

Report of the Long-Term Care Reform Committee

**New York State Bar Association
Elder Law Section**

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The first printing of this Report, on February 15, 2005, was distributed in Albany primarily to legislators and their aides on committees whose responsibilities include the Medicaid program.

This printing adds an Appendix C with a digest of basic rules for Medicaid coverage at home and in nursing homes. It also corrects some typographical errors in Chapter 6 on the proposed Long-Term Care Insurance Compact.



Report of Long-Term Care Reform Committee

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Executive Summary

Efforts to chart the future of long-term care face a host of challenges, high among them changes in the demographic landscape and the spiraling costs of long-term care.

- Nationwide, more than 35 million people are age 65 or older; the number is expected to be 70 million by 2030. By 2025, the over-65 population in New York State will be 3.3 million, an increase of 30% since 1995.
- The under-60 population will decline, reducing not only the number of wage-earners to pay taxes to finance programs such as Medicaid but also the availability of family members and paid workers available to care for the elderly.
- Court decisions such as *Olmstead* have made it clear that there will be increasing scrutiny of whether institutionalization is justified.
- New York's Medicaid program spent \$6 billion on nursing home care in 2003; New York spends more Medicaid dollars for nursing home and other institutional care than any other state, nearly double the amount spent by Pennsylvania, the next highest-spending state.
- New York ranks 18th among the states in the percentage of its elderly who live in nursing homes, but its percentage of those age 65 or more in nursing homes (4.4%) is higher than the national average (3.8%).
- Rational discussion of Medicaid's role is hindered by myths such as the perceptions that Medicaid recipients fraudulently shelter assets, "millionaires are on Medicaid," and Medicaid recipients leave large estates.
- Planning is hampered by insufficient data on issues such as the true effect of asset transfers on Medicaid costs, how long nursing home residents pay privately care before they receive Medicaid, and whether Medicaid is effectively administering the rules for spousal refusal.
- No single financial solution is likely, but promising approaches include long-term care insurance, the "Partnership" policy program, efforts to encourage assisted living options, incentives to remain at home, reverse mortgages, pre-death benefits from life insurance.

Proposal for a New York State Long-Term Care "Compact"

To encourage focused discussion on options that would avoid harm to New York State residents who must turn to the government for assistance, yet also curb the expenses of the Medicaid program, Chapter 6 of this Report proposes a "Compact" in which New York State and its chronically ill citizens would agree to share the risks of paying for long-term care. The key elements of the Compact:

- Rather than be required to divest themselves of virtually all of their assets before qualifying for Medicaid, individuals diagnosed as chronically ill would become Compact participants by pledging, at their option, either a set maximum amount (a figure such as \$300,000 based on the average cost for three years of nursing home care) or up to one-half of their assets, whichever was smaller, to pay for their long-term care needs.
- Participants would then pay for their own medical and long-term care (either for home health aides or for care in a nursing home) until the amount spent totaled their pledge. They would be allowed to keep all of their income while paying privately for their care. After spending the asset amount pledged, they would have two options.
- Under the first option, they would qualify for standard Medicaid coverage and be required to provide their income, minus the standard allowances, to Medicaid.
- Under the second option, they could elect to remain private patients but would qualify for Medicaid to subsidize their long-term care expenses at a rate equal to 90% of Medicaid's normal rates. They would pay 25% of their income to Medicaid from that point onward. The remaining 75% and assets they retained would be used to pay the balance of their expenses for long-term care and all other related medical expenses (Medicaid would pay only for long-term care).
- For Compact members, the assets they would retain (and for those who took the second option, the remaining 75% of their income)

would provide resources to pay for needs such as occasional private duty nurses or assistance from geriatric care managers that are not available from Medicaid.

- To show how the Compact would work in practice, Chapter 6 uses an illustration based on a scenario for fictional but fairly typical

“Mrs. Jones”—an elderly woman with \$2,000 in monthly income and \$300,000 in assets who requires two years of home care, followed by anywhere from three to five years of care in a nursing home. The bottom-line differences between standard Medicaid and the Compact outcomes are shown in the following table.

Standard Medicaid

Mrs. Jones lives 5 years		Mrs. Jones lives 7 years	
Total Mrs. Jones Cost	\$ 92,400	Total Mrs. Jones Cost	\$135,600
Total Medicaid Cost	\$ 90,570	Total Medicaid Cost	\$156,870

First Compact Option

Mrs. Jones lives 5 years		Mrs. Jones lives 7 years	
Total Mrs. Jones Cost	\$168,000	Total Mrs. Jones Cost	\$196,800
Total Medicaid Cost	\$ 28,500	Total Medicaid Cost	\$109,200

Second Compact Option

Mrs. Jones lives 5 years		Mrs. Jones lives 7 years	
Total Mrs. Jones Cost	\$164,417	Total Mrs. Jones Cost	\$188,317
Total Medicaid Cost	\$ 36,850	Total Medicaid Cost	\$123,400

Digest of the Chapters

By Howard F. Angione

The Demographic Landscape

Members of the “Baby Boom” Generation¹—officially anyone born between January 1, 1946, and December 31, 1964—need only look at the long-term care expenses of their parents and grandparents to worry about how they will finance the care they will ultimately need for themselves.

Nationally, more than 35 million people are age 65 or older. That number is expected to increase to 70 million by 2030.²

In New York, the Office for the Aging estimates that by 2025 the over-65 population in the state will be 3.3 million, an increase of 30% over 30 years.³ Another 1.1 million residents will be in the 60-65 age range.⁴

During the same time, however, the under-60 population will not be increasing at the same rates. It is expected to total 15.4 million in 2025, an increase of only 3% over 30 years.⁵

Not only does the decline of the under-60 population presage a decrease in the percentage of wage-earners contributing to Social Security and paying the taxes that finance programs such as Medicaid assistance, it also means that fewer individuals will be available to provide the home care that is the setting in which a majority of the elderly receive care today. This trend is likely to be accelerated by the decline in the number and size of extended families whose younger generations now provide care for their older relatives. At the same time, the percentage of available paid workers in relation to the number of elderly individuals will also be declining.⁶

Statistically, the average expected lifetime nursing home stay was 2.7 years in 1995, but a projected 7% to 8% of those 45 or older could need 5 years or more of nursing home care during their lifetimes.⁷

Limitations on Today’s Projections Today’s projections do not necessarily have the certainty that a graph may imply. A variety of changes in medicine and lifestyles could well lead to a demographic landscape far different than projections alone may suggest.

On the plus side, improvements in medical care and lifestyles may decrease the need for care of individuals in their 60s and 70s. On the minus side, longer life expectancies may well lead to a need for chronic care late in life for even larger numbers of the elderly.

With the benefits of hindsight, it appears that an “institutional bias” developed in the public’s perception of long-term care in 1965 when the government’s early efforts to provide financial assistance for long-term care focused almost exclusively on funding for nursing home care.⁸ Development of alternatives was slowed by this perception, but one of the challenges that remains is to determine how future needs can be met by efforts to foster alternatives such as home care, adult day care, respite services, congregate living settings, assisted living and continuing care retirement communities.⁹

Court decisions such as *Olmstead v. L.C.*¹⁰ have also made it clear that there will be increasing scrutiny of whether institutionalization is justified. In *Olmstead*, the U.S. Supreme Court determined that the “most integrated setting” provision of the Americans With Disabilities Act prohibits unnecessary institutionalization of individuals who are eligible for publicly funded programs. The long-term impact of this decision is impossible to determine at this time, but the ultimate findings of New York’s Most Integrated Setting Council¹¹ will be vital in developing plans for the future.

The Costs of Long-Term Care

Even if greater creativity in finding solutions can slow the pace of increases in government expenditures for long-term care, the current baseline figures provide an ominous foundation for future projections.

In fiscal year 2003, New York’s Medicaid program spent more than \$8.7 billion on institutional care—\$6 billion on nursing home care, \$1.2 billion at institutional care facilities for the developmentally disabled, and \$1.5 million for the mentally retarded.¹² In addition, \$3 billion was spent on various types of home care such as personal and home health services, private duty nursing and hospice programs.

New York now spends more Medicaid dollars for nursing home and other institutional care than any other state—nearly double the next highest spending state, Pennsylvania.¹³ New York also has the most nursing home residents of any state in the nation—109,788 out of 1,346,686 persons living in nursing homes in the nation.¹⁴ New York also uses Medicaid funds for a greater percentage of its population than the national average—75% of its nursing home resi-

dents receive Medicaid assistance compared with a national average of 67%.

New York ranks only 18th among the states in the percentage of its elderly who live in nursing homes, but its percentage of persons age 65 and over who are in nursing homes (4.4%) is higher than the national average (3.8%).¹⁵

According to the most recently available figures, the average private-pay cost for nursing home care in New York State is \$269 per day, or \$98,185 per year, compared with a nationwide average of \$180 per day.¹⁶ The New York figure is deceptive, however. Care in downstate areas now routinely exceeds \$300 per day and can range to \$400 or more per day.¹⁷

Medicaid has become the single largest appropriation in many New York county budgets.¹⁸ Counties report that Medicaid caseloads have increased by an average 7% and that in 2002 counties were budgeting an average 10% caseload increase.¹⁹

Myths and Unanswered Questions About Long-Term Care Financing

One year in a nursing home costs \$109,500 at a \$300/day rate, or \$135,050 at an increasingly common rate such as \$370 per day.

When round-the-clock care is provided at home by non-family members, a per-hour rate of even \$15.41 yields the same \$370 per-day expense as care in a nursing home.

Confronted with these realities, it is not surprising that individuals who need long-term skilled care ultimately have no alternative except the Medicaid program. In the words of the Court of Appeals, it is not surprising that “middle class people confronted with desperate circumstances choose voluntarily to inflict poverty upon themselves” as the only way to obtain “government assistance in the defraying of the costs of ruinously expensive, but absolutely essential, medical treatment.”²⁰

Nevertheless, rational assessment of the Medicaid program continues to be plagued by mythological stereotypes and the lack of sufficient data to analyze the impact of existing rules for coverage.

Myth: Medicare Will Pay Unfortunately, too many people only learn that Medicare will not pay for long-time care when they are faced with the need for it. Aside from limited coverage for a maximum of 100 days after a hospital stay, Medicare does not pay nursing home bills or the cost of extended in-home services. Some high-end private insurance policies provide longer coverage, but it seldom lasts more than a few months beyond the end of Medicare’s 100

days. Even within the 100-day period, neither Medicare nor the typical health insurance policy covers strictly “custodial” services for those who have ailments such as arthritis, dementia or Alzheimer’s disease but do not need skilled nursing care and will not benefit from rehabilitation.²¹

Myth: Medicaid Recipients Fraudulently Shelter Assets High among the frequently promulgated myths is the notion that individuals receiving Medicaid have somehow fraudulently concealed assets. If they have, they have committed perjury on their application forms that require a statement identifying all income, resources and gifts made. And if assets were sheltered, Medicaid retains the statutory right to make a claim for reimbursement from the estates of those who received services provided through the Medicaid program.

To qualify for Medicaid, individuals may retain only \$4,000 in assets after providing for their funerals and retain a \$50 per month “personal needs allowance” from their income.²² If an individual is married, his/her spouse may retain title to a “homestead” (a house, coop apartment or condominium) if they have one, up to \$95,100 in assets, and \$2,378 in income.²³ By filing a “spousal refusal,” a spouse may retain additional assets and decline to contribute 25% of any income beyond the \$2,378 figure. Medicaid retains the right, however, to sue the refusing spouse to obtain reimbursement from assets and income for amounts that the program has paid on behalf of the recipient. The extent to which Medicaid is pursuing this option is unclear.²⁴

Medicaid’s “tape match” process provides a mechanism to discover assets not disclosed on an application. Periodically, the local agencies administering Medicaid receive tapes from the U.S. Internal Revenue Service listing interest on bank accounts and other assets. If the Social Security number on such a report matches the Social Security number of a Medicaid recipient, the Medicaid agency checks to see if the asset was disclosed on the original application (and presumably depleted after the period covered by the tape). If it was not, the agency asks for an explanation.

Myth: Millionaires Are Receiving Medicaid Any current millionaire who is receiving Medicaid has probably filed a fraudulent application. If the recipient’s spouse has more than a homestead and \$95,100, the Medicaid program is failing to use its statutory right to obtain reimbursement for expenditures on behalf of the recipient.²⁵

Any former millionaire on Medicaid would have had to give away his/her millions more than three years before seeking Medicaid assistance, or five

years before seeking Medicaid if the millions were placed in trust. The transfer penalty rules²⁶ applicable to those who do not divest themselves of assets until faced with imminent nursing home admission would require a millionaire to retain a minimum of as much as \$346,032 (on Long Island) to pay for nursing home care in the next three years before giving away any remaining assets.

Myth: Medicaid Recipients Leave Large Estates Medicaid has a right to recovery from any assets of a recipient that are subject to administration or probate in the Surrogate's Court. Most local Medicaid agencies periodically send a representative to Surrogate's Courts to determine whether the Social Security numbers of decedents match those of deceased Medicaid recipients or their spouses.²⁷

Unanswered Question: What Is the Effect of Asset Transfers on Medicaid Costs? There is insufficient data to answer the question in New York State, but a nationwide study estimated that if every older individual with a significant incentive to divest countable assets to become eligible for Medicaid actually did divest every penny, the amount transferred would equal about 4% of Medicaid nursing home expenditures.²⁸

Unanswered Question: How Long Do Medicaid Recipients Pay Privately? No analysis is known to be available, but every application for nursing home Medicaid requires information on the extent of private-pay coverage in the nursing home. Without violating any individual's privacy, this information should be analyzed and made available to those who must make decisions about eligibility rules for Medicaid.²⁹

Unanswered Question: Is Medicaid Effectively Administering the Rules for Spousal Refusal? Empirical evidence drawn from the experiences of elder law attorneys suggests that there are great varieties among the counties in the way the spousal refusal rules are interpreted.³⁰

Financial Strategies for the Future

No single financial solution is likely to be found to the challenges that lie ahead for long-term care, but a mix of complementary actions holds the potential for incremental improvements in the overall picture.

