outcome for the individual and for the payer. Senior centers prevent/delay frailty and dependency. They are an essential part of a strong community-based long-term care system for older adults.

Central to any effort to rebalance long-term care is the existence of a healthy community-based service sector (especially non-medical supports), one that delivers a range of high quality services that are relevant to the needs and preferences of a very diverse population. As we seek to maintain individuals in their

communities and reap the benefits of containing public expenditures we : ". . .must be vigilant of unintended consequences such as pressure on agencies to provide services with too few staff and low reimbursement rates." Further, we must: "Expand funding for public programs, especially under the Older Americans Act" (*From Hospital to Home: Improving Transitional Care for Older Adults*; University of California, Berkeley, 2007).

In order to do no harm, as we continue to shift care from institutions to community, adequate community-based services must be in place, they must

First among the painful lessons learned as New York sought to rebalance care for persons with mental impairments, from an institutional delivery system to a community care system, was the need to have sufficient community-based services in place at the point that persons were returning from, or were no longer entering, the institutions. While it was rational to expect a shift of dollars from institutional financing to community financing, that is a long-term consequence, not an immediate result. In order to do no harm as we continue to shift care from institutions to community, adequate community-based services must be in place, they must be forward funded.

What People Want - Shared Values for LTC Reform

We value choice, self-determination, connection with community along with meaning and purpose. These are what should define our lives, not our medical conditions.

We want control over our lives. We want to have meaning, dignity and purpose to our lives. When we do need help, we want to have support in the least intrusive and least costly way. These things we value. Any of our efforts in long- term care reform must embrace what consumers have told us; they want what we all want, they value what we all value.

For those living with physical impairments, there are three separate public systems of supports: Medicaid, Aging (e.g. Area Agencies on Aging, senior centers, adult day care, etc.) and Independent Living Centers (ILCs). Care in Medicaid, the dominant system, is seen through a medical lens that includes nursing assessment, doctors' orders, and certified and licensed home care agencies as the principal delivery mechanisms. People want access to medical care, but people do not want to live their lives solely determined by medical protocols and medical values. Medical care for all of us should be an aspect of our lives, not the center of our lives. It is emotionally and physically good for us to live with these values.

The section discusses the evolution of public policy coming into alignment with what consumers want. **We now know that emphasizing community-based consumer-centered care is not only good for consumers; it is also good for the payer.** It is the answer to how we, as both individuals and as the public payer, can afford to pay for long-

term care. As we reform long-term care to be more consumer-centered, we must imagine the system in a way that medical needs are addressed as an aspect of care.

Values for LTC Reform as CSCS/Aging Network Values

CSCS, its members and the entire aging network in New York State, have embraced the values set forth in the Older Americans Act (OAA) since inception. The OAA, adopted in the 1960s and funded in the 1970s, has as its mission the dignity and independence of older adults. "Our vision for older people is embodied in the OAA and is based on the American value that dignity is inherent to all individuals in our democratic society, and the belief that older people should have the opportunity to fully participate in all aspects of society and community life, be able to maintain their health and independence, and remain in their own homes and communities for as long as possible." (U.S. Administration on Aging Strategic Action Plan 2007-2012).

The aging network has developed its services to meet the mission of the OAA and that mission is especially pertinent to what must be accomplished to modernize long term care. The philosophy of care, at the core of New York's aging services, is applied to the services that are offered in our communities by the aging network. The philosophy of care management for frail older adults focuses on all aspects of a person's life, including the well-being of any informal supports.

The values and practice of the aging network are intimately aligned with what consumers want and historically have resulted in positive consumer outcomes. The aging network offers a wide array of non-medical support services that are low-cost and non-intrusive while collaborating with medical professionals to address consumers' medical conditions. Furthermore, the full range of a community's supports, not just the services offered by the aging service agency, are known and understood by the care coordinator. All of the community's supports are seen as available in addressing a consumer's needs.

Care plans are often quite modest because of the philosophy of care that is characteristic of the aging network. At the very center of their work is the dignity of the individual and their right to make informed decisions, even if those decisions may involve an element of risk. An ethic in the aging network is to build upon the strengths of the consumer, empowering the person to achieve all that they can for themselves. The consumer's quality of life, and the vitality of their informal supports, is central in any plan of care.

CSCS believes that the way forward in long term care is to place these values and philosophy of practice of the aging network at the center of modernizing long term care.

Recommendations

This paper sets out 31 major policy and program recommendations. CSCS believes that the implementation of these recommendations is central to achieving a high quality, affordable, rational, consumer-centered system of support for those living with physical disabilities and cognitive impairments.

There are nine initiatives/actions in New York we believe have moved the state forward in reforming long term care. Taken together, they identify the foundation on which to build. Strengthening the community service system, implementing the long term care structuring waiver, developing a community-based Point of Entry system and strengthening personal responsibility are all a part of developing the strong and diverse community-based system of care required for reform/modernization.

CSCS believes that the way forward in long term care is to:

- Place the values and philosophy of practice of the aging network at the center of modernizing long term care
- See state services (NYSOFA services, Medicaid services and housing) as a coherent system and not disparate services, a perspective that brings with it the opportunity to build on the strengths found in each system and to take action in each system with the goal of positively affecting quality and cost system-wide
- Implement a balanced, holistic approach to care, one that achieves positive customer and payer outcomes
- Value choice where the consumer understands all the service options that are available and he/she chooses the type[s] of service as well as the provider[s]); self-determination whereby the person maintains control over his/her life including accepting levels of risk, connection with community along with meaning and purpose
- Learn from the painful lesson taught when New York sought to rebalance care for persons with mental illness from an institutional delivery system to a community care system and provide for sufficient community-based services to be in place at the point that persons are returning from, or are no longer entering, the institutions
- Change the reality that access is generally controlled by those who provide the service with the consumer only knowing what she/he is told by those who have a vested interest in what that consumer "chooses."