Long-Term Care Insurance Policies that cover long-term care needs at home and/or in a nursing home are a promising vehicle for individuals who seek a way to protect their assets and to provide for their own care. The policies are not a cure-all panacea, however. The cost (\$4,000 or more per year for a typical couple in their early 60s) is beyond the

means of many, and it is generally prohibitive by the time individuals are in their late 70s. Other potential purchasers have medical conditions that preclude them from obtaining coverage.³¹

Expansion of tax incentives for purchase of policies could lead to greater acceptance of the concept.³²

"Partnership" Policies These policies represent an early attempt to encourage individuals to purchase insurance that would allow them to retain assets and qualify for Medicaid after the minimum three-year coverage provisions of the policies had paid for the first three years of their care in a nursing home.³³

The value of the partnership approach is yet to be fully calculated. A provision that required an individual to return to New York State to obtain Medicaid coverage has discouraged some from purchasing the policies, although recent changes may allow states to make reciprocal agreements on this matter.

Expansion of Assisted Living Options Many elderly who can no longer function on their own do not need the extensive services provided in nursing homes, but can benefit from various types of senior living homes, assisted living facilities, continuing care communities, etc.³⁴

Assisted living costs that can range well beyond \$3,000 per month when an individual needs supportive services that go beyond meals and housekeeping have prevented many of the elderly from using this option. Expansion of the "Assisted Living Program" now available on a limited basis may help to address this issue by allowing eligible individuals to receive assistance from the Medicaid program that is otherwise not available in most assisted living facilities.³⁵

An October 2004 law authorizing eight fee-for-services communities will provide an opportunity to gauge the long-term viability of a benevolent care fund to make assistance available to qualifying subscribers unable to pay certain fees.

Incentives to Remain at Home Modifications in homes, perhaps encouraged by tax deductions, could make it possible for some to remain home.³⁶ Other options include home sharing, day care programs and respite options that allow family caregivers to obtain occasional breaks in what often is an otherwise multi-hour, seven-day-a-week responsibility.³⁷

Reverse Mortgages These offer an opportunity for the elderly to benefit from accumulated equity in their homes. Up-front costs are significant, however, easily topping \$10,000 on a \$200,000 loan.³⁸ Programs to reduce costs and interest rates might lead to greater acceptance of this option.³⁹

Pre-death Benefits from Life Insurance New York's 2004-2005 budget calls for a feasibility study of allowing life insurance companies to pay accelerated benefits in the form of some or all of the insured's death benefits before death.⁴⁰

"Viatical Settlements" allow the sale of life insurance for a sum less than the death benefit when the insured is terminally ill. "Life Settlements" allow such a sale if life expectancy is longer than 12 months. Both require careful monitoring.⁴¹

Rethinking the Role of Government Some have suggested that public financing of long-term care be viewed as analogous to public financing of retirement security. AARP and others support the development of a broader, social insurance program that would form the basis of long-term care financing.⁴²

Proposal for Long-Term Care "Compact"

To encourage focused discussion on options that would avoid harm to New York State residents who must turn to the government for assistance, yet also curb the expenses of the Medicaid Program, the Committee on Long-Term Care Reform offers a proposal to create a "Compact" program.⁴³ The objective is to provide an alternative to the impoverishment process as the way to obtain government assistance.

Once individuals were diagnosed as chronically ill, instead of frantically giving away their assets to qualify for Medicaid assistance, they would "pledge" to use a defined amount of their then-existing assets to pay for their long-term care needs. The amount pledged would be either a set maximum (perhaps \$300,000 as the average three-year cost of nursing home care, using the \$98,185 yearly average⁴⁴), or up to one-half of their assets, whichever was smaller.

Until they spent that amount, they would remain responsible for their own care without Medicaid assistance, whether at home or in a nursing home. During that time, however, they would have full access to all their income and their assets, rather than be reduced to a poverty level of assets and a net income (after contributing the amount required by Medicaid as a condition of coverage) that is seldom adequate to meet the needs of those who remain at home.

Once they had spent their pledged amount, Compact participants would have two choices—they could either become regular Medicaid recipients subject to its normal rules, or they could retain a "private pay" status but become eligible for Medicaid to subsidize their long-term care costs at the rate of 90% of its normal payment rates. Those who chose the first option would be required to turn over to Medicaid

virtually all of their income (all but \$50 if in a nursing home or a figure such as the current \$677 that home Medicaid recipients are allowed to retain). Those who chose the second option would give Medicaid only 25% of their gross income, but out of the remaining 75% they would be required to pay the portion of their long-term care expense not covered by the Medicaid subsidy at its 90% rate, and to pay for their ancillary medical expenses.

Whichever option they chose, however, they would still retain the portion of their assets not covered by their "pledge." These funds would be available to pay for services not covered by Medicaid. Notable among them would be items such as the services of a private duty nurse if they were seriously ill, or assistance from a geriatric care manager, particularly if they remained at home but needed someone to handle errands, manage finances, etc.

In short, rather than continuing as the "first resort" for so many, Medicaid would become a true "safety net" for those whose needs grew so large that they had to expend half of their assets on long-term care. There would be no need for "look back" periods and the other complications associated with Medicaid applications today. When the time came to seek Medicaid assistance, Compact members would simply need to produce receipts for long-term care expenditures equal to the amount they had pledged when they joined the compact.

An illustration of how the Compact would work in the case of a fictional but fairly typical elderly woman is provided at the end of Chapter 6.

Caregiving Strategies

Concerns about containing costs should not blot out consideration of long-term actions designed to improve the quality of care.

Programs are needed to assure respect for everyone's individual dignity and assure that they do not receive treatments that are unnecessary, ineffective or harmful. Steps should also be taken to facilitate changes in the training of health care professionals and finance initiatives to refocus the use of healthcare dollars. Much remains unknown about medical diagnosis and interventions. Among the least well understood are chronic conditions and age-related ailments.⁴⁵

Endnotes

1. 1.2
2. 1.2
3. 1.3
4. 1.3

5. 1.3
6. 8.2
7. 1.7
8. 8.1
9. 1.7, 3.2. 8.2, 8.5
10. 2.1 *et seq.*
11. 2.4
12. 2.2
13. 2.2
14. 2.2
15. 2.2
16. 4.1 17. 4.1
18. 8.2
19. 8.2
20. See Introduction
21. 4.1
22. 5.1
23. 5.1
24. 5.2
25. 5.2
26. 5.1, see note 5.
27. 5.1
28. 5.2, endnote 9
29. 5.2
30. 5.2
31. 4.3, 4.6, 4.7, 5.3, 8.5
32. 4.14
33. 4.12, 5.4
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37. 3.2, 5.6
38. 3.2
39. 3.6
40. 4.9
41. 4.9
42. 8.3, 8.4, 8.5
43. Chapter 6
44. 4.1
45. Chapter 7

Introduction

By Louis W. Pierro

Chair, NYSBA Committee on Long-Term Care Reform

Consider the following quote:

[N]o agency of the government has any right to complain about the fact that middle class people confronted with desperate circumstances choose voluntarily to inflict poverty upon themselves when it is the government itself which has established the rule that poverty is a prerequisite to the receipt of government assistance in the defraying of the costs of ruinously expensive, but absolutely essential, medical treatment. N.Y.S. Court of Appeals, *In re Shah*, 95 N.Y.2d 148, 163 (2000).

What has led New York State's highest court to make this bold statement? Is our health care system in such dire straits that honest, average, hard-working Americans who have survived the Great Depression, World War II, the Cold War, Vietnam and all of the personal and public tragedies during their lifetimes, now face the real possibility that an illness at the end of their lives will render them destitute in a matter of 1, 2 or 3 years, wiping out a lifetime of sacrifice and savings? Have we as American citizens abandoned our dream of building a better America by providing our children and grandchildren with equal opportunity to life and liberty, which cannot be guaranteed without adequate health care?

With federal government revenues dwindling as a percentage of gross domestic product, and spending on domestic programs such as Social Security, Medicare and Medicaid bearing the cross for a society whose policies have shifted to foster the accumulation of wealth within a privileged class, New York State and its counties find themselves wedged between unfunded federal mandates and an aging population that will continue to demand more services with less money to pay for them.

In 2001, the Elder Law Section of the New York State Bar Association formed a Task Force on Long-Term Care Reform to study the issues of health care, housing and services for New York's seniors and persons with disabilities. The initial mission of the task force was to follow up on the work of the 1996 Governor's Task Force on Long-Term Care Reform. The 1996 group had attempted to set the stage for securing a system that had developed instability in its foundation, and which under the projected weight of

the mounting population of frail elderly and the disabled, faced the real possibility of a future collapse.

The work of the Elder Law Section's Task Force, now called the Committee on Long-Term Care Reform, began in 2001 during a period of relative fiscal security, with a federal budget that for the first time had shown surpluses, and state and county budgets that were not in crisis situations. The view was forward-thinking, with demographic changes to our population and the anticipated upheaval in the health care system driven by the retirement of the Baby Boom generation beginning in 2010 as its focus. Today, as we publish the Report of our Committee, the crisis in long-term care has been accelerated by a series of events that has thrown fuel on the health care and long-term care fire, including capitation of the Medicare and Medicaid programs. From Washington, to Albany, to every county seat in New York State, long-term care reform is at the top of the agenda.

Gravity of the Current Problems

To appreciate the gravity of the current problems plaguing the health and long-term care systems and the Medicaid program, one need only read the headlines published daily across this state and the nation. The federal government recently announced that it "could save \$60 billion in Medicaid funds over the next ten years through the closure of 'loopholes' that allow middle class seniors to receive benefits, the ban of 'accounting gimmicks' used by states to receive more federal matching funds and the reduction of spending on prescription drugs."

The *New York Times* reported on February 8, 2005, that "Dr. Mark B. McClellan, Administrator of the Centers for Medicare and Medicaid Services, said the proposals would reduce payments to pharmacies and state governments *without hurting Medicaid recipients.*"

The *Washington Post* on February 9, 2005, reported: "The budget proposal also includes recommendations for long-term Medicaid reforms to establish a 'more sustainable cost structure.'" Although the budget proposal includes few details, the administration officials said they hoped to 'build on the success' of SCHIP, which could indicate that the administration plans to *implement a block grant system for Medicaid.*" (emphasis added) The federal government's desire to capitate health care costs under both the

Medicare and Medicaid systems is premised upon federal deficits, and the 'unsustainable growth' of programs that must serve a population of increasingly aging and needy health care recipients.

In a February 8, 2005 *New York Times* editorial entitled "Avoiding the Real Challenge," the dynamics of the federal deficit and its impact on New York State were brought into focus. "Programs benefitting low income citizens, like community development and health care, are destined to bear close to half of the cuts even though they accounted for less than 10% of the spending increases during the first Bush term. Some of the cruelest cuts would affect hundreds of thousands of working poor people who rely on childcare assistance and food stamps." What has caused this problem? According to the *Times*, "The deficit problem is a reflection of lowered revenue more than high spending . . . meanwhile, expensive outlays will continue for the Pentagon, homeland security and mandated costs like Medicare."

Responses by the States

Other states have reacted to the specter of a block grant program, including Florida, which is entertaining a proposal that would allot money to its 2.1 million Medicaid recipients to buy their own health care coverage from managed care organizations and other private medical networks.

On January 23, 2005, the *New York Times* reported: "If enacted, the program would make Florida the first state to allow private companies, not the state, to decide the scope and extent of services to the elderly, the disabled and the poor, half of them children." By adopting a second tier of capitation, the Florida program would be the first to allow private companies to make decisions without government interference as to the allotment of health care services to Medicaid recipients.

According to Governor Jeb Bush, "Our proposals put the focus back on the patient by encouraging strong patient-doctor relationships and allowing competition in the market to drive access and quality of care." With the demand for publicly financed health care certain to increase due to the skyrocketing cost of private health insurance, and a swelling population of those in need of long-term care, the impact of block grants and a capitated system on both consumers and providers of services must be carefully scrutinized.

The Burden in New York

In New York State, there is an added burden on local governments, which bear a portion of the cost of Medicaid services. In 2004, it was the effort of New

York State's counties and local governments that brought the Medicaid budget issue to a head, as the "local share" of Medicaid expenditures has swamped county budgets.

The total cost of Medicaid in New York State for fiscal year 2004-05, which ends in April, is projected to be \$44.5 Billion. That is up from \$24 Billion in 1995, and Medicaid is the fastest growing part of the state's \$100 Billion budget.

Of the \$44.5 Billion, the federal share is \$22.9 Billion, and the state's share is \$14.5 Billion. County governments and New York City must pay the balance of \$7.1 Billion, a total of approximately 16% of New York's Medicaid budget.

New York is one of very few states that mandate local counties to share in the cost of Medicaid benefits, a policy that has an uneven impact on counties with the lowest income and tax base. Conversely, these counties also have the poorest populations in need of the greatest amount of public health care.

Impact of New Programs

One critical fact that must be focused on with regard to the near doubling of New York State's Medicaid budget over the last 10 years, and the related rise in county Medicaid expenditures, is that the vast majority of the increase is due to new programs that were implemented over that time period in New York State, including Family Health Plus and Child Health Plus.

As individuals have lost their employment, and employers have been increasingly unable to afford health care coverage, enrollment in the health programs for families and children has vastly exceeded expectations. New York State expected to enroll approximately 350,000 people in its new health programs, but instead attracted approximately 550,000 people, resulting in costs greatly in excess of expectations. In addition, the costs of health benefits and prescription medications paid for through these programs are financed 25% by the counties, whereas local governments pay only 10% toward the cost of traditional long-term care services. Contrary to popular belief, in New York State the cost of those long-term care services, which include both nursing home and home health care, has gone up only slightly more than the 3% annual inflation rate.

How have New York State's population of frail elderly, disabled individuals, and seniors who are likely to become future consumers of long-term care services been affected by the various forces at work in shaping government policy? The Report of the Committee on Long-Term Care Reform outlines in detail

the demographics of New York State's population, and the startling facts that must be addressed in current policy in order to avoid a complete health care catastrophe.

Consider, for example, that estimates show that by 2025 the over-65 population in the state will increase by approximately 30%, while the under-60 population during that same time period will increase by only 3%. The impact of this demographic change on the workforce, and the base of taxpayers who must bear the burden for all government programs including Medicaid, by itself creates a burden on the long-term care system that renders it unsustainable.

At the same time, the cost of care in New York State has escalated, with the average private pay nursing home rate now at \$269 per day, or \$98,185 per year. The Report also discusses the *Olmstead* decision, which resulted in President Bush signing the "New Freedom Initiative," requiring that states provide care to individuals in the least restrictive setting possible. *Olmstead* has far-reaching implications for all states including New York, and must be considered in any policy-making that will impact the provision of services to the elderly and persons with disabilities.

Another area that has seen dynamic change nationally is the senior housing market, with assisted living, continuing care retirement communities and other home-care options being developed. The choices available in New York State, and the cost of care in each, are carefully examined in the Report, including positive recommendations to improve upon the current system through development of alternatives to nursing home placement, with a particular emphasis on community-based services.

Planning for the Future

In the end, we must all focus on what is truly at stake in this debate—the health and lives of real people. There is a scarcity of empirical data on how the cost of long-term care has gotten to where it is, especially in the area of financing long-term care through Medicaid. The Elder Law Section Report strongly encourages the use of private long-term care insurance, and the promotion of new and creative products that can penetrate a younger age group, so that the sale of policies will cover a sufficient number of individuals to curb the rising cost of public financing.

The Report also addresses deficiencies in the current market in New York State for long-term care insurance, the New York State Partnership for Long-Term Care, new and proposed changes to tax policy

to encourage the use of long-term care insurance and other issues surrounding private insurance products.

It is clear to anyone who operates in the "trenches" of the Medicaid system, as Elder Law attorneys do, that a client is never well-served if counseled to rely upon Medicaid to finance long-term care. The access to services and the choice of providers, two critical elements in any individual's health care and long-term care plan, are severely limited under the Medicaid program.

Contrary to popular belief, millionaires are not lined up at the door of the Social Services office anxious to apply for Medicaid benefits. One need only visit a Social Service office to understand what population is compelled to rely upon Medicaid for its existence: those who are now or quickly become bankrupted by the astronomical cost of health care and long-term care.

Although long-term care insurance is an integral part of the solution to the long-term care crisis, it cannot be relied upon as the only solution, and a proposal for complete reform of the Medicaid system is included in the recommendations contained in the Report. Prepared by Gail Holubinka, the former director of New York State's Long-Term Care Partnership Program, the "New York LTC Compact" is a creative and resourceful plan that could give real people meaningful choices in financing long-term care services. The Report contains other proposals for new long-term care initiatives, and for the reconsideration of the existing Medicaid program.

Medicaid is often cited as the "payor of last resort" for long-term care services, but it has in fact become much more than that—it is now the *only* payor for many services that were once contained in traditional health benefits under Medicare and private insurance. The curtailment of traditional health benefits, and the increasing cost of those benefits, have compelled many individuals to rely upon Medicaid when a critical illness strips them of their ability to live independently. Medicaid eligibility rules require *total impoverishment* prior to allowing eligibility, however, and are biased in favor of institutional care, resulting in premature institutionalization, the complete opposite result of federal and state policy. The complex maze of rules and regulations governing Medicaid eligibility is difficult even for the courts to comprehend. The Committee Report addresses the current state of the Medicaid program in New York, and makes several recommendations regarding how it could be made more efficient, and improved upon.

The Report concludes with a long-range view of the alternatives for long-term care reform, relying heavily on New York State's own work in preparing

“Project 2015: State Agencies Prepare for the Impact of an Aging New York.” As critical as the current budget crisis is to state and county governments, the impact of the baby boom generation beginning to age into its 70s and 80s will dwarf the current problem. As stated by Ken Dychtwald, Ph.D., in his testimony before the U.S. Senate Special Committee on Aging on September 20, 2004:

When the first U.S. census was taken in 1790, half the population was under the age of 16 and less than 2 percent of the 4 million people who responded were 65 and older. Few men and women could expect to live more than 35 to 45 years—about the same as in Europe and Asia. As a result, societies rarely concerned themselves with the needs, problems or aspirations of their aging citizens. The elderly were too few to be of much consequence. However, beginning in the 20th century, something remarkable began. Thanks to advances in sanitation, public health, food science and modern medicine, most of us will have the opportunity to live long lives. During the past 100 years, our life expectancy at birth has climbed from an average of 47 to nearly 77 today. We are creating—for the first time—a mass population of long-lived men and women. However, it’s important to remember that this longevity revolution is not over. Already, the longer you live, the longer you’ll get to live. A 65 year old today has an average life expectancy of 83 years and there are many indications that with further scientific breakthrough, living to 90 or even 100 years will become commonplace for today’s middle-aged generation.

In fact, this longevity revolution may well create greater changes in our lives—our families, our communities, our industries and our economy than either the industrial or technological revolutions of previous eras. (Emphasis added)

Dr. Dychtwald’s testimony went on to describe new and innovative ways for seniors to redefine their retirement, remain vital and active, and remain an integral part of society and their families’ lives well into their 80s and 90s. New York State must be just as creative in its approach to the problem of long-term care financing, and take a view that targets reform of the infrastructure and funding modalities for long-term care which can address the problems of the coming baby boom generation.

On November 5, 2004, experts from the long-term care and technology industries from around New York State, as well as representatives from state government, gathered at the Albany Law School’s Government Law Center for a roundtable discussion on long-term care in the 21st Century. Among the topics discussed at the roundtable were technological innovations already used in long-term care, the potential of technological innovation to ensure medication compliance, and barriers to successful implementation of new technologies. New York State has become a leader in fostering and building a high technology economy, and has an opportunity to become the national leader in the development of jobs and the creation of new innovative businesses that can reduce the rising cost of long-term care for consumers, providers and government.

The Elder Law Section of the New York State Bar Association stands ready, willing and able to assist in the development of solutions to the current crisis in long-term care financing, and the creation of innovative solutions to ensure that quality long-term care services are available for New York’s future generations.

Chapter 1

The Demographics and Economics Of Long-Term Care in New York

OVERVIEW: As the over-65 population grows nationwide, current trends indicate that it will increase 35% in New York State by 2025, yet be accompanied by a decline in the under-60 population that provides a large percentage of the services for the elderly.

In 2004, the Legislature adopted recommendations of a 1996 task force regarding long-term care insurance, “partnership” insurance policies and regulation of assisted facilities, but other issues raised by the task force have not been addressed.

Surprisingly to some, New York relies less on institutions to care for the elderly than other states, but its home care expenditures are extensive. In 1995, Medicaid-financed home care services in New York accounted for 35% of all Medicaid spending for home care in the nation.

Projections using current demographics data and spending trends point to dramatically increased spending for long-term care, yet even these may be conservative. Shortages in the numbers of both family providers of home care and of the salaried workers likely to be available suggest the possibility of higher expenses. In addition, the pressure on the state and federal governments could well increase from two conflicting directions—a need to reduce deficit spending and a call to respond to the needs of individuals whose financial circumstances have worsened due to downturns in the economy.

By Ellen G. Makofsky

1.1 Defining Long-term Care

Long-term care is essentially custodial in nature. It is designed to assist chronically disabled individuals with their daily activities of living over a prolonged period of time as they compensate for their loss of the physical and mental ability to function independently.

Long-term care includes help with activities of daily living (“ADLs”) such as walking, bathing, dressing, eating, transferring and continence.

Long-term care services may also help with instrumental activities of daily living (“IADLs”). These include preparing meals, shopping, managing

medication, using the phone, light housework, and transportation.¹

Those with cognitive impairments who need supervision, protection or verbal reminders to perform everyday activities also require long-term care.

1.2 Nationwide Demographics

In 1995 approximately 12 million people required long-term care.² Significant dramatic demographic changes in the 21st century are expected to significantly increase this number.

The aging of the baby boomers (those born between 1946 and 1964), combined with improved medical technology and lower fertility rates, is greatly expanding the older population as a proportion of the total population.³

Since 1950, the 65-and-over population has almost tripled from 12.3 million to almost 35 million people, while the total population has not quite doubled, rising from 150.7 million to 281.4 million people.⁴

In the 20-year span between 2010 and 2030, the number of people aged 65 and older in the United States is projected to increase by 30 million, or 7%, to a total of 70 million, or twice the number of people in this age group today. The number of people aged 85 or older will increase by more than 3 million.

Decline in Potential Caregivers At the same time, the number of potential caregivers for those who need long-term care is declining. During the same 2010-2030 time period, the United States will experience more than a six percentage-point decrease in persons 18 to 64 years old.⁵

The problem is compounded by changes in basic family structure that affect the pool of potential caregivers. The elderly of today and tomorrow have fewer adult children than previous generations did. Adult children are increasingly more likely to be separated from their parents by geography. Women, who traditionally provided long-term care to family members, are less available for the task because they are in the work force.

As life expectancies increase, so does the size of the 85-and-over population, the one most likely to require long-term care services. Their traditional

caregivers, spouses and adult children, are often elderly themselves and less able to provide care.

1.3 New York State Demographics

The demographic projections for New York State are startling.

In 1995, the state had 3.1 million residents over 60 years of age. The New York State Office for the Aging estimates that between 2010 and 2025, the over-60 population in the state will increase from 3.4 million in 2010 to 4.4 million in 2025 when all baby boomers will be 60 to 79 years old. This is an increase of 40% over 30 years.

The state's over-85 population will grow from approximately 275,000 in 1995 to more than 390,000 in 2025, a 30-year increase of 41%.

The over-75 population will grow from 1.07 million in 1995 to 1.15 million in 2005 and to 1.4 million in 2025, a 30-year increase of 32%.

The over-65 population will remain at 2.3 to 2.4 million through 2010 and then increase to 3.3 million in 2025, a 30-year increase of 35%.

During the same time, however, the growth of the under-60 population will not be increasing at the same rates. This is troubling, because those under 60 are the potential providers of long-term care for the elderly.

The under-60 population in New York is projected to grow steadily but slowly from 15 million in 1995 to 15.4 million in 2025, an increase of only 3% over 30 years.⁶

When contrasted with a 40% growth of those over 60 years old during the same period, some of the potential problems and issues in regard to long-term care begin to emerge.

Numerous reports and analyses have attempted to assess issues such as:

- How to pay for care.
- How to plan for it.
- The burden long-term care places on individuals, families and society.
- Concerns about the quality of care provided.

1.4 Report of the New York State Task Force

Under Chapter 81 of the Laws of 1995, the Legislature established an 11-member Task Force on Long-term Care Financing. It was charged to:

- Study alternatives to the current public funding mechanisms for long-term care.
- Review demographic trends and their impact on long-term care financing.
- Review the limitations of current long-term care financing mechanisms.
- Review alternative models of financing and providing long-term care services through public, private and public-private financing systems.

In June 1996, the Task Force Report, *SECURING NEW YORK'S FUTURE: REFORM OF THE LONG-TERM CARE FINANCING*, was submitted to Governor George E. Pataki, Joseph L. Bruno, majority leader of the State Senate, and Sheldon Silver, speaker of the Assembly. Its recommendations included, but were not limited to, the following three items:

- To increase personal responsibility in paying for long-term care services while preserving Medicaid as a safety net for the poor and those who have fulfilled their obligations by providing the appropriate amount of private funding, the state should pursue three complementary financing strategies:
 - (1) Promote the development of affordable long-term care insurance products and increase the number of individuals purchasing the products;
 - (2) Tighten Medicaid eligibility rules for long-term care.
 - (3) Develop a "Defined Private Contribution" option to assure access to long-term care for the uninsurable and to serve as a transition for current elderly while the long-term care insurance market matures.
- To ensure the development of service delivery approaches that would appeal to the private sector and allow Medicaid to participate in an inherently cost-effective manner, the state should:
 - (1) Support the expansion of managed long-term care;
 - (2) Encourage the development of continuing care programs, including Continuing Care Retirement Communities ("CCRC") and Life Care at Home
 - (3) Promote the further development of assisted living as a cost-effective, high-quality service alternative for those who

choose to live in a supportive housing setting.

- To encourage the purchase of long-term care insurance and the selection of appropriate services, the state should facilitate a public education campaign, in partnership with consumers, providers and insurers.⁷

1.5 Response to the Task Force Report

In the 2004 Budget Bill, the Legislature took the first steps to implement some of the recommendations of the Task Force Report.

To encourage New Yorkers to take personal responsibility for their own long-term care needs by purchasing and retaining of long-term care insurance, the bill included the following provisions:

- The tax credit for obtaining qualified long-term care insurance was increased from 10% to 20%
- To make Long-term Care Insurance Partnership policies [“Partnership Policies”] more attractive, the legislation:
 - (1) Sought to make premiums more affordable, by reducing the minimum policy term from 36 months to 12 months, with a corresponding amount of asset protection equivalent to the value of benefits received.
 - (2) Authorized New York State to make reciprocal agreements with other states that administer Partnership Policies, thereby eliminating the restriction that later government benefits be used only in New York State.
 - (3) Required insurers to permit the insured to designate a third party to receive notices of nonpayment of Partnership Policy premiums.
 - (4) Provided for a public education campaign to encourage the purchase of long-term care insurance. This is to be accomplished through an insurance education and outreach program and the creation of long-term care insurance resource centers.
 - (5) Created a mandate for the commissioner of health, the director of the Office for Aging and the superintendent of insurance to file reports with the governor, the speaker of the Assembly and the president of the Senate regarding the use of long-term care insurance and recommendations for promoting its purchase.

- To implement the Task Force recommendation that New York State ensure the development of service delivery approaches that appeal to the private sector, The Assisted Living Reform Act was enacted. It defines an assisted living residence, requires licensure of assisted living residences, and requires a written residency agreement and provides certain other consumer protections.

Although the proposed Budget Bill contained provisions to tighten eligibility criteria for long-term care, this legislation was not enacted.

To date, the Legislature has not addressed the other Task Force recommendations.

1.6 The Stone Report

In 2000, the Milbank Memorial Fund sponsored a significant analysis of long-term care issues. The author, Robyn I. Stone, concluded that three significant questions must be addressed:

- Who should pay for long-term care and how?
- How should services be designed and who should deliver them?
- How can the labor force delivering the care be recruited, trained and maintained?

The Stone Report does not answer these questions, but it does analyze the status of the key issues of long-term care policy: financing, delivery and workforce. It also identifies some of the demographic and policy trends affecting long-term care in the future.⁸

The report provides data on the fragmented patchwork of funds from private consumers, insurance companies, and federal, state and local governments that now funds long-term care.

The consumer pays one-third of the out-of-pocket expenditures, a figure that does not include the value of informal long-term care provided by family members.

Although the market for long-term care insurance has grown, private long-term care insurance pays only a small fraction of long-term costs.