Our priority is to grasp the implications of the future, make a positive contribution to modernizing long term care in New York and to effectively serve our growing consumer base. **Focused and thoughtful work must begin now.**

Policy and Program Recommendations

There are four areas that we believe to be critical in modernizing long term care in New York. They are:

I. A Strong Community-Based Service System
II. Develop a Community-based Point of Entry System for Success
III. The Long Term Care Restructuring Waiver
IV. Personal Responsibility

I. A Strong Community-Based Service System

As New York conducts its work on reform and rebalancing long term care, it has become obvious that to achieve an affordable, consumer-centered system, a systems approach is essential. Medicaid dwarfs other public funding mechanisms for long term care, yet it is equally true that other programs and policies have an enormous impact on Medicaid spending. It is now understood that by taking certain actions including long term care insurance product reform, supporting informal caregivers (families, friends and neighbors), and stabilizing an individual's medical and social situations, it is possible to defer or delay costly levels of care and defer or delay utilizing Medicaid as the principal payer.

Failure to modernize long term care will likely result in the collapse of Medicaid in New York State in the next 5 to 8 years…Modernizing long term care will require leadership; it is now time for that leadership.

Failure to modernize long term care will likely result in the collapse of Medicaid in New York State in the next five to eight years as the baby boom generation begins to be afflicted by major impairment. There is, quite literally, no more time to wait. It will take three to four years to complete rebalancing and it will be just in time. Previous cost containment strategies aimed at cutting expenditures by cutting provider cost will not yield the cost efficiencies that will be necessary. **Modernizing long term care will require leadership; it is now time for that leadership.**

Community-Based Services and Senior Centers

Axiomatic to modernizing long term care is the existence of a strong and diverse community-based system of care. The long term care restructuring waiver, developing a community-based Points of Entry system and strengthening personal responsibility are all part of developing such a community-based care system.

CSCS recommends the following:

A) New York State officials work closely with New York's congressional delegation to increase funding in the federal Older Americans Act (OAA). At a minimum, all titles relevant to delivering community-based care should be funded in a manner that will:

- Account for all cost of living increases since the initial funding of each of the current OAA titles and initiatives
- Account for the increases in the number of older adults since the initial funding of the title

B) New York State increases its investment in state-funded aging programs in the same manner described for the increases to the OAA. As has been done in the Medicaid program, the local match communities must supply to draw down state funds should be frozen as state funds expand. Maintenance of Effort (MOE) must be maintained at every level.

C) New York State makes an investment in services supporting caregivers to frail persons comparable to the federal investment. New York currently receives $10 million from the federal government (Title III-E of the Older Americans Act). However, this falls short of the need for services that strengthen the ability of individuals to go on caring for frail relatives or friends. Given that caregivers provide 80% of the care that frail, community-dwelling older adults receive, this is a very prudent investment.

D) New York State establish a Community-Based Long Term Care Reinvestment Program. As we shift to a greater reliance on community-based long term care and lessen our reliance on nursing homes, a significant deferment of anticipated costs in Medicaid will accrue to the state. However, in order to achieve those savings, community-based care must be in place to divert individuals away from nursing home care. Community-based care must be forward funded. A reinvestment program would begin this process by allocating, $100 million dollars upfront to strengthen the non-medical social services network. This will enhance the capacity of existing programs and provide opportunities for new programs/services to evolve to meet emerging needs in community-based care.

E) Fund the Expanded In-home Services for the Elderly Program (EISEP) to a level that would expand the services to ensure that case management caseloads do not exceed 45 per case manager and that there are no older adults waiting for in-home services because of a lack of EISEP money. Local match should be frozen at current levels (MOE).

F) New York strengthens, and builds upon, existing senior centers. Senior centers are a central part of a strong community-based long term care system. They play a significant role in preventing/delaying physical and/or mental decline in older adults. Yet, funding for senior centers, in real dollars, has declined dramatically. As the state builds out a strong community-based care

Senior centers are a central part of a strong community-based LONG TERM care system.

system, it is essential that New York strengthen its senior centers by creating a new senior center initiative. The senior center initiative would:

- Provide an initial grant program for senior centers to upgrade their current staffing and programs, fund kitchen renovations, physical plant upgrades ($20 million) as well as expand community outreach and access services.
- Provide $10 million annually to promote senior center innovation focusing on, but not limited to:

- Caregiver support
- Optimizing older adult nutrition programming through the expansion of congregate and home-delivered meal programs as well as nutrition education targeted to those living with chronic illness
- Providing support for persons with dementia
- Coordinating with acute care facilities and supporting the discharge of frail persons back to the community
- Testing “senior center without walls” models
- Promoting evidence-based wellness and disability prevention
- Promoting evidence-based chronic care self-management programs

G) Expand the availability of adult day care by:

- Increasing funding for social adult day services (in SFY ’09 by $5 million) as we **rely** less on nursing home care to ensure the community infrastructure continues to be available and is an affordable choice for those persons not qualifying for Medicaid.
- Developing and funding a “blended adult day care/services” model built on the existing social day care model and would supply various “medical” (as defined in the medical model adult day service program) services on an as needed, consumer-specific basis. As in rebalancing community-based long term care from a medical model, taking this approach in adult day services will produce cost efficiencies and increase consumer control.
- Eliminating restriction in NY state law to allow Medicaid dollars for adult day services to be utilized in nursing homes, a long overdue action. This does not serve the broad array of seniors and caregivers who would benefit from ADS services. New York is the only state that has this restriction in law.

Housing and Transportation

In addition to direct supports for elderly persons including those living with a disability, housing and transportation are the essential underpinnings for remaining in the community as frailty occurs. As the state implements a community-based long term care system, moving away from the bias towards institutionalization, policy and programs must reflect the financial challenges older New Yorkers face living on limited incomes in an increasingly expensive world. A critical way to lessen the pressure on seniors from having to choose among food, medical care and housing or transportation is to lower their rent and provide supportive services in the community. This will provide more choice for seniors on how to spend their money to remain in the community.

CSCS recommends the following:

A) Establish a task force to coordinate the development of affordable senior housing with services with either DHCR or HFA as the coordinating agency

B) The New York State agencies of Aging, Housing and DOH co-convene a task force which includes the relevant state agencies and community stakeholders to define the key housing issues that promote, or inhibit, persons living with the greatest independence possible

- The task force shall map out what policies (at all levels of government) need to change, what level of public investment will be necessary to achieve the goals the task force believes are necessary and how to fund the needed public investment

- The task force would report its findings to the Executive and Legislative branches of government

C) Additionally, designate a central coordinating government agency, modeled after the Housing Trust Fund, to expedite the development of affordable senior housing and assisted living. This coordinating agency, comprised of experts from aging, health and housing fields both inside and outside government, would serve as a "one stop" model to expedite bringing senior housing to fruition in an affordable and timely manner. At a minimum this task for will examine and make recommendations concerning:

- Affordability of housing for older adults. Our urban areas, especially in New York City, do not have a sufficient supply of affordable apartments for older adults and persons with special needs. In rural areas, where home ownership is the norm, property taxes and other costs have increased to a point where older adults of modest means cannot stay in their homes.

…costs have increased to a point where older adults… cannot stay in their homes.

- Use tax credits and other financial fiscal mechanisms to expedite development of affordable housing.

- In New York City less than half of older adult households participate in the Senior Citizen Rent Increase benefit. Improved methods of reaching older adults are required.

- Assisted living, as a residential choice for older adults, needs to be expanded. In order to expand this service and make it more affordable:

  - Revisit the NY Assisted Living Reform Act - Adjustments are necessary to NY's Assisted Living Reform Act that will allow more nonprofit entities to

develop assisted living by emphasizing community-based housing designed to meet a continuum of supportive housing needs with and without licensure. State structure and regulations must act as a facilitator to develop such supportive housing opportunities to meet the growing demand to allow older New Yorkers to age in place in their communities.

- Develop government strategies such as loan guarantees, tax credits and grants for affordable assisted living

- Apply current resources of the NY State Housing Finance agency (HFA) and the Division of Housing and Community Renewal (DHCR) subsidies and programs to develop a flexible housing model program for independent seniors to age in place with supportive services. This includes a model of co-locating senior centers in senior buildings

- A Medicaid waiver should include the ability to use Medicaid funds in conjunction with other housing subsidies to develop affordable low income and mixed income senior housing

- Use Project-Based Section 8 subsidies in conjunction with other supportive housing tools to lower costs of developing affordable housing with supportive services

- Continue and expand the successful special DHCR Low Income Housing Trust Fund program that designates special allocations for senior projects with services

- Low Income Housing Tax Credits (LIHTC) – Federal tax credits used to finance the development and rehabilitation of affordable housing for low income rental tenants. NY State also has its own LIHTC program. DHCR should develop a plan to allocate a fair share of these federal and state tax credits for affordable senior housing with services, including assisted living

- Utilize tax exempt bonds and 501 (c) (3) tax exempt bonds to lower development costs through the state Housing Finance Agency and NYC Housing Development Corporation for senior housing

- Include assisted living projects in state legislation exempting nonprofits from paying certain real estate taxes to encourage construction and affordability by lowering debt service. The lower the debt, the less senior residents' monthly fees are

- Establish mechanisms to provide easier access to mortgage insurance and assume part of the **lease-up** risk under through the State of New York Mortgage Agency (SONYMA)

- Further develop Naturally Occurring Retirement Communities (NORC) and Neighborhood Naturally Occurring Retirement Communities (NNORC)

- Initiate a program that makes available to older adults an assessment of their living environment with the goal of reducing the possibility of injury (e.g. falls prevention) and increasing the living space's habitability as physical needs change (e.g. universal design)

I) The New York State agencies of Aging and Transportation co-convene a task force on transportation for older adults with a charge that mirrors the housing task force and, like the housing task force, creates a strategic view for transportation.

The cornerstone to keeping people in he community is transportation. Therefore, the State needs to establish financing mechanisms for vehicle purchase and operating costs. Strengthening community-based transportation systems for frail or disabled older New Yorkers and those who cannot access public transportation would include:

Expand funding for operational costs of vans run by senior centers, meals-on-wheels programs, NORCs, adult day service programs and other senior service organizations. Include an automatic annual trend factor to meet increased fuel, insurance and repair costs. A statewide study in 2006 documented the average operational cost per van was $37,000 in NYC and $33,000 elsewhere in the state.

- Exempt vans from local and state gas taxes

- Enhance the 5310 van purchase program administered by the state Department of Transportation to expedite the purchase of vans and make more vans available to community-based agencies.

- Encourage the use of group purchasing programs to buy new vans and group insurance to more efficiently utilize funds

    - Allow the use of paratransit and Medicaid funds for community-based agency vans.

II. Organizing Community-based Points of Entry (POE) for Success

CSCS believes that New York must modernize its long term care system. To do so, a systems view is essential and bringing balance to the system is vital. A systems approach requires that we see long term care services in the context of all who are in need of long term support.

Long term care reform cannot be solely about Medicaid. In fact, a significant part of the answer to solving the Medicaid financing challenge lies in the further development of a continuum of non-medical community-based services that will divert or delay non-Medicaid individuals from the Medicaid door.