Medicaid is the primary public payer for long-term care. On the national level, Medicaid maintains a strong bias toward financing institutional services,⁹ yet statistics show that in New York, Medicaid services are not as heavily skewed toward institutions. Instead, New York is spending extensively on home care—in 1995, an analysis shows that 35% of all Medicaid spending on home care in the United States was spent in New York.¹⁰

Although Medicare is not considered a major payer for long-term care, Medicare spending has increased substantially¹¹ in recent years due to the blurring of lines between acute care and long-term care and to efforts by the states to encourage more federal spending.¹²

Responses to Trends After reviewing the trends in delivering long-term care services, the Stone Report observed:

- Initiatives to integrate federal, state and provider levels for acute and long-term care services have not been altogether successful and there are questions about whether integrated care provides significant cost savings.
- While assisted living facilities have attracted attention, they lack consistent definition and government regulation. The affluent are the primary users of the assisted living market because little public financing is available to subsidize those who cannot afford to pay privately. The lack of regulation of assisted living facilities has caused some concern about the long-term care services provided residents.
- Trends point to more consumer-directed home and community-based care, which offers both choice and autonomy. Inherent to this approach, however, are ethical issues that must be addressed, namely how to balance autonomy and safety, how to prevent the potential exploitation of personal care workers, how to judge the appropriateness of self-direction for a cognitively impaired person, and how to diminish the potential for fraud and abuse by family members.¹³
- The adequacy and availability of a trained workforce to deliver long-term-care is a significant problem likely to worsen as the baby boomers become the elderly. Training in geriatrics for physicians and other health care professionals is limited, and there are few financial or cultural incentives for careers in the geriatric arena. A shortage of paraprofessionals exists, together with a high turnover in existing staff because of inadequate wages, benefits, professional recognition and career advancement opportunities.¹⁴

1.7 The Continuum of Care Alternatives

Long-term care is provided in a variety of settings that depend on the individual's needs and preferences, the availability of family caretakers and available reimbursement sources.

Home Care The majority of the elderly who require long-term care live in their own homes or in the home of a close relative. Spouses and adult children are the key caregivers and provide approximately 65% of the unpaid care received by those in the community.

In 1994 approximately 7 million family members provided an estimated 120 million hours of care for elderly relatives. In addition, more than 3.9 million family members provided assistance to those under the age of 65 who needed long-term care.¹⁵

Home health care may include skilled nursing care, supervised custodial care and help with both the activities of daily living and the instrumental activities of daily living.

Congregate Living Settings Long-term care can also be provided in congregate living settings such as assisted living facilities, board and care and adult foster homes. These congregate residential facilities provide an option for those who can no longer live at home independently but do not require the services of a skilled nursing facility. In total, approximately 80% of those who require long-term care receive the care in a home setting or as a resident in a congregate living facility.¹⁶

Adult Day Care In many cases, those receiving long-term care at home attend adult day care programs that facilitate their ability to remain at home because the programs provide respite for the caregiver family member. The most common type of adult day care is provided for elderly individuals with moderate disabilities who receive supervision and personal care, as well as social integration and companionship in a group setting.¹⁷

Adult day care serves both physically and cognitively impaired individuals, but it tends to serve a disproportionate population of those with Alzheimer's disease and other dementias.¹⁸

Nursing Home Care The longer an individual lives, the more likely it becomes that care in a skilled nursing facility will be required. The proportion of those over 65 years of age likely to require nursing home care ranges from 39% to 49%, depending on the database consulted.¹⁹ Many of those who require nursing home care will remain for short stays.

Statistically, the average expected lifetime nursing home stay is 2.7 years, although it is projected that 7% to 8% of those 45 or older in 1995 could expect to need 5 years or more of nursing home care during their lifetimes.²⁰

1.8 Current Costs and Future Projections

Statistics provided by the Centers for Medicare and Medicaid Services [“(CMS”) formerly known as the Health Care Financing Administration (“HCFA”)] show that \$106.5 billion was spent on long-term care in 1995.

Of that amount, public resources paid for 57.4%. Medicaid provided the largest portion of the public funding, 37.8%. Medicare paid 17.8%. Lesser amounts were paid by public sources such as Veterans Affairs, Older Americans Act, Social Services Block Grants and by state general assistance. Those requiring long-term care and their families paid 32.5% of the billions of dollars spent on long-term care in 1995. Private long-term care insurance accounted for 5.5% of the expenditures. CMS estimated that the sources of payment for expenditures on nursing home and home health care in 1995²¹ were as follows:

Recipient and /or family	32.5%
Medicaid (federal)	21.1%
Medicaid (state)	16.7%
Medicare	17.8%
Other public funds	1.8%
Other private funds	4.6%
Long-term care Insurance	5.5%

These estimates did not include the value of unpaid care contributed or the value of wages lost by caregivers. In 1999 unpaid care by friends and family was reported by value at approximately \$196 billion.²²

Annual Cost Increases Statistics²³ show that the annual average cost of providing long-term care is rising dramatically. In the 10 years from 1987 through 1996, nursing home expenses in the United States rose 150%—from \$28 billion in 1987 to \$70 billion in 1996. During the same period, annual expenses per nursing home resident increased 63%.

In 1999, the Congressional Budget Office estimated that between 2000 and 2040 inflation-adjusted expenditures for long-term care for the elderly would grow 2.6% annually. The projections estimated that expenditures would reach \$207 billion in 2020 and \$346 billion in 2040,²⁴ but the numbers are sensitive to assumptions about future users. If the assumptions turn out to be faulty, the projections cannot be relied upon.²⁵ Uncertainties about future demand for services and the resulting costs make planning for long-term needs more difficult.

1.9 The Federal Economy

The difficulties inherent in projection are illustrated by attempts to estimate the extent of the federal budget deficit and the national debt.

In April 2001, the Federal Budget estimated there would be a \$281 billion 2001 surplus. At the time, the federal government was \$3.2 trillion in debt. One of President Bush’s objectives in the 2001 budget was to retire \$2.0 trillion of this debt over the next 10 years.²⁶

Instead, by the end of 2004, a record \$413 billion deficit was expected, due to tax cuts, spending on national security, military operations in Afghanistan and Iraq, and interest payments on existing debt. In the recent presidential campaign, President Bush said the deficit could be cut in half, but he has not identified how the objective can be accomplished.²⁷

The possibility that budget pressures will result in fund cutbacks at the federal level suggests that pressure will increase to find alternatives to long-term care financing.

1.10 The New York State Economy

The 2001 recession and the slow recovery that followed had a significant impact on the New York State economy. According to the Business Council of New York State, Inc., New York State’s economy has performed more poorly than economies in other states, and the state has lost jobs at twice the rate of the nation since the recession began in March 2001.²⁸

Employment in New York has been slow to recover from the recession. Unemployment began to increase soon after the beginning of the recession and peaked at 6.9% in January 2003. Employment declined by 0.6% in 2003, which meant a loss of 47,000 jobs. The decline in employment depressed income growth in 2003, and wages and salaries grew by only 1.2%.

The outlook for 2004 was better, and year-end figures were expected to show that the New York economy had begun to grow as a recovery finally took hold.²⁹

The long-term path of the state budget will ultimately depend on the strength of New York’s economy. A less-than-robust economy could well have an unfortunate two-pronged effect on the delivery of health care services—the state could have less money to spend, while diminished income and reduced savings would leave individuals less able to pay privately.

1.11 Summation

Both the percentage and absolute number of elderly people are expected to grow significantly through 2030.

Fewer caretakers, both paid and unpaid, will be available to care for the larger older population expected.

Fiscal restraints on financing for long-term care will continue and may become exacerbated because of an expanded population base likely to require services, while the funds available diminish because of budget deficits, a soft economy, future federal tax reductions, expanded national security costs and ongoing military expenses.

Endnotes

1. M. Merils, Financing Long-term Care In The Twenty-First Century. The Public And Private Roles, Institute for Health Policy Solutions, 4 (1999).
2. Although the risk of needing long-term care certainly increases with age, according to Citizen's For Long-term Care, in 1995 46% of the long-term care population was under age 65. Of that non-elderly population, children ages 5-7 who needed long-term care accounted for 3% of the long-term care population.
3. Life expectancy has grown substantially this past century. A man who is currently 65 years old had an original life expectancy of 64 on the date of his birth. Now as a 65 year old he has a life expectancy of 83.
4. Hobbs, F. & Stoops, N.(2002). Demographic Trends in the 20th Century-Census 2000 Special Reports. Retrieved from <http://www.Census.gov/population/www/cen2000/briefs.htm>
5. Greater New York Hospital Association Center for Continuing Care, *Final Report, Continuing Care Staffing in the New York City Region, 2001, 4* (June 2001).
6. D. Sutton, *Demographic Projections to 2025*, NYS Office for the Aging (May 1999).
7. Task Force on Long-term Care Financing, *Securing New York's Future: Reform of the Long-term Care Financing System* (May 1996).
8. R. Stone, *Long-Term Care for the Elderly with Disabilities: Current Policy Emerging Trends. And Implications for the Twenty-First Century*, The Milbank Memorial Fund (New York 2000).
9. *Id.* at 24.
10. *Id.* at 17.
11. A survey by the Medical Expenditure Panel of the Agency for Healthcare Research and Quality, (a division the Department of Health and Human Services) confirms this and reports that between 1987 and 1996 Medicare payments went from 1.9% of total nursing home payments in 1987 to 18.9% in 1996.
12. Stone, *supra*, at 24.
13. *Id.* at 36.
14. *Id.* at 40.
15. Citizens For Long-term Care, *supra*, at 12 (citing Stone).
16. M. Merlis, *supra*, at 4.
17. Other forms of the adult day care are the adult day health model, which combines primary care with long-term care and The Program of All Inclusive Care for the Elderly "PACE", which Is a Federal demonstration model for long-term care for frail elders who are both eligible for Medicaid and nursing home certifiable.
18. Stone, *supra*, at 5-7.
19. *Id.* at 10.
20. M. Merlis, *supra*, at 4.
21. This percentage dramatically understates individual out of pocket expenditures as it does not include unpaid care contributed by families and friends.
22. Stone, *supra*, at 16.
23. J. Rhoades and J. Sommers, *Nursing Home Expenses, 1987 and 1996*. Rockville (MD) : Agency for Health Research and Quality: 2001. MEPS Chartbook No. 6. AHRO Pub. No. 01-0029.
24. Stone, *supra*, at 61.
25. M. Medis notes that the following factors may suggest a degree of uncertainty in the projections.
 1. Although life expectancy is predicted to increase, it is unclear whether longer life will bring more years of good health.
 2. New modalities for delivering long-term care services may appear which will affect utilization patterns and costs.
 3. The supply of services may not be available in the future. There may be fewer nursing home beds available or there may be fewer informal caregivers to provide volunteer care.
 4. Inflation may be an issue.
 5. Changes in public policy may affect financing sources.
26. Budget of the United States Government, Fiscal Year 2002.
27. *Where [Bush and Kerry] Stand on Taxes and the Budget*, *Detroit Free Press*, October 23, 2004. Retrieved from http://www.freep.com/news/politics/taxgrid23e_20041023htm.
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Chapter 2

The Status of New York’s Compliance With the *Olmstead* Standards Prohibiting Unnecessary Institutionalization

OVERVIEW: The 1999 *Olmstead* decision by the U.S. Supreme Court established the principle that the Americans With Disabilities Act prohibits unnecessary institutionalization of individuals eligible for publicly funded programs.

The assessment of the potential effect in New York State begins with the realization that the state’s Medicaid program already spends more for community-based home care services than any other state. The state also spends more Medicaid dollars for nursing home and other institutional care, yet it ranks 18th among the states in the percentage of its elderly who live in nursing homes.

In preparing plans for New York, the “Most Integrated Setting Council” formed by state law in 2002 will be able to draw from the best *Olmstead* plans of other states.

Subsequent federal decisions have also given guidance on how to develop a framework for assessing whether providing community services for a particular individual would represent a “reasonable accommodation” to the needs of the individual, regardless of age.

By Valerie J. Bogart

2.1 “Most Integrated Setting” Required

A major unknown in attempts to assess the financial outlook for long-term care services is the 1999 decision by the U.S. Supreme Court in *Olmstead v. L.C.*¹ It interpreted the “most integrated setting” provision of the Americans with Disabilities Act to prohibit unnecessary institutionalization in publicly funded programs.

Under *Olmstead*, once there is a finding of unnecessary institutionalization in providing long-term care for the elderly or disabled, states may be required to provide community services if they would represent a “reasonable accommodation,” a term of art still being defined by litigation in the federal courts. (See 2.8).

New York is in the process of developing a plan to comply with *Olmstead*, but the process appears to have moved more rapidly in 29 other states. (See 2.4)

2.2 Statistical Picture in New York State

The Medicaid program in New York already spends more for community-based home care services than any other state.²

That fact alone does not mean that New York is complying with *Olmstead*, however. The state also spends more Medicaid dollars for nursing home and other institutional care than any other state—nearly double the next highest spending state, Pennsylvania.³ New York also has the most nursing home residents of any state in the nation—109,788 out of 1,346,686 persons living in nursing homes in the nation.

Despite the total figure for nursing home residents, New York ranks only 18th among the states in the percentage of its elderly who live in nursing homes.⁴ New York is one of 12 states with more than 35,000 residents in nursing homes.⁵ A greater percentage of New York’s population of persons age 65 and over are in nursing homes (4.4%) than for the elderly population in the United States (3.8%).

New York has the highest number of nursing home beds of all states—118,198 beds out of a total of 1,573,990 beds in the United States, or 7.5% of all nursing home beds in the nation.⁶ California and Texas have the next highest number of beds, also more than 100,000. New York has the third highest occupancy rate of nursing home beds in the nation, behind Hawaii and North Dakota, and the same as Alaska. New York’s occupancy rate is higher than the national average of 82.7%.⁷

Because Medicaid funds care for so many nursing home residents in New York—75% compared with the national average of 67%—even with no increase in funding, the re-allocation of these Medicaid dollars to community based care would markedly increase opportunities for community living.⁸ The federal “Money Follows the Person” demonstration grants awarded to nine states (not including New York) under the New Freedom Initiative permit money to follow the individual from the institutional to the community setting.⁹

Implications of Olmstead in New York At this point, it is impossible to predict whether New York

already has, in effect, a head start on complying with *Olmstead* because of its record on providing home care services.

At a minimum, however, *Olmstead* means that New York will need to pay constant attention to how it can provide services outside the institutional environment by fostering home care itself and assuring the availability of related services such as transportation assistance.