There should be balance so that community-based care is ruled out before nursing home care is considered. Additionally, community-based care itself should be balanced. We must end the current medical model that exists in Medicaid and ensure that it, along with all community-based long term care programs, be based upon a more balanced approach. In order to accomplish balance we not only need to make financing and programmatic changes to Medicaid along with other state administered programs, but we must also create informed consumers. Informed consumers will create a marketplace in long term care that will, in turn, improve service quality, service relevance and responsiveness as well as service efficiency. To do these things the state needs to invest in a Community-based Points of Entry (POE) system.

…community-based care is ruled out before nursing home care is considered. And community-based care itself should be balanced, ending the current medical model that exists in Medicaid.

With a systems view for the consumer, we can expect:

- An end to consumer confusion
- The consumer to assume a greater control over their care
- The consumer to have true choice (not simply choice among providers, but choice in what types of care arrangements best meets their needs and desires);
- Non-medical and medical care will come into balance for the consumer
- Accountability for how the consumer fares across the entire long term care system

With a systems view for the community, we can expect:

- Far fewer barriers to accessing care
- Decline in gaps and failures in care
- Improved service quality
- Smoother, safer and quicker transitions for consumers from different sites of care
- Service investments can be made rationally.

Community-based Points of Entry Implementation

CSCS recommends that:

I) The values and philosophy of practice of the aging network, which are closely aligned with consumers' values, balanced, and very cost effective, be the base on which a modernized long term care system rests

- There is strong stakeholder input in the development of the policies, regulations and outcome/performance measures

- New York State contract with an independent entity to monitor performance of community-based POEs and that the evaluation process includes a strong feedback mechanism from the community stakeholders (providers and consumers)

- Financial resources are provided to localities to have a fully competent community-based POE infrastructure to carry out all tasks and functions in a timely manner

- A comprehensive, interactive web-based, HIPAA compliant, IT platform be developed and that it possess the ability to exchange data with all providers and reduce system redundancy (e.g., gathering of customer information, populating eligibility forms)

- Continuous quality improvement is built into the systems change responsibilities of the community-based POE at both the local and state levels

- Demonstration initiatives are needed regarding expediting discharge from acute care and rehabilitation settings to community; to finding the best fit between aging services and services for the young disabled; and expediting Medicaid eligibility determinations.

Leaving the hospital, and being in need of long term care, is a very critical transition. Improving this transition has significant, positive implications for the hospital, for the payer, for the patient/consumer and for their caregivers. A recent study by the University of California, Berkeley, *From Hospital to Home: Improving Transitional Care for Older Adults*; 2007, concluded that it was essential to take action in a number of areas.

Leaving the hospital. . .is a very critical transition. Improving this transition has significant, positive implications. . .

CSCS believes that three recommendations, in particular, to be very important in improving transitions from the hospital to home:

A Begin discharge planning before hospitalization (or at the time of hospitalization)

B Simplify program eligibility by expanding care integration efforts that create single points of access to determine eligibility and connect older adults to multiple services

C Conduct demonstrations in enhanced discharge planning.

CSCS believes it vital that demonstration initiatives focus discharge planning personnel on early identification of individuals who will likely need long term support after discharge. Further, that hospitals and nursing homes integrate personnel from both medical settings and community-based organizations in defining post acute care options for the patient/consumer and their caregivers as well as providing the assistance necessary to initiate the consumer's preferred discharge plan (or utilize an arrangement of community-based personnel that includes staff from entities that are supportive non-medical in character [e.g. case management programs serving EISEP consumers, senior centers, adult day services, caregiver support services]).

. . .the delivery of community-based long term care services is highly nuanced and very community specific

It is widely acknowledged that the delivery of community-based long term care services is highly nuanced and very community specific and must be done in a collaborative manner in order to serve elderly individuals appropriately, maximizing all available resources.

CSCS strongly endorses that view and recommends:

A) In NYC (and in other large urban areas) there are numerous community-based POE's whose boundaries correspond to natural neighborhoods

B) Where POEs will serve less than a county, the key stakeholders within the greater urban area will play a significant role in defining the CAPS neighborhoods (perhaps the best vehicle to utilize in mapping out the neighborhood service areas would be a city-wide Long Term Care Coordinating Council). The definition of a community-based POE service area, the urban neighborhood, should be consistent with the view of those who live in that neighborhood.

Technology must play a significant part in providing good information to consumers, to providers and to payers.

CSCS recommends that computerized information systems, along with 2-1-1 (3-1-1 in NYC):

A) Be developed in ways that reduce or eliminate the LTC consumer's confusion in accessing supports

B) Be designed and implemented with the provider stakeholders to mitigate disruptions to service delivery and promote service quality

C) Provide quality data to strengthen service quality, identify gaps and weaknesses in the delivery system, and promote the efficiency and effectiveness of LTC services

D) Promote integrated customer care (while being HIPAA compliant, allowing those supporting frail persons to have a holistic look at the care the customer is receiving)

E) Be data transparent, providing quality data to all the stakeholders

Computerized information systems do not constitute a community-based POE program and they are not a substitute for a POE system. They should be tools to be used by, and in conjunction with, a community-based POE system. There comes a point when general information is insufficient (and, arguably, dangerous) to the consumer and the consumer needs a face-to-face consultation. CSCS recommends that:

A) Any web-based information system or 2-1-1/3-1-1 system, have the capacity to identify LTC consumers who would benefit from a face to face consultation**, such as a case manager,** and quickly make the link for a consultation.

III. Long Term Care Restructuring

CSCS believes it is a vital strategy to move from a medical orientation in community-based care to a more efficient and effective balanced model of care and one that is consumer-centered. The current options have abandoned the essential cost containment and quality of life strategies of intervening as early as possible and partnering with families, including non-traditional families such as in the LGBT community and other family networks comprising the breadth of diversity within the state.
CSCS recommendations to strengthen New York's Medicaid program to meet the long term care needs of its population include:

A) Develop a financing model, including Medicaid and other state and federal dollars which give access to a set of supportive, non-medical services for low income persons living with impairments up to 250% of the poverty level. While counter-intuitive, the evidence supports the approach of providing support early as a person begins to experience decline. Such intervention stabilizes both the medical and the social domains of the individual. It also keeps the family and other informal supports active in providing care/support for the person experiencing impairment.
B) Need to address fiscal program for non-Medicaid eligible older New Yorkers who comprise the majority of the New York aging population.

The community-based aging network provides a broad array of services:

- Social adult day care
- Multi-service center and congregate meals
- Home delivered meals
- Care coordination/case management/case assistance
- Social work/counseling
- Daily money management

- Housing both independent and with services
- Respite
- Transportation: social & medical
- Escort service
- Personal care
- Consumer directed personal assistance
- Chore Services
- Personal emergency response services
- Community integration counseling
- Behavioral management
- Home and community support services
- Independent living skills training
- Moving assistance
- Environmental modifications
- Nutritional counseling (dietician)
- Physical therapy & Occupational therapy counseling
- Independent living skills training
- Peer mentoring
- Community transitional services
- Wellness counseling services
- Vision services
- Substance abuse services

IV. Personal Responsibility

Personal responsibility is a concept, a value, which is embraced by CSCS. Over the past several years New York State has undertaken regulatory and program actions to strengthen the capacity for personal responsibility, giving individuals better information and better options for them to protect their future. Most notable among these have been the regulatory reforms in the state's long term care insurance market and the initiative to establish Long Term Care Insurance Resource Centers throughout the state. There are additional actions that New York State can take to promote personal responsibility and we urge the state to take these actions.

CSCS recommends the following to promote and support personal responsibility:

A) The New York State Department of Insurance issue an expanded list of community based services that require long term care insurance policies issued in New York to mirror the services
   - The New York State Department of Insurance and the New York State Office for the Aging establish, and co-convene, a workgroup comprised of representatives of the insurance sector and representatives of those who provide the range of community based long term care services delineated in the previous recommendation. The workgroup would have two principal tasks:
     - To make recommendations to the Department of Insurance on how it can contribute to creating a more balanced long term care system.

This includes ending any bias toward nursing home utilization in long term care insurance policies and how the covered community-based services are delivered so as to be complementary to creating a less medically oriented, more balanced community based care system as well as covering people above Medicaid eligibility levels.

…ending the bias toward nursing home utilization in long term care insurance…

- To make recommendations for actions to be taken that will meet the insurers need to have assurances that community-based organizations, which provide services to the customer, are capable of delivering a quality service in an efficient and effective manner. The recommendations shall not be unduly burdensome to providers.

B) Make consumer direction both an option in public programs (e.g. programs administered by the New York State Office for the Aging and Medicaid) and in long term care insurance.

Our priority is to grasp the implications of the future, make a positive contribution to modernizing long term care in New York and to effectively serve our growing consumer base. Focused and thoughtful work must begin now.

CSCS believes that the implementation of these recommendations is central to achieving a high quality, affordable, rational, consumer-centered system of support for those living with physical disability(ies) and cognitive impairments.

Modernizing long term care will require leadership; it is now time for that leadership. THERE IS NO TIME TO WAIT.

The Context for Change and Investment

This section provides the background for those recommendations for change and investment in New York State's long-term care system. It demonstrates that long-term care in New York State is fatally flawed and must be reformed. It also presents the rationale that underpins CSCS's recommendations. The implementation of these recommendations is central to achieving a high quality, affordable, rational, consumer-centered system of support for those living with physical disabilities and cognitive impairments.

Rebalancing LTC is not only about relying less on nursing home care and more on home care. It also must be about a shift from a medical model of delivering care to persons at home to a balanced model of community-based care. The delivery of care should be more closely aligned with what the consumers' daily needs are (in most cases non-medical services with health care as adjunct services) and quality of life considerations. Doctors' orders and nursing assessments make sense in delivering needed health care. They do not for delivering non-medical support. A system which is driven by a medical model, be it in home care or in a nursing home, is expensive and predisposed to the limiting of a person's self determination.

The Policy and Program Environment

National

New York State's long term care dilemma due to the costs to the Medicaid program is, arguably, the most dramatic in the nation

Most states are well down the road in reforming the delivery of long term care (49 states/territories have implemented, or are now implementing, a point of entry system for long term care). Yet, New York State's long term care dilemma, due to the costs to the Medicaid program is, arguably, the most dramatic in the nation and little progress has been made. The Federal government's policy for long term care has taken shape. The following are significant public policy decisions that illustrate the direction the Federal government is taking on long term care:

1. Olmstead – In 1999 the United States Supreme Court decided the Olmstead case, interpreting Title II of the Americans with Disabilities Act (ADA) to require that persons with disabilities be supported in the "most integrated setting." The Court specified that community-based care was to be the norm and institutional care be considered only after community-based care was ruled out. This decision aligned the consumer preference with human rights.

2. New Freedom Initiative – In 2001, President Bush issued an executive order requiring all Federal government agencies to examine their practices in the light of supporting persons with disabilities in the most integrated setting possible. The executive order provided the impetus for the development of the Real Choice Systems' Initiative. This federal initiative instituted the Real Choice Systems' Change grants to states and introduced the concept of "money follows the person"

as an ideal to be worked toward. Program and policy to actualize "money follows the person" have not been detailed. **The "money follows the person" model must account for funds for the infrastructure and capacity needs of agencies.** Imbedded in the New Freedom Initiative is an important set of ideas for consumer-centered long term care:

- The long term care array of services needs to be rebalanced, relying more on community-based care and less on institutionally-based care.
- The consumer can, and should, make informed choices about her/his care.
- The consumer should direct her/his care.