Moreover, *Olmstead* requires consideration of the entire scope of available resources for long-term care. In fiscal year 2003, New York's Medicaid program spent more than \$6 billion on nursing home care plus \$1.2 billion at institutional care facilities (ICFs) for the developmentally disabled, and \$1.5 billion on inpatient OMR care. This total of \$8.7 billion spent on institutional care, which does not include care in state psychiatric hospitals or adult homes, is nearly three times the \$3 billion spent on the various types of home care (waiver, personal and home health care, private duty nursing, and hospice).¹⁰

Institutional care costs grew by 6.3% from 2002-2003, compared with an increase in the community-based care costs of only 2.5%.¹¹ The number of persons receiving care in Medicaid nursing homes and in home care programs has not markedly changed since 2001, except for a 12.4% decrease in persons residing in ICF/DD settings.¹² Clearly, complainants may be able to show that resources already present in the long-term care system could be distributed to provide community-based alternatives to institutional care.¹³ Moreover, it is not only Medicaid programs that must be considered as available in deciding the extent of resources available for community-based care.¹⁴

Effect of Mandated Cost-Saving Targets In nearly each year since 1993, the state Legislature has enacted cost-saving targets, requiring certain local Medicaid districts to cut specified millions of dollars from their Medicaid home care services, under threat of a stiff financial penalty. The counties selected for the targets were those that have traditionally spent more on home care services—New York City, Nassau and Suffolk, Westchester, Erie, and a few others.

The targets required New York City to cut services by as much as \$100 million in each of several years—nearly 10% of the annual expenditures. It is in large part these targets that motivated New York City and other counties to develop the “task-based assessment” tool that has led to arbitrary cuts in hours of care authorized, and to eliminate vital care for people with dementia. The targets give counties incentives to slash services in arbitrary ways—even by simply

delaying processing of home care applications, counties save hundreds of thousands or even millions of dollars.

When home care hours are cut, more people are forced into institutions—potentially violating *Olmstead*. Even apart from the ADA implications, however, the targets are not effective from a fiscal perspective. They simply shift the costs from one Medicaid budget line to another, from home care to nursing home care. The targets give counties an incentive to cut home care budget costs, but take no account of the global long-term care budgeting—the balloon is squeezed elsewhere with increased nursing home costs. Any claim that the targets have achieved budget savings is illusory.

2.3 Extent of Waivered Services in New York

Another factor that may lessen the urgency in New York to develop an *Olmstead* plan as a defense to potential lawsuits is that the state relies less on Medicaid waived services. Thus, the waiting lists that potentially violate the ADA under *Olmstead* standards are less of a concern.

New York's Medicaid package uses predominantly non-waivered services for personal care, home health, and private duty nursing,¹⁵ which cannot, as a matter of law, have waiting lists. Combined, the waived programs in New York serve 28,000 persons per year, compared with 87,000 who receive personal care services alone, plus tens of thousands who receive home health care and private duty nursing care. (See Appendix B.)

Up to 5,000 waiver slots for nursing home-eligible persons over age 18 were authorized on October 19, 2004, when the Nursing Home Transition and Diversion Waiver bill was signed into law.¹⁶ This law extends the TBI waiver by making services available to persons with any type of disability. Unlike the TBI waiver, however, it includes no specified housing subsidies. The program is conditioned on approval by federal CMS of the necessary waiver under section 1915(c) of the Social Security Act.

Despite its extensive spending on community-based care, and the lesser reliance on home care programs that have waiting lists, New York is not immune from potential liability for ADA violations under *Olmstead*. There are, in fact, waiting lists for some of the waiver programs that may be the most appropriate for certain individuals. Even the new waiver program enacted in October 2004, with its 5,000 slots, will hardly meet the demand for community services, in light of the 118,000 nursing home beds in New York.

Moreover, existing policies and practices in the Medicaid and other programs may violate *Olmstead*. Some of these issues are outlined in the section below (2.7) on the *Olmstead* plan, such as the need for an assessment procedure to identify those persons in institutions who prefer to and could live in the community with services.

2.4 Most Integrated Setting Council

New York is behind most other states in developing a specific plan to comply with *Olmstead*, as suggested in the first of five letters the federal agency overseeing Medicaid sent to State Medicaid directors.¹⁷ As of June 2004, 29 states had developed and issued *Olmstead* plans to comply with *Olmstead*. In 2003 four other states were working on their plans. New York was not among any of these 33 states.¹⁸

On September 17, 2002, after aggressive lobbying by the disability community in New York, a state law was enacted creating the “Most Integrated Setting Council” (MISCC) charged with overseeing and making recommendations for implementing the *Olmstead* decision.¹⁹

The Council is composed of the commissioners of all the relevant state agencies—the Department of Health (DOH), the Office of Mental Retardation and Developmental Disabilities (OMRDD), the Office of Mental Health (OMH), the Department of Transportation (DOT), the Division of Housing and Community Resources (DHCR), the State Office for the Aging (SOFA), the Office of Children and Family Services (OCFS), and the Office of Alcoholism and Substance Abuse Services (OASAS). (See **Appendix A** for a full list of council members.)

In addition, the law called for appointment of nine non-governmental members, three in each of the following categories: (1) consumers of services for persons with disabilities, (2) individuals with expertise in community services for people with disabilities of all ages, and (3) individuals with expertise in services for seniors. In each category one representative was to be appointed by the governor, one by the Senate, and one by the Assembly. By September 2003, all nine non-governmental slots had been filled.²⁰

Meetings of the Council began in late 2003. Since then, the Council has held hearings and in March 2004 it established four committees to work on the areas of data, assessment, community services and quality assurance.²¹ A transportation committee has also been established.

A series of public hearings were scheduled around the state through the fall of 2004, at which members of the public testified. As of November

2004, committees were continuing to develop and share reports and recommendations with members of the Council. A report or plan is expected some time in 2005.

Presumably the representatives of long-term care providers and persons with disabilities are involved in the committees drafting sections of the plan, but a significant part of the committee work appears to be in the hands of state agency staff members who work for the designated state commissioners. It is not known whether teams of advocates for older persons or persons with disabilities have been invited to participate in these working committees.

It is not known whether a draft plan will be made available for public comment. No drafts or information about the MISCC work are posted on the NYS DOH website, except for the meeting schedule.

2.5 The Plan Development Process

In designing its *Olmstead* plan, the MISCC has the benefit of 29 completed state plans, which are largely available on the Internet.²² National policy institutes and the National Conference of State Legislatures have reviewed plans for the degree to which they address eight elements.²³

Stakeholder Involvement Stakeholder involvement in developing plans is viewed as critical to success—from representation on the drafting committee to public hearings to collect testimony of all interest groups. Also, many states made a working draft plan available for public comment, and incorporated these comments into a final plan.

Assessing the Appropriateness of Community Services The federal *Olmstead* directive to Medicaid directors in January 2000²⁴ required states to ensure that “individuals with disabilities benefit from assessments to determine how community living might be possible (without limiting consideration to what is currently available in the community).”²⁵

There are two central issues in assessment: (1) Designing the content and procedures for the assessment, and (2) defining the concepts of “institutional setting,” a frequently controversial task.

In designing a content and procedures assessment, the state must evaluate “the adequacy with which the State is conducting thorough, objective and periodic reviews of all individuals with disabilities in institutional settings, . . . as well as establishing similar procedures to prevent institutionalization. States are to evaluate their procedures for identifying which institutionalized persons could live in the community, and which persons in the community are at risk of

being institutionalized. They are also expected to determine the number of persons in these groups.

The Center for Health Care Strategies, Inc. points out that to comply with the spirit of *Olmstead*, an assessment process will require additional evaluations beyond the existing federal requirements—the Minimum Data Set (MDS) done annually of nursing home residents, which asks a “yes/no” question of whether nursing home placement continues to be appropriate, and the PASSARR review of appropriateness for admission for persons with mental illness or developmental disabilities. Instead, the process of developing an effective assessment procedure must assess both the needs and preferences of individuals living in institutional settings, and of those living in the community but at risk of placement. The Iowa plan recognizes that a simple paper questionnaire is not enough, and includes these elements:²⁶

- Two personal interviews of the individual being assessed (and guardian, if any). One interview must include any family, friends, or advocates the individual would like to have involved in planning.
- Assessment teams should include persons who have no vested interest in continuing the current living arrangement, *i.e.* not nursing home staff. The teams may include treating professionals, or community living specialists.
- Assessments must consider the service and support needs of the person, and the type and scope of services that could be provided in the community, including any reasonable accommodations that might be necessary. Assessments should include the individual’s current level of community involvement and support, and the potential level of community involvement anticipated or desired.
- The assessment should include an information and education component; an assessor cannot elicit the consumer’s preferences without educating him or her about resources, choice, their rights and responsibilities.
- The assessment process should begin with the premise that community placement is appropriate for each individual if reasonable accommodations can be made to assure health and safety. Restrictions on service options contrary to the person’s wishes will require justification.
- The timeline for individual assessments—when they begin, when they are completed, with a plan for nursing homes, state hospitals, ICFs.

- Ongoing assessment process—Assessments must be repeated at least annually, or upon request of the individual.

Other states incorporate community living assessments into a discharge plan that must be initiated upon admission to a state psychiatric hospital or ICF.

The Process in New York No details of the draft assessment process have been made public in New York. It is hoped that the state will not rely on the federal mandated PASSARR or MDS assessments described above, nor on state assessments such as the Patient Review Instrument (PRI). These assessments draw only vague conclusions about whether a community placement is actually available.²⁷

The assessment should follow Iowa’s lead, eliciting the preferences of the individual and identifying the resources that would be needed to make community living possible, *i.e.* housing. The assessment should include interviews of the individual’s family and advocates, and be completed by assessors with no vested interest in the outcome.

Populations at risk of institutionalization need an entirely separate assessment system, which New York must develop. When an elderly or disabled person is denied any type of home care, or is denied a requested increase in home care—the individual must be assessed for risk of institutionalization as a result of the denial of home care services. Also, anyone placed on a waiting list for any of the Medicaid waiver services must be assessed, along with individuals in or attempting to access the community-based mental health system. The absence of any plan for assessing these individuals, let alone for providing them with services that will prevent institutionalization, may well violate the ADA.

What Is an Institutionalized Setting? New York, like all states, must decide which settings are “institutional” within the meaning of *Olmstead*. In what settings do residents have the right under *Olmstead* to be assessed for possible discharge to the community?

Beside the obvious settings of state psychiatric hospitals, and nursing homes, there is disagreement about whether some settings are considered “institutions”—intensive care facilities for the mentally ill and disabled, foster care or juvenile justice programs for children. Also, adults soon to leave the prison system,²⁸ or who are in veterans hospitals, homeless centers, and substance abuse programs must be assessed for possible community placement. Persons now in the community who are at risk of being placed in any of these settings may also require assessment.

In July 2003, Disability Advocates Inc.²⁹ filed a complaint in the Eastern District of New York, claiming that the placement of New Yorkers with mental illness in adult homes violated the Americans with Disabilities Act (ADA) “by causing their needless institutionalization in substandard facilities when their needs could be more appropriately and effectively met in integrated residential settings.”³⁰ In part, this lawsuit was prompted by the revelations of substandard care in adult homes in a 2002 series of *New York Times* articles. The plaintiffs charged that “impacted” adult homes (facilities in which 75% or more of the residents are mentally ill) are segregated institutional settings that fall under the purview of the ADA and the *Olmstead* decision. The lawsuit targeted 26 adult homes in New York City where an estimated 4,000 people with mental illnesses live.

Statewide, an estimated 12,000 individuals with mental illnesses are served in such facilities. Although adult homes nominally provide limited services to residents and are not classified as mental health facilities, residents of these facilities also receive Medicaid-funded health and mental health services from other vendors. The plaintiffs charge that these services do not adequately or appropriately meet the needs of adult care home residents.

The plaintiffs in the Disability Advocates suit asked the court to order the state to expand the availability of “supported housing” and to improve conditions in adult homes. The state’s response on October 1, 2003, disputed all the allegations, arguing that the plaintiffs lacked standing to bring the complaint, and that state agency personnel had not determined that the adult home residents in question were appropriate candidates for a more integrated community setting. The state also argued that providing the supportive housing sought by the plaintiffs would involve a “fundamental alteration” in services, an action that the *Olmstead* decision does not require states to take.

Identifying Needs and Describing Services A state plan must identify those individuals who have a current or potential need for community services. This is accomplished partly through the assessment process described above, but also by studying the demographics of how resources are currently allocated.

The Connecticut plan, for example, provides an extensive overview of the number of people currently served by the institutional and community components of its MR/DD, mental health, alcoholism, and nursing home and home care waiver programs.³¹ Other states estimated future need based on population growth, aging, and disability incidence rate.³² Review of AIDS/HIV programs was included in certain plans.

The federal January 2000 guidance requires that the plan identify

... what community-based services are available in the State. It assesses the extent to which these programs are able to serve people in the most integrated setting appropriate . . . The State reviews what funding sources are available (including Medicaid and other funding sources) to increase the availability of community-based services. It also considers what efforts are under way to coordinate access to these services . . . Planners also assess how well the current service system works for different groups (e.g. elderly people with disabilities, people with physical disabilities, developmental disabilities, mental illness, HIV-AIDS, etc.). The assessment includes a review of changes that might be desirable to make services a reality in the most integrated setting appropriate for all populations.³³

In New York, where all of the relevant state agencies are members of MISCC, each agency is presumably compiling its baseline information of services provided and numbers served, based on types of disability.

Providing Information to Affected Individuals State plans should include methods to provide information about community services to all individuals who may be eligible for them.

Plans such as Iowa’s include information about appeal rights, and the right to get a second opinion from a treating professional of their choice regarding their eligibility for community living options.³⁴ Utah’s plan institutes a project to inform nursing home residents of options regarding community services. The campaign uses both Area Agencies on Aging and local independent living centers, and other community-based organizations.³⁵

In New York, no details have been disclosed on how this information would be provided. Past proposals, such as the Single Point of Entry proposal of the State Office for the Aging made in 2004, raise questions, including whether the agency providing information will have a bias or self-interest that affects the provision of information on choices.

Quality Assurance This principle addresses the inclusion of procedures to implement independent evaluation and monitoring of state community place-

ment activities. Methods in completed plans include consumer satisfaction surveys, on-site Inspection of Care teams, self-advocacy training for consumers, ombudsman service, clearly defined provider standards, rights, and expectations, and fully developed grievance and appeal procedures.³⁶

Analytic tools include identifying individuals who have had lengthy institutional service intervals or stays to analyze the reason. Arizona and 20 other states are piloting a set of quality measures of “Core Indicators.” Consumers are surveyed to determine the extent of community integration, satisfaction with service coordination, service access, safety, and satisfaction with providers.³⁷

Funding State plans should describe current funding levels for community services as well as methods to gain additional funding.

Some state plans propose to use tobacco settlement money, to seek federal grants, expand Medicaid services and seek Medicaid waivers. Other states include increased budgets to provide higher wages to direct care workers to ensure an adequate workforce. Funding for transportation and, in particular, housing must also be addressed.

2.6 Challenges Facing Home Care Services in New York

Attempts to assess future needs for home care are further complicated by shortages in the staffing available for home care, the lack of mechanisms to fund the support services needed for community living, and differing standards that local districts use for approving home care.

Staffing Shortages As is happening nationwide, there are staffing shortages in the various forms of home care. While the downward shift in the economy may alleviate this problem somewhat in the short term, the lack of competitive wages, benefits, and job security in home care lead to shortages of adequate home care providers.

The ADA may require the state to make reasonable modifications that would include improved wages and benefits and working conditions to ensure the availability of quality home care. The Medicaid act and Fair Labor Standards Act also provide a basis for increasing wages and, in turn, the size of the workforce. Developments in this area include:

- Increases in wages for certain downstate home care workers were enacted in 2003 in a state budget compromise. These wage increases are important, but benefit only certain workers who are members of the Service Employees International Union (SEIU) and some other

workers. This increase, then, is not available to most workers outside New York City, nor to non-unionized workers in New York City.

- In July 2004, the 2nd Circuit struck down a federal labor regulation as a violation of the Fair Labor Standards Act that exempts home care aides from overtime requirements of that law.³⁸ This case was brought by the SEIU on behalf of a union member. While this case could have the effect of increasing home care aide wages, by ensuring them overtime pay when due, it is already having the opposite effect. Home care employers are shifting aide schedules so that none work overtime, effectively decreasing their pay.
- The federal Medicaid “equal access” provision requires that states assure that payment rates are sufficient to attract enough providers so that care and services are available to the Medicaid population at least to the extent that they are available to the general population in the geographic area.³⁹
- In a series of administrative hearing decisions in which Medicaid recipients have complained that the local Medicaid provider lacked sufficient staff to provide the hours of home care authorized, the State Department of Health has held that the county “has the ultimate responsibility in assuring that the Appellant receives her services authorized. . . . If the home health agencies under contract with the [County] Agency are unable to provide the required services, the {county} must make other arrangements for the provision of the authorized services, such as by contracting directly with other aides . . . or by requesting an increase in fees.”⁴⁰
- In a March 2004 settlement of a federal ADA lawsuit challenging inadequate staffing in private duty nursing cases, the State Department of Health agreed to ensure better case management and supervision by nursing agencies, to advise recipients of procedures to file complaints to the agency and DOH when care is inadequate, to direct home care agencies to develop written emergency care plans, to direct agencies to accept and retain only those patients that can be cared for safely and appropriately and to contract with sufficient staff to meet its responsibilities.⁴¹

Additional relief was agreed to for Nassau and Suffolk counties — an enhanced hourly Medicaid rate is available under certain circumstances, such as

when necessary to make discharge from the hospital possible.

The state clarified that enrollment in the Consumer Directed Personal Assistance Program does not preclude someone from receiving CHHA or other nursing services as a supplement.⁴²

Limited Availability of Some Programs The Traumatic Brain Injury (TBI) and Developmental Disability waived programs are limited, with strict eligibility criteria and limited slots. The Care at Home program for medically fragile children, for example, has only 500 slots statewide.⁴³

Individuals ineligible for these programs, though, are often also denied services in the personal care program because they need prompting and cueing, not physical assistance. Also, the State does not currently have a mechanism to fund other support services necessary for community living, including home modifications, rental subsidy, and transition costs (furniture/security deposit) for people outside the limited number of existing Medicaid Waiver programs.

Neither the OMRDD nor the TBI waivers take advantage of federal policy changes that allow an individual to receive case management services for up to 180 consecutive days before discharge from an institution. This would increase the provider base willing to work with individuals who require significant assistance to be de-institutionalized.

Practices That Deny or Limit Home Care Around the state, each local district applies its own unwritten rules and standards for approving or denying personal care or waived care in the Medicaid programs. Because they have the effect of denying access to care, each of these policies and practices can force someone into institutionalization. Changes in these policies may be required as a “reasonable modification” of the program.

Examples of how practices vary include:

- Many counties refuse to approve more than a few hours a day or week, regardless of medical necessity, and regardless of state law authorizing care up to 24 hours per day.
- Many counties refuse to approve care for persons who live alone or lack family to act as unpaid “back-ups” to supplement the Medicaid home care. This is related to issues of the “dignity of risk” — the right of persons with disabilities to choose to take risks inherent with living in the community rather than an institution. When counties invoke lack of a “back-up” as a reason to deny care, it is often a pretext for

the refusal to authorize an adequate amount of care.

- Many counties use “task-based assessment” and other tools that, by their very definition, do not take into account an individual’s need for assistance and supervision at different times of day or night. As a result, insufficient hours of care are authorized, forcing nursing home placement. The exclusion of safety monitoring from the personal care program for people with dementia was permitted by the 2d Circuit, which in *Rodriguez v. City of New York* expressly found that the exclusion of this “task” did not violate the ADA. The Court reasoned that the ADA does not require states to provide new and different services. Finding “safety monitoring” to be a task different and separate from regular personal care services, the court rejected the ADA claim.⁴⁴
- The ill effect of the *Rodriguez* decision in the 2nd Circuit (see 2.8) and of restrictive local policies have been partly ameliorated by a 2003 State Department of Health directive. It clarifies that county programs must authorize time for the “appropriate monitoring of the patient while providing assistance with the performance of . . . task[s] such as transferring, toileting, or walking, to assure the task is being safely completed.”⁴⁵ Advocates report, however, that compliance with this directive is poor.
- Many counties still have not complied with state law mandating access to a Consumer-Directed Personal Assistance Program (CDPAP). In addition to maximizing autonomy for many people with disabilities who have skilled needs and would otherwise need skilled nursing care, CDPAP is the sole type of home care that would be appropriate or desirable to meet their needs. Moreover, because CDPAP care is far less costly than skilled care, whether at home or in a facility, it cannot be claimed to be an undue fiscal burden. New York State has also not taken advantage of the federal policy change which would allow CDPAP providers to be given a “personal assistance retainer” payment and allow the individual to “hold” the attendant for up to 30 days when hospitalized. Now, when an individual is hospitalized, the home care aide cannot be paid, and must take another job, jeopardizing the continuity of care for the individual who may lose the aide.
- A number of counties offer no personal care services whatsoever. They offer only waived services, with a potential waiting list, or home health services, which are costlier. In addition

to violating federal requirements that Medicaid services be offered state-wide, the absence of this alternative may violate the ADA by forcing institutionalization in those counties.

- Delays in accessing home care place many people in the community at risk of institutionalization, and delay discharges of many people in nursing homes and other institutions. Such delays may violate federal Medicaid requirements for timely processing of applications, but also the ADA by increasing institutionalization. Establishing short deadlines to process applications, and implementing a system for providing temporary care while an application is pending may be “reasonable modifications” that the ADA requires.

Finally, there are other barriers to community living in New York beside the availability of adequate home care. Housing that is both affordable and accessible is a primary barrier statewide. Adequate transportation is lacking for people with disabilities.

2.7 *Olmstead* Background

A review of *Olmstead*'s history provides insights into the standards likely to apply when assessing the viability of home care for the needs of the elderly and disabled.

Lower Court Proceedings The two *Olmstead* plaintiffs, women with mental illness, had been voluntarily admitted to psychiatric hospitals in Georgia. After their psychiatric conditions stabilized, their treating physicians found that their needs could be met appropriately in one of the existing Medicaid community-based programs.

They were found eligible for a Medicaid “waiver” program, but it had a finite number of slots, and they were put on waiting lists. Their lawsuit charged that placing them on a waiting list for community care, for which they were undisputedly eligible, was a violation of the ADA provision requiring that public-funded services be provided in the “most integrated setting appropriate” to the individual. The district court ruled in the plaintiffs favor, rejecting the state’s defense that providing community-based services would require a “fundamental alteration” of their program. In fact, the court noted, the cost of care for these two plaintiffs would be considerably less in the community than in an institution.

The Court of Appeals for the 11th Circuit affirmed the judgment, but remanded for reassessment of the state’s cost-based defense, finding that the district court had applied a standard that virtually no state could meet to show a “lack of funding”

justification. The remand directed consideration of “whether the additional expenditures necessary to treat L.C. and E.W. in community-based care would be unreasonable given the demands of the State’s mental health budget.”⁴⁶

Supreme Court Decision Affirming the 11th Circuit in finding a violation of the ADA, the U.S. Supreme Court stated, “Unjustified isolation, we hold, is properly regarded as discrimination based on disability.”⁴⁷ The Court recognized that “confinement in an institution severely diminishes the everyday life activities of individuals.”⁴⁸ It observed that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”⁴⁹

The Court then discussed the extent of the state’s obligations under the ADA. First, the state may rely on the “reasonable assessments” of its own professionals to determine whether community placement is appropriate.⁵⁰ In *Olmstead*, there was no dispute about this factor.

The Court also gave some guidance to lower courts for determining what constitutes “reasonable modification” versus a “fundamental alteration” of a long-term care service program:

Sensibly construed, the fundamental-alteration component of the reasonable-modifications regulation would allow the state to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the state has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities. When it granted summary judgment for plaintiffs in this case, the District Court compared the cost of caring for the plaintiffs in a community-based setting with the cost of caring for them in an institution. That simple comparison showed that community placements cost less than institutional confinements.⁵¹

... [T]he State must have more leeway than the courts below understood the fundamental-alteration defense to allow. If, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less

restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met. . . In such circumstances, a court would have no warrant effectively to order displacement of persons at the top of the community-based treatment waiting list by individuals lower down who commenced civil actions.⁵²

The Court thus identifies several factors to be considered in evaluating a state's obligation: (1) the cost of providing services to the individual in the "most integrated setting appropriate;" (2) the total resources available to the state considering its entire long-term care program, which is not limited to Medicaid programs; and (3) how the provision of services to the individual claiming discrimination affects the ability of the state to meet the needs of others with disabilities—services must be distributed with an "even hand."

The high court rejected the lower court's interpretation that home-based services must be provided to the complainant as long as the cost is reasonable when measured against the state's entire mental health or long-term care budget. Instead, the state must show "that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities."⁵³

2.8 Reasonable Modification vs. Fundamental Alteration

Olmstead requires⁵⁴ states to make reasonable modifications in existing programs to promote community integration, but states need not make "fundamental alterations." Where the line is drawn in any case depends in part on the individual facts of the program.

Rodriguez v. City of New York If a request is characterized as changing basic eligibility criteria for the program, or adding a new service, courts find that this to be a fundamental alteration and thus the accommodation standard does not apply. In *Rodriguez v. City of New York*,⁵⁵ the 2nd Circuit used this rationale to deny a request to cover "cueing" services for persons with dementia under the Medicaid personal care program. "Cueing," or safety monitoring, was described as a totally separate service from the physical assistance with activities of daily

living provided in the personal care program, even though cueing for safety had always been incidental to physical care in the home.

Rodriguez shows how crucial the definition of the service is to the *Olmstead* ADA analysis. If the service is defined very narrowly, such as "cueing," then the requested expansion of coverage to include this "new" service is seen as a fundamental alteration. If the service is defined more broadly, as the larger bundle of long-term care services, then the claim against the refusal to provide "cueing" focuses on discriminatory procedures of administering the service, and not as one requesting a fundamental alteration.

Fisher v. Oklahoma Health Authority In *Fisher v. Oklahoma Health Authority*,⁵⁶ Medicaid recipients in the community challenged the limit of five prescription drugs per month imposed by the Oklahoma Medicaid program. Because nursing home residents on Medicaid could receive unlimited drugs, the plaintiffs argued that the drug limit forced them into nursing homes, and that lifting the limit would not be a fundamental alteration in the program.

The federal court agreed. "If every alteration in a program or service that required an outlay of funds were tantamount to a fundamental alteration, the ADA's integration mandate would be hollow indeed. . . . [Plaintiffs] are not demanding a separate service or one not already provided by the state."⁵⁷

Sanon et al. v. Wing In a challenge to a legislatively imposed fiscal limit on the cost of Medicaid home care services, a New York State court held that *Olmstead* requires analysis of whether the provision of high-cost home care is an "undue burden" under the ADA, and thus the fiscal cost limitation violates the ADA.

The decision, *Sanon et al. v. Wing*,⁵⁸ required New York State to analyze the cost factors using *Olmstead* guidelines. This analysis was not done because the challenged state law that set the fiscal limits expired under a sunset clause.⁵⁹

Radaszewski v. Maram A 7th Circuit decision suggests, however, that a cost analysis may require home-based services. In *Radaszewski v. Maram*,⁶⁰ the court ruled that a state's failure to provide community-based care may violate the ADA. In *Radaszewski*, a medically fragile young adult receiving private-duty, in-home nursing care lost all but five hours of care per day as a result of turning 21 and aging out of the Medicaid program that had provided care. Because his condition required round-the-clock private nursing, and the cost of the care was three to four times greater than the Illinois state threshold for adult community services, the beneficiary faced admission to a nursing home.

Initially, the district court ruled for the state, reasoning that the ADA did not require it to fully fund at-home private-duty nursing where it did not provide that service to any adult individual. On appeal, the 7th Circuit reversed, holding that even though the state might need to increase substantially the expenditures it would otherwise incur to care for the beneficiary at home, that expense was not, by itself, sufficient to defeat his claim of discrimination.

The case was returned to the trial court to give the state an opportunity to show that, in view of its obligations to all individuals with similar disabilities, funding services for the beneficiary would fundamentally alter the care it provides to others with similar needs. Importantly, however, the court also said that if the cost of institutional placement equaled or exceeded the cost of home care, it would be difficult to see how requiring the state to pay for home care would amount to an unreasonable, fundamental alteration of its programs and services.

Townsend v. Quasim In *Townsend v. Quasim*,⁶¹ the 9th Circuit granted plaintiffs' request for a reasonable modification in how the state administered its long-term care program, rejecting the state's characterization of the request as a demand for a new benefit. The plaintiff was an elderly man whose income increased slightly, converting him from "categorically needy" to "medically needy" under the state Medicaid plan.

In Washington State, this conversion meant that he could no longer receive home care services, which were limited to the categorically needy, and he would thus have to enter a nursing home to receive long-term care. Instead of viewing this as request for a "new" home care service, the 9th Circuit recast it as a case of discrimination:

Characterizing community-based provision of services as a new program . . . not currently provided by the state fails to account for the fact that the state is already providing those very same services. If services were determined to constitute distinct programs based solely on the location in which they were provided, Olmstead and the integration regulation would be effectively gutted. . . Olmstead did not regard the transfer of services to a community setting, without more, as a fundamental alteration.