3. Real Choice Systems Change – The Centers for Medicare and Medicaid Services (CMS), in partnership with the Administration on Aging (AoA), issued a series of grants to states for the purpose of: 1.) Rebalancing their long term care systems, creating a bias toward community-based care and 2.) Deinstitutionalizing those persons who could return to community living with supports. A fundamental strategy was the development of Aging and Disability Resource Centers (ADRCs). ADRCs are single points of entry (POE) for individuals and families who need help in navigating the long term care system.

4. Deficit Reduction Act (DRA) – The DRA of 2006 provided the states greater flexibility to adjust their Medicaid programs. Certain actions in a state's Medicaid program, which previously would have required a waiver, now could be included in a modified state plan (for Medicaid). The DRA had a strong emphasis on personal responsibility. It employed both a carrot and a stick approach to promote personal responsibility. It tightened up certain eligibility criteria and a number of "loopholes" that were perceived as enabling individuals with personal resources to avoid using their money first. On the carrot side, it allowed all states to develop "Partnership" long term care insurance products, like New York's.

5. Choices for Independence – A new initiative embedded in the updated language of the reauthorized Older Americans Act in 2006. This initiative, Choices for Independence, emphasizes three key directions in strengthening the capacity for persons to live independently and in their communities:

   - Promoting disease and disability prevention along with wellness promotion

   - Ensuring that all persons have access to an Adult and Disability Resource Center (ADRC) (ADRCs are Points Of Entry [POE]) to support personal decision-making in long term care for the expressed purpose of promoting the ability of individuals to remain integrated within their communities longer and reduce the reliance on high cost care

   - Increasing the use of evidence-based chronic disease management practices.

New York State

Over the span of the last six years an enormous amount of work has gone into renewing the State's long term care structure and delivery systems. Some of this effort was prompted by external forces (the Olmstead Decision along with the Federal Government's policy and programmatic choices) and some by actions that the state took independent of the national scene. From these efforts we have learned that:

- We are spending too much
- The way forward is to rebalance long term care to a consumer-centered system

There are effective ways to empower the consumer with unbiased information about the choices they have and provide consumers with the level of support they need to live a life which continues to have meaning and purpose for them

There are nine initiatives/actions in New York we believe have moved the state forward in reforming long term care. Taken together, they identify the foundation on which to proceed.

1. Project 2015

A dynamic, strategic planning initiative to make ready state government as our population becomes increasingly older and much more diverse. The effort was important in focusing NYS government on the long term care challenges and opportunities confronting the state in the near future. Contribution/Outcome: A substantial body of new information brought greater clarity to the implications of this unprecedented demographic shift. It produced an outline of directions for public policy to take as we become and older and more diverse state.

2. Most Integrated Setting Coordinating Council (MISCC)

The Council brought together the major state agency stakeholders, along with advocates for persons living with disabilities, to work in a deliberative process to guide New York's effort in reforming long term care. Contribution/Outcome: An extensive list of views of persons living with a disability, of principles to be followed by state agencies in service to individuals. The MISCC formulated principles and recommendations for state agencies relevant to long term care reform. It called for a consumer-centered long term care system.

3. The Health Care Reform Working Group

The bipartisan Working Group was charged by the Governor to describe the challenges confronting the state's health care infrastructure and to make preliminary recommendations on how to meet the challenges. The group's Interim Report (January, 2004) made a number of significant recommendations concerning the delivery of long term care. Contribution/Outcome: Chief among its recommendations was the establishment of a point of entry system for long term care and collapsing the Medicaid program's multiple long term care waivers into a single waiver.

4. Commission on Health Care Facilities in the 21st Century

The Commission completed its work at the end of 2006. The Commission's principal focus was on "right-sizing" New York's hospital and nursing home sectors. Contribution/Outcome: An understanding of state spending on nursing homes and their belief: "To create a future system where the right person is served in the right setting at the right price …consideration should be given to issues and opportunities beyond the walls of the nursing home."

5. The Community Alternative Systems Agency (CASA) Initiative

In the early 1980s, the then NYS Department of Social Services invited counties to submit applications to "demonstrate" new ways of organizing local governments' response to persons in need of long term care. This initiative did not provide new service dollars or new administrative dollars, rather a basic premise was that through organizing existing public long term care services in a different manner two things were possible:

- Administrative and service money could be used more efficiently
- Persons in need of long term care could be served more efficiently and effectively.

Contribution/Outcome: The more successful of these "experiments" demonstrated the "how-tos" for organizing local long term care to make it more responsive to the consumer and, at the same time, be very cost effective. The work done in this New York State initiative has produced an extensive body of technical information very relevant to how we should proceed to reorganize and modernize long term care.

6. The Partnership between the State agencies of Aging and Health

New York State Office for the Aging and executive staff of the New York State Department of Health's Office of Medicaid Management has developed a partnership to advance reform in long term care. Contribution/Outcome: To guide their work together the two agencies agreed to a vision for what long term care in NYS should be. This unique partnership, which brings together the (governmental) representatives of the payer and of the consumer, has been a productive force in promoting the public discourse on the future of long term care in NYS.

7. Community-Based POE System

NYSOFA and the NYSDoH held listening sessions throughout the state and more than 1,100 individuals participated in these sessions. At the listening sessions the consumers stated that they saw the long term care system as extraordinarily difficult to navigate, generally not responsive to their desires, preferences and aspirations as well as controlling; they, along with the payer, saw the system as broken. Contribution/Outcomes: The development of a community-based point of entry (POE) model to improve access to long term care (consistent with state and national trends and experience) and a proposed long term care restructuring waiver. Such as system would integrate:

- what we know consumers want
- what our past experience has shown us will work in New York

- what the evidence from research and other states' experiences tell us are important intervention and processes
- **CSCS believes that consumer-directed services is one component of a community-based long term care system. Safeguards for both consumers and community-based agencies need to be put into place. Community-based agencies need to have consistent funding to meet the fixed costs of the agency infrastructure to deliver services.**

8. Expanded In-Home Services for the Elderly Program (EISEP)

A program originally designed to serve growing numbers of older adults, who did not qualify for Medicaid, who were of low-to-modest incomes and who needed supports to remain independent. Operational experience with EISEP revealed that early intervention, while families were still intact, and building partnerships with the family, along with case management, low-level social services**,** and home care could divert or defer a frail person's use of Medicaid.