Using the reasoning in *Fisher and Townsend*, the *Rodriguez* decision would have had a different analysis and outcome. The court would have looked at the program's refusal to assess the need for cueing and

safety monitoring as a discriminatory method of administration of the same personal care services benefit that the New York Medicaid program has always provided. Plaintiffs in *Rodriguez* were not seeking a new benefit, but were instead challenging the failure to ensure equal access to the existing personal care services by people with dementia.

Laguna Honda Suit In December 2003, a federal court in California approved a settlement in a two-year-old lawsuit that challenged improper placement of elderly and disabled residents in the Laguna Honda nursing home, a 1,200-bed facility, without providing community-based alternatives.⁶² The settlement requires San Francisco to develop a system of assessment and hospital-discharge planning that allows people who are in Laguna Honda or eligible for admission there in the future the option of receiving supports and services in the community.

By March 29, 2004, San Francisco had agreed to start a state-of-the-art program to screen, assess and develop individual service and discharge plans to members of the plaintiff class and provide ongoing case management after their discharge. Plans were developed to give program staff training on community-living alternatives and provide Laguna Honda residents with training and support resources.

The U.S. Department of Justice had filed an *amicus* brief in the case, after citing the city of San Francisco in April 2003 with violating the ADA, and questioning the city's plan to build a new facility to replace the nursing home, noting that "community integrated options could be provided at a fraction of the cost of staying in LHH."⁶³

2.9 Defining the "Most Integrated Setting"

The Office of Civil Rights within the Department of Health and Human Services has investigated numerous complaints of ADA violations.

From 1996 through mid-2001, 27 New York State residents filed individual complaints with the Office of Civil Rights (OCR), claiming violations of the "most integrated setting" requirements of the ADA.⁶⁴ Nationally, 334 complaints were filed, with New York ranking fourth in the nation in the number of complaints filed (after Georgia, Colorado, and Louisiana). As the authors of a study on these complaints point out, the number of complaints is not necessarily indicative of the degree of unnecessary institutionalization, because it may indicate a greater availability or organization of advocacy.

Nationwide, the majority of complainants were institutionalized, but 30% were residing in the community but at risk for what they considered to be

unnecessary institutionalization.⁶⁵ Of the community-residing complainants, 57% were living with families, showing that living with family members, alone, does not provide a buffer against unjustifiable institutionalization. Of the institutionalized complainants, 60% were in nursing homes, and 30% in psychiatric facilities.⁶⁶

2.10 Waiting Lists and Reasonable Promptness

Several courts have applied *Olmstead's* mandate that a public program must have in place an “effective working plan” of “community integration” that is moving at a “reasonable pace.”

Benjamin v. Ohl Courts have rejected the argument that insufficient funding justifies excessive waiting times. In *Benjamin H. v. Ohl*,⁶⁷ the district court noted, “The defendant cannot escape liability by a conclusory declaration that no more money will be provided to meet the state’s obligations under the Medicaid Act or the ADA.”

The court required West Virginia to develop a compliance plan to eliminate waiting lists and establish reasonable time frames for the provision of ICF-MR services. The Medicaid Act has its own provision requiring states to furnish benefits with “reasonable promptness,” which courts have applied to waiting lists for community-based long term care services.⁶⁸

Lawsuits on Reasonable Promptness Several courts have rejected an argument made by states that the reasonable promptness requirement in the Medicaid statute applies only to mandatory Medicaid services, not to optional services such as waiver programs or personal care services.

The New Hampshire Medicaid program argued, for example, that it complied with the “reasonable promptness” requirement by finding that applicants for a home care waiver program were eligible within 90 days, even though they were then placed on waiting lists for years. The court rejected this claim, finding that the duty of reasonable promptness applies both to the administrative aspect of benefit delivery and the actual delivery of services.⁶⁹

2.11 Federal and State Policy-Making Activity

Because *Olmstead* holds that states may be liable for violating the ADA if they fail to provide community-based alternatives to institutional care, states have been understandably concerned about taking the steps necessary to prevent and prevail in any future litigation brought by persons seeking community-based care.

States have seized upon one concrete guideline provided by the Court to avoid liability—*Olmstead*

specifically permits states to have waiting lists for community placements, provided the state can “demonstrate that it had a comprehensive, effective working plan for placing qualified persons with . . . disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated.”

2.12 Federal Grants to Assist States

In 2000, Congress created the Real Choice Systems Change Grants for Community Life, a federal grant program that awards competitive grants to states to experiment with new models for providing long-term care. Since 2001, CMS has awarded nearly \$160 million in Real Choice grants to states.

“Real Choice” Grant New York’s “Real Choice” grant request was initially denied in September 2001, but was awarded in April 2002. CMS approved \$1.385 million for a three-year period, one-third of the amount New York originally requested. The grant runs from September 30, 2002, through September 30, 2005. The grant and its administration are shared by the Department of Health and the Office of Mental Retardation and Developmental Disabilities (OMRDD).

The portion assigned to OMRDD was contracted to the Self-Advocacy Association of NYS, Inc., to transition a limited number of residents to the community from Institutional Care Facilities (ICFs) in Chemung, Monroe, and another county. The Department of Health portion was awarded to five demonstration projects to develop systems for central point of access and information, using Internet information systems (Clinton, Essex and Franklin counties), linkages with various agencies working on long-term care (Fulton, Broome and Monroe counties), and to identify barriers to community living and educate consumers on community alternatives (consortium of eight independent living centers and state Coalition for Aging).

Independence Plus In 2002, as part of its New Freedom Initiative, the Bush administration announced a new Medicaid waiver initiative called Independence Plus, described as a comprehensive plan designed to assure that people with disabilities have an opportunity to participate fully in community life.

In the effort to encourage consumer-directed long term care services, the plan provides people enrolled in this waiver with a voucher that allows them to recruit and manage home care aides according to a plan of care developed with their input. Notably, states may permit individuals to hire family members to serve as aides.⁷⁰

This initiative goes beyond long-term care needs to help people with disabilities of all ages, education and home ownership become integrated into the workforce and have access to adequate transportation. The initiative included Executive Order 13217⁷¹ requiring various federal departments to implement *Olmstead* swiftly by coordinating the use of existing resources. Examples of implementation activities by the Department of Justice, for example, under the New Freedom Initiatives include evaluating residential placements under the Civil Rights of Institutionalized Persons Act, together with enforcing ADA accessibility and requirements and the prohibitions against discrimination in housing.⁷²

Other Grants Other federal grants to the state DOH include:

- Quality Assurance and Quality Improvement in Home and Community Based Services \$495,811 (2003)—In the TBI waiver and Long-Term Home Health Care Program (LTHHCP), survey consumer satisfaction and develop method to measure outcomes, and institute Quality Assurance database.
- Respite Care Feasibility Project, \$74,285 (2003)—Study which modalities of community-based respite care for adults are feasible in New York.

Endnotes

1. 527 U.S. 581 (1999).
2. Kaiser Family Foundation, StateHealthFacts.org. Distribution of Medicaid Spending (Federal and State) on Long Term Care, http://www.statehealthfacts.org/cgi-bin/healthfacts.cgi?action=compare&category=Medicaid+%26+SCHIP&subcategory=Medicaid+Spending&topic=Distribution+of+Spending+on+Long+Term+Care&link_category=&link_subcategory=&link_topic=&datatype=currency&printerfriendly=0&viewas=&showregions=0&sortBy=Nursing+Facilities#sorttop.
3. *Id.*
4. Kaiser Foundation, *Total Nursing Facility Residents as a Percent of the State 65+ Population*, 2002, statehealthfacts.org. Notes: Please note that while these rates are a measure of a state's share of the 65+ population in nursing homes, the total number of nursing facility residents used in these calculations also includes residents who may be under 65 years of age and in need of nursing facility care. Sources: Harrington, 2003, *supra*; citing population data from the US Census Report, State Population Estimates by Selected Age Categories and Sex. Population data as of July 1, 2002. Available at, <http://eire.census.gov/popest/data/states/files/ST-EST2003-AS2002.csv>.
5. Kaiser Family Foundation, statehealthfacts.org., Total Number of Nursing Facility Residents, 2002 <http://www.statehealthfacts.org/cgi-bin/healthfacts.cgi?action=compare&category=Providers+%26+Service+Use&subcategory=Nursing+Homes&topic=Number+of+Residents>. Sources: Charlene Harrington, Ph.D.; Helen Carrillo, M.S.; Valerie Wellin; and Anna Burdin, M.A., "Nursing, Facilities, Staffing, Residents, and Facility Deficiencies, 1996 Through 2002," Department of Social and Behavioral Sciences, University of California, San Francisco, August 2003. Available at http://nccnr.newsc.com/public/50_155_4541.cfm. Based on the Online Survey, Certification, and Reporting system (OSCAR), Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services (hereinafter "Harrington 2003")
6. Kaiser Foundation, *Total Number of Certified Nursing Home Beds*, 2002, statehealthfacts.org. Source: Harrington 2003.
7. Kaiser Foundation, *Average Facility Occupancy Rates for Certified Nursing Facilities*, 2002 statehealthfacts.org. Source: Harrington 2003, *supra*.
8. New York ranks fifth of all states in the percentage of nursing home residents whose care is paid by Medicaid. New York ranks behind Alaska, District of Columbia, Mississippi, and Georgia, and is equal to Louisiana in terms of the percentage of residents dependent on Medicaid. Kaiser Foundation, *Percent of Certified Nursing Facility Residents by Primary Payor Source*, 2002, statehealthfacts.org. Source: Harrington 2003, *supra*.
9. <http://www.cms.hhs.gov/newfreedom/2005budgetsum.pdf>
10. NYS Dept of Health Office of Medicaid Mgt., On-Line SURS Information Retrieval System (November 2004). See **Appendix B**.
11. *Id.*
12. In 2003, the New York State Office of Mental Retardation and Developmental Disabilities announced that after five years, the state's NYS-CARES program (New York State Creating Alternatives in Residential Environments and Services) had provided residential services to more than 7,000 individuals. As the program reached the last year of its five-year duration, the state began a new initiative, NYS-CARES II, which is expected to add 1,900 residential options during the next 10 years; it also would increase day services and family support services. SOURCE: National Conference of State Legislatures, *The States' Response to the Olmstead Decision: A 2003 Update* (Feb. 2004), *supra*; See also http://www.omr.state.ny.us/budget/2004/hp_budget2004.jsp.
13. In a challenge to a fiscal limit on the cost of Medicaid home care services, one court held that *Olmstead* requires analysis of whether or not the provision of high-cost home care is an "undue burden" under the ADA, in which case the fiscal assessment limitations would violate the ADA. *Sanon et al. v. Wing*, 2000 N.Y. Misc. LEXIS 139, Ind No. 403296/98 and 402855/98 (Sup. Ct. N. Y. Co., Moskowitz, J.) (N.Y.L.J. Mar. 3, 2000 p. 27 col. 2). The decision required New York State to analyze the cost factors using *Olmstead* guidelines. This analysis was not done because the challenged state law that set the fiscal limits expired under a sunset clause. Soc. Serv. L. § 367-k.
14. Resources for mental health care, transportation, housing, and other services must also be considered. As one analyst points out, "It is important to bear in mind that the issue in the *Olmstead* case is not the state's Medicaid program, but rather its overall medical services program for persons with chronic.... conditions that require long-term care." Thus the funding streams for housing and mental health treatment for people with disabilities must also be considered. Sara Rosenbaum, Center for Health Services Research and Policy, The George Washington University, *Olmstead v. L.C.: Analysis and Implications for Medicaid Policy* (May 2000) <http://www.chcs.org/publications/pdf/cas/Olmstead.pdf>
15. "Personal care" services—known as "home attendant" services in New York City—are authorized under NY Soc. Serv. L. § 365-a(2)(e). The other non-waivered home care programs are "home health services," which include visiting nurse, home health aide, and physical therapy, Soc. Serv. L. § 365-