Positive customer and cost outcomes, over time, made EISEP a vital component within the state's broader long

Contribution/Outcome: Positive customer and cost outcomes, over time, made EISEP a vital component within the state's broader long term care system's change strategy. Lessons learned: about the value of case management in both coordinating care and forestalling going onto the Medicaid, thereby containing costs

9. New York's Long Term Care Restructuring Waiver

There are three broad goals and four objectives fundamental to the efforts to restructure how New York's Medicaid program finances, and delivers, community based long term care services in the original restructuring waiver. The broad goals are to:

- Strengthen the individual's ability to live in the community,
- Contain costs
- Rationalize the system

The underlying objectives are to:

- Eliminate the silos in Medicaid community based long term care services
- Achieve cost efficiencies
- Build partnerships with **family caregivers** who are caring for frail persons
- Emphasize early intervention as a person begins to experience frailty. Contribution/Outcome: The original waiver approach would modernize the service offerings/options covered by Medicaid. It would make Medicaid services more responsive to the preferences of the consumer, offer the services that are most appropriate, and contain costs.

The Consumer Perspective

Consumer Preference

It is one of those self-evident truths that we prefer to live in our own residences and receive support in our homes as we face frailty. It is, simply, what we would all want for ourselves. We want to stay connected to the community in which we live. We want control over our lives. We want to understand our circumstances and understand what choices we have. We want to have meaning and purpose to our lives. When we do need help we want to have support in the least intrusive and least costly way. Remaining home and, to the degree possible, in control of one's life, is good for us and it is good for the payer. There is a direct correlation to health and wellness (along with the ability to be independent) and depression. Depression increases when our ability to exercise control over our life decreases. This basic human condition, the need to control one's world, to live as independently as possible is "at the heart of human rights in old age (Hawkins, 1999)."

Remaining home, and, to the degree possible, in control of one's life, is good for us and it is good for the payer.

. . .to control one's world, to live as independently as possible is "at the heart of human rights in old age."

Considerable research has been done on the preferences of baby boomers. Similarly, a significant body of research exists on the preferences of minorities as a cohort within the baby boom generation. For both, the preference for living in the community and in one's own home is even more powerful than it is for the current, non-minority, older adult cohort. The "hell no, we won't go" generation along with minority older adults will drive the future delivery of long term care; that care will be community-based. The growth in poverty and in minority elderly equates with a growth in frailty. There is also a generational shift in expectations of how care will be delivered.

The shift to community-based care and away from skilled residential care is well underway. This decline is primarily a result of consumer preference and the development of community-based options. While the numbers of frail older adults have accelerated over the previous 15 years (a 25+% increase in the previous decade alone) nursing home utilization has been in decline. As a percent, there are fewer older adults residing in nursing home than there were 20 years ago (4.3% now versus 5.4%; a 20% decline – *Older Americans 2004*).

Consumer Confusion and Its Outcomes

Persons living with disabilities of any age, along with their families, face a confusing array of public and private long term care services and providers. Difficulty in navigating these networks, without assistance, often means:

- That people cannot find quality services
- They only know what they are told by those who are present where they enter the system (e.g. hospital discharge planners, personnel from a nursing home, personnel from a Certified Home Health Agency, aging service providers)
- They have limited to no ability to exercise informed choice
- They may spend too much money on the wrong services

- They may have a very real chance of being placed in a nursing home when their needs might have been met with community-based services (Young, 2007 [awaiting publication]; AARP, 2001)

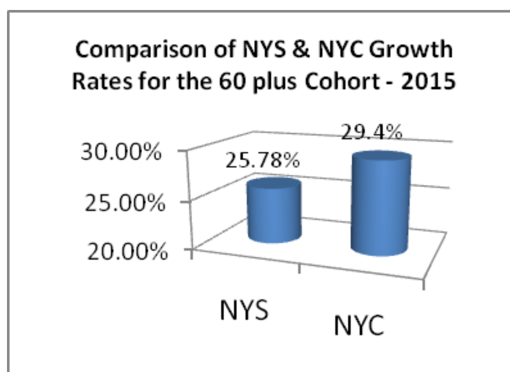
Consumers, and family members supporting them, want a "long term care consultant" to provide them with a "roadmap." They do not want lists of services that they do not understand let alone how the services relate to their particular set of circumstances (an evaluation of working caregivers at AT&T; unpublished, 1999). When they are supported by a "consultant" (someone very knowledgeable and someone who has nothing to gain from which services they choose) and when they have a roadmap describing how particular services can address the needs of the frail person, where to find quality providers, what are the costs, are there public supports available, and how to access any relevant public supports, they are more competent in the marketplace. Armed with the "consultant's" assistance and with the "roadmap" in hand, consumers make very good choices. They choose least restrictive, least intrusive, most appropriate and least costly services. Those are good choices for themselves and good for the payer.

Most persons entering the long term care system do so from the hospital. This transition from hospital to home or to a nursing home is particularly problematic. "Quite simply, elders of all income levels have difficulty locating adequate services." "Patients and caregivers must fend for themselves after discharge. …The system of care for older Americans is badly fragmented and outdated" ("Aging Today"; March/April 2007).

Consumer Profile and Projected Growth

New York State's population profile is shifting significantly due to three major demographic trends: (1) the aging of the State's population as a result of increasing longevity among the State's already large older adult population, (2) the passage of the transforming baby boom generation into the older adult cohort, and (3) the increasing diversity of the State's population including minorities, and LGBT older adults. This diversity is reflected in high rates of growth in the number minority older adults, in the number of people with disabilities, and growing numbers and types of nontraditional family households.

From 1990 to 2000, New York State's older population grew by a very modest 1/2%. However, that simple statistic hides a very significant demographic trend that is well underway and will continue into the foreseeable future. During the same time period the 75+ population grew by more than 15% and those most vulnerable, the 85+ population, grew by more than 25%.



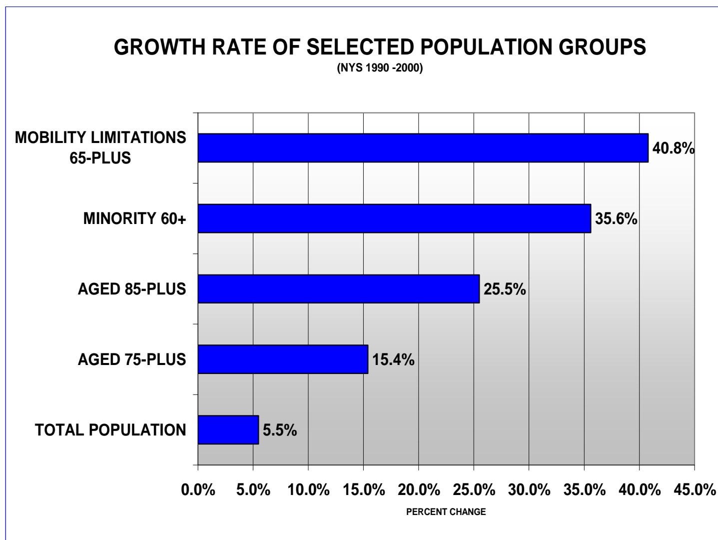
As we look to our future, we expect NYS growth rates in the 85+ cohort to be above 28% for the 15 year period, 2000-2015. Overall, the 65+ population will

grow from 12.9% of the total population in 2000 to approximately 17% by 2025.

In New York City, the 60+ population will grow at a rate significantly faster than the state taken as a whole (29.40% vs. 25.78%). Those over the age of 65 and living in the City will grow by 21%, an increase of nearly 200,000 older adults. And by 2015, we will have at least 20,000 more persons that have reached and/or exceeded age 85. To place remarkable demographic shift in context, during the same time frame, the City's population will grow by a modest 9%.

Vulnerable Populations' Growth Rates

The number of older adults most affected by long term care needs and compounding health, social and economic problems (the older aged, older adult with mobility limitations and minority older adults) is growing at a much faster rate than that of the general population. This is even more the case for New York City than it is for the state as a whole.



As reflected in the adjacent chart, in comparison to a 5.5 percent growth in the total population of the State since 1990, the 2000 Census attests to the dramatically greater rate of growth in the most vulnerable older adult population cohorts. Over the previous decade, the number of older adults (age 65+) with mobility limitations and minority older adults (age 60+) grew most dramatically - by 40.8 percent and 35.6 percent, respectively. The State's age 85 and older and 75-plus populations increased by 25.5 percent and 15.4 percent respectively.

...increases that will lead to the doubling of older adults with disability are already underway

Looking to the future there is every expectation that the growth of older adults living with impairments will accelerate. In a May, 2007 report, "Meeting the LTC Needs of the Baby Boomers; 5/07," The Urban Institute projects that the number of older adults with a disability will double by 2040. It is essential to understand that the increases that will lead to the doubling of older adults with disabilities are already well underway.

Consumer Demographic Implications: An Unprecedented LTC Scenario

This confluence of skyrocketing growth in numbers of older adults age 75+ and minority older adults occurs at the same time that we will be seeing dramatic declines in the number of workers and caregivers per older adult. On the near horizon, the aging of the baby boomers reaches maturity. The first boomers are now 61 and in four years they will become 65. Large numbers of them will begin to experience frailty; currently 38% of those over 65 have a disability. This creates a long term care scenario unlike any in our history. Half of all of our older adults age 85+ (our fastest growing cohort) require the daily assistance of another person to meet their basic needs. The reality of growing old, with minority status, means experiencing higher rates of frailty at a younger age than non-minority older adults (e.g. 55+% of Puerto Ricans 65 or older have a disability [U.S. Census, 2001]). It also means that you are three times more likely to be poor than are your white counterparts. In summary, we have:

- Dramatic increases in the old, old, half of which require direct support.
- Rapid rates of growth of minority older adults who have lower incomes and are beset with a higher incidence of frailty than the general population.
- With lower birth rates, we are witnessing a shrinking workforce and fewer caregivers.
- NYS has an outflow of well and wealthy older adults and an influx of frail and poor older adults.
- The boomers will begin to confront serious disability within the next five years.
- The boomers' retirement income will be less likely to be based on fixed pensions and they will be more subject to fluctuations in the economy.

Because of these demographic shifts, we will see escalating demand for long term care services along with rising unit costs ("Meeting the LTC Needs of the Baby Boomers; Urban Institute; 5/07). The fastest growth in demand will occur among those who are poor and who will qualify for publicly funded services, especially Medicaid. Shortly, New York State's Medicaid program will return to double-digit inflationary growth, much like what it witnessed in the early to mid 1980s and again in the early 1990s. Unlike the 1990s, unless long term care reform occurs, the Medicaid growth rate will not drop below annual double digit growth, it will accelerate.

Unlike the 1990s, unless LTC reform occurs, the Medicaid growth rate will not drop below annual double digit growth, it will accelerate. . . .our current model for delivering long term care is unsustainable.

It is an undeniable reality that our current model for delivering long term care is unsustainable.

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