- a(2)(d) and Private Duty Nursing Services, Soc. Serv. Law § 365-a(2)(l). Waivered services include the Long-Term Home Health Care Programs (LTHHCP) or ALombardi; Soc. Serv. L. §§ 367-c, 366(6) and the Home and Community-Based Services Medicaid Waiver for Individuals with Traumatic Brain Injury (HCBS/TBI)(1600 slots) or the Developmental Disability HCBS waiver program.
16. S.7073, A11350A.
<http://assembly.state.ny.us/leg/?bn=S07715>, adding new Social Services Law § 366(6-a).
 17. In the Clinton administration, the U.S. Health Care Finance Administration (HCFA, now known as the Centers for Medicare and Medicaid Services, or CMS), in conjunction with the Office of Civil Rights (OCR) within the Department of Health and Human Services (HHS), issued five joint letters to state Medicaid directors providing guidance on *Olmstead*.
The first letter, dated January 14, 2000, issued guidelines to State Medicaid Directors for developing their state plans. (Department of Health & Human Services Health Care Financing Administration Center for Medicaid and State Operations, Letter to State Medicaid Directors (Jan. 14, 2000) <http://www.cms.hhs.gov/states/letters/smd1140b.asp>)
These guidelines clarify that *Olmstead* applies to persons with all types of disabilities, not just mental disabilities. HCFA's guidelines also clarify that a plan must include prevention of institutionalization for persons at risk in the community, in addition to persons who are already in institutions. The guidelines also contain a specific list of criteria that states should include in their plans, and encourage states to "actively include people with disabilities, and where appropriate, their family members or representatives, in design, development and implementation." The specific guidelines are discussed in the section highlighting aspects of the 29 completed state plans, below.
HCFA issued four more letters to states under the Clinton administration—two on July 25, 2000 and two on January 10, 2001. (See <http://www.cms.hhs.gov/states/letters/>) These reiterate the importance for states to implement *Olmstead* plans, summarize HCFA efforts to review relevant federal policies such as transitioning from nursing homes to the community, and address issues regarding waivers.
In 2001, the Bush administration launched the Independence Plus initiative in Executive Order 13217 requiring federal departments to coordinate the use of existing resources. (See 2.11)
 18. National Conference of State Legislatures, *The States' Response to the Olmstead Decision: A 2003 Update* (Feb. 2004) <http://www.ncsl.org/programs/health/forum/olmstead/2003/olms2003report.htm>; Sara Rosenbaum, Joel Teitelbaum, *Olmstead at Five: Assessing the Impact Kaiser Commission on Medicaid and the Uninsured*, June 2004. Descriptions and website links for many state plans are posted at Alexandra Stewart et al., *Implementing Community Integration: A Review of State Olmstead Plans* (Center for Health Care Strategies, Inc. Oct. 2002)
 19. NY Exec. L. § 700 et al., eff. Dec. 16, 2002.
 20. The composition of the MISCC as of July 2004 is listed in App. A. Some of the listed members are not the original ones appointed in 2003.
 21. Unofficial minutes of the meetings are posted on the website of the Rochester Center for Disability Rights, www.rochestercdr.org.
 22. National Conference of State Legislatures, *The States' Response to the Olmstead Decision: A 2003 Update* (Feb. 2004) <http://www.ncsl.org/programs/health/forum/olmstead/2003/olms2003report.htm>
 23. Sara Rosenbaum, Joel Teitelbaum, *Olmstead at Five: Assessing the Impact Kaiser Commission on Medicaid and the Uninsured*, June 2004 link. Descriptions and website links for many state plans are posted at Alexandra Stewart et al., *Implementing Community Integration: A Review of State Olmstead Plans* (Center for Health Care Strategies, Inc. Oct. 2002).
 24. See note 17.
 25. *Id.* January 14, 2004 letter.
 26. CHCS, National Conference of State Legislatures, *The States' Response to the Olmstead Decision: A 2003 Update* (Feb. 2004) <http://www.ncsl.org/programs/health/forum/olmstead/2003/olms2003report.htm>
 27. The inadequacy of these assessments for meeting *Olmstead* standards was a factor in settlement of the Laguna Honda nursing home case in San Francisco, described in 2.8.
 28. A complaint was filed in October 2003 on behalf of hundreds of New York parolees for the failure to furnish substance abuse treatment services that would permit individuals with serious and persistent mental illnesses who also have a chemical addiction to be released from New York City jails. The plaintiffs allege that they have been discriminated against because other similarly situated individuals who have a chemical addiction but no or minor mental illness are released to community treatment programs more quickly. *William G. and Walter W. v. Pataki, et al.* The complaint is available online at <http://www.bazelon.org/nycjails/>. The plaintiffs ask for access to New York State's expanding supervised housing programs that serve and treat individuals with co-occurring disorders, either in the form of community residences or supported housing programs. They allege that the costs of needlessly confining these individuals are substantial and the dollars spent on incarceration should be redirected to underwriting community services for them.
 29. Disability Advocates is an agency under the Protection and Advocacy for Individuals with Mental Illness Act. Co-counsel include New York Lawyers for the Public Interest, Inc., the Bazelon Center for Mental Health Law, MFY Legal Services and the Urban Justice Center.
 30. See *Status Report: Litigation Concerning Medicaid Services for People with Developmental and Other Disabilities* by Gary A. Smith at <http://www.hsri.org/index.asp?id=news>. The complaint and a discussion of the lawsuit are at http://www.bazelon.org/newsroom/7-1-03ny_pressrelease.htm
 31. *Id.* at 15-17.
 32. *Id.* at 17.
 33. See note 22.
 34. Sara Rosenbaum, Center for Health Services Research and Policy, The George Washington University, *Olmstead v. L.C.: Analysis and Implications for Medicaid Policy*, at 20 (May 2000) <http://www.chcs.org/publications/pdf/cas/Olmstead.pdf>
 35. *Id.* at 21.
 36. *Id.* at 23.
 37. *Id.* at 26.
 38. *Coke v. Long Island Care At Home, Ltd.*, 376 F.3d 1118 (2d Cir. 2004).
 39. 42 USC 1396a(a)(30)(A), 42 CFR 447.204. See, e.g. *Arkansas Med. Soc'y v. Knickrehm*, reprinted in *Medicare & Medicaid Guide* (CCH ¶ 300.434 (E.D.Ark. 2000)(mental health managed care program enjoined as violating 1396a(a)(30)(A) and previous decisions).
- In *Ball v. Biedess*, No. Civ 00-0067-TUC (August 13, 2004), a federal district court ruled that this provision required the Arizona Medicaid program to increase wages for attendant care workers so as to attract enough workers to deliver serv-

- ices to all the individuals who qualify for them. The case was brought by a group of Medicaid beneficiaries who were unable to receive adequate home and community-based care services because there was a severe shortage of attendants due to low payment rates. For additional information, see Schlosberg, C. *Medicaid Payment Rates: What's a Provider to Do*, ANCOR Links, Vol 34, No. 4 (April 2004), www.ancor.org. See also *Arkansas Med. Soc'y v. Knickrehm*, reprinted in *Medicare & Medicaid Guide* (CCH ¶ 300.434 (E.D.Ark. 2000))(mental health managed care program enjoined as violating 1396a(a)(30)(A)).
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 42. NYS DOH GIS 02 MA 024.
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 45. State directive issued January 24, 2003 (GIS 03 MA/003)
 46. *Olmstead v. L.C.*, 138 F.3d 893, 905 (11th Cir. 1998).
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 50. 527 U.S. at 602.
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 56. 335 F.3d 1175 (10th Cir. 2003).
 57. *Id.*
 58. 2000 N.Y. Misc. LEXIS 139, Ind No. 403296/98 and 402855/98 (Sup. Ct. N. Y. Co., Moskowitz, J.) (N.Y.L.J. Mar. 3, 2000 p. 27 col. 2).
 59. Soc. Serv. L. § 367-k.
 60. 2004 U.S. App. LEXIS 18940 (7th Cir. Sept. 8, 2004).
 61. 328 F.3d 511 (9th Cir. 2003).
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 63. *Id.*
 64. Sara Rosenbaum, Joel Teitelbaum, and Alexandra Stewart, Center for Health Services Research and Policy, The George Washington University, *An Analysis of Olmstead Complaints: Implications for Policy and Long-Term Planning* (December 2001) <http://www.chcs.org/publications/consumer.html#complaints>
 65. *Id.* at 4.
 66. *Id.* at 5.
 67. Civ. No. 3:99-0338 (S.D.W.V. 1999).
 68. See, e.g., *Boulet v. Cellucci*, 107 F. Supp. 2d 61 (2000)(finding waiting list of three to ten or more years for residential habilitation services for mentally retarded children “far outside of the realm of reasonableness”). *Id.* at 72. This court also found inadequate funding was not a defense. *Id.* at 80.
 69. *Bryson v. Shumway*, 17 F. Supp.2d 78 (2001).
 70. Jeffrey S. Crowley, *An Overview of the Independence Plus Initiative to Promote Consumer-Direction of Services in Medicaid* (Kaiser Commission on Medicaid & the Uninsured Nov. 2003).
 71. <http://www.whitehouse.gov/news/releases/2001/06/20010619.html>
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Chapter 3

The Continuum of Care: Community-Based Alternatives To Nursing Home Care

OVERVIEW: As New York's baby-boomers reach retirement, major financial challenges face the state's health care system. New York may be able to accomplish more with fewer dollars if serious consideration is given to new alternatives. This requires thinking "out of the box," but the long term savings could be substantial.

After a review of basic demographic information and trends, this chapter looks at the status of alternatives to nursing home care in the context of the current law in New York.

Finally, this chapter recommends alternative approaches.

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3.1 Trends

Demographics The population is living longer. The largest percentage increase in the U.S. population is in persons over age 65. According to a 1996 study by the Department of Health and Human Services, by the year 2030 there will be 65 million "elderly," 7.3 million of whom will be "frail."

The corresponding financial resources needed to care for and provide a quality of living for our aging population likewise will continue to grow and present challenges of unprecedented proportion. The survival of Social Security and Medicare are political hot topics.

Retirement Funds Despite losses in market value in 1987, retirement funds, both in qualified plans (such as IRAs, 401(k)s) and non-qualified plans, will play an increasingly large role in providing available cash for housing.

Rule changes promulgated by the IRS for IRAs and qualified plans have expanded the available planning options whereby retirement funds can be used to fund the unified credit. Income tax need no longer be paid within five years from date of death so that retirement funds can continue to grow tax free for generations.

Long-Term Care Insurance Although long-term care insurance was relatively rare 10 years ago, persons over age 60 increasingly have policies. Although

still a modest percentage, more employers offer long-term care insurance policies as a benefit of employment.

The modern long-term care policies offer more flexibility than prior policies. They are more affordable, and consumers have learned how to purchase them for lower cost.

In the past, underwriters would provide reimbursement only for care at a licensed facility. Because assisted living facilities were not licensed, long-term care policies were unavailable to pay for that form of institutional care. Over the years, the insurance industry has made adjustments to cover the lifestyle choices of older adults. Changes in New York law have now established license standards for assisted living facilities, thereby facilitating long-term care insurance coverage.

Government Assistance—Although many of the elderly believe that Medicare provides for all of their medical needs, funding is essentially available only for critical care and rehabilitation. No funds are available for purely custodial (non-skilled) care, including assisted living, even when medically necessary. Insurance policies that supplement Medicare benefits are similarly limited.

Medicaid has thus become the major payor of nursing home and other forms of custodial care for middle income as well as low-income persons. As a consequence, Medicaid budgets have expanded beyond what Congress anticipated when Medicaid was originally designed as a program for the poor.

The reimbursement rate for all services has been reduced in response to the financial strain. Staffing levels have been reduced at facilities with substantial Medicaid populations (which includes most facilities). Various states, including New York, have considered proposals to further limit Medicaid eligibility.

3.2 Living at Home

Many options are open to people wishing to remain in the community. Some allow them to remain at home; others involve going to senior communities or facilities.

Home Modification The simplest way to stay out of a nursing home is to remain at home. Although homes are typically not designed to accommodate the

physical limitations of older adults, modest changes can make the home far more accommodating to seniors who need some level of assistance.

Universal design or barrier-free design, an architectural approach to the built environment, has evolved to offer numerous ways to design or retrofit a residence to meet the needs of older adults and persons with disabilities. This includes widening halls, installing an elevator, modifying a bathroom to accommodate a wheelchair, installing an alert system, installing adjustable counter tops, etc.

Homeowners can install fittings and use appliances specifically designed for persons with limited physical capacity due to the effects of diseases such as arthritis. For example, the homeowner can replace door knobs with larger knobs or levered handles that are easier to manipulate by hands with limited flexibility. A plastic chair and grab bars reduce the risk of injury in a shower. Many companies now manufacture kitchen utensils and dressing aids that make daily activities of living easier.

Other solutions include removing the rugs and replacing them with wall-to-wall carpeting or linoleum flooring to avoid the risk of falls. Use of rubber soled shoes or socks with a rubberized bottom work best for walking on wooden floors.

Depth perception diminishes with age. Illumination suitable for older adults can be easily addressed. For those who are visually impaired, appliances are available with large dials and touch pads. A phone can have oversized buttons. For the hearing impaired, phones can be purchased with amplifiers.

Reverse Mortgages A home is often the primary, though illiquid, financial resource. The reverse mortgage, also known as a “home equity conversion loan,” is designed to convert the equity built up in a home into a source of monthly income.

In a typical reverse mortgage, the lender offers a monthly payment to supplement income. The owner does not repay the borrowed money to the lender until the home is sold. Other variations include loans in which the lender provides a lump sum loan up front that can be used for the homeowner’s needs.

The reverse mortgage has an advantage for those who are considering Medicaid home care. The monthly payments, viewed as a loan, are not deemed income in the month of receipt and not budgeted under Medicaid guidelines.

Reverse mortgages have significant financial implications, however. The up-front costs of obtaining these mortgages are significant. Closing costs and mortgage insurance on a \$200,000 loan can easily

exceed \$10,000. Interest compounds on the outstanding principal balance, which means that the balance ultimately owed may far exceed the cash actually received. As a result, the equity in the home may quickly be reduced, or even exhausted, although the homeowner is guaranteed the right to live in the property until death.

Because of the financial dangers, New York law insists on protections. In particular, individuals may not apply for a reverse mortgage unless they have received counseling from a not-for-profit organization that has advised them of the long-term financial risks.

Given the potential loss of equity, it may be more desirable to consider a *private* reverse mortgage. Family members, individually or together, may be willing to commit to make monthly payments to an elderly homeowner. Any equity build-up thus belongs to a family member and not an institution. However, according to state law, the owner must nevertheless obtain counseling for the mortgage for it to qualify as a reverse mortgage in order to receive the same treatment under Medicaid rules.

Home Sharing Some seniors who want to remain at home can opt for home sharing. They barter use of a portion of their home in exchange for companionship and assistance with home maintenance. Sometimes a local college student will take a room. The student may be responsible for caring for the yard, cooking, shopping, household cleaning, or similar light chores. Home sharing is often promoted by faith-based groups that help students and seniors find one another. Not-for-profit housing agencies also provide counseling and assistance to homeowners who seek this housing option, including interviewing both parties to facilitate a good match.

Senior Retirement Communities Naturally occurring retirement communities—“NORC’s”—are locations where residents age in place. They may be apartment buildings, attached housing communities, condominium complexes, or other designed communities. NORC’s were not designed as retirement communities. Residents live and remain there to and through old age. Thus, the nature of the community lends itself to planning for seniors.

These communities have recreation areas and other common areas that are adapted as residents age. The fact that so many seniors live in reasonably close quarters allows residents to share assistance. A resident with limited needs can share one aide with one or more other residents with limited needs. Because most home health care agencies insist on a four-hour minimum before sending an aide, the shar-

ing offers the ability to reduce costs while providing safety.

NORC's offer a variety of social and recreational activities, together with transportation for shopping, medical appointments, theater and recreational outings.

Apartment Living Cooperative apartment living represents a lifestyle choice for hundreds of thousands of New Yorkers, many of whom wish to stay at home as they age. To assure the continued health and well-being of older residents, co-op and condo boards throughout New York City and other urban areas face the challenge of responding to the needs of these residents, while sometimes having to balance them against the needs of other building residents.

For example, an impaired memory may cause an older resident to forget to discard the garbage. Failure to do so can result in a health hazard to the elderly tenant and to residents of the building. Inappropriate intervention can result in unnecessary alienation of the older resident. Another older resident may forget to turn off the stove. This, too, presents an obvious safety hazard to all building residents. To minimize such risks, cooperatives and condominiums can recruit part-time social workers to visit designated residents regularly, both to check on their needs and to assist in minimizing health and safety risks to the residents in the rest of the building.

Buildings with numerous older residents may find it cost-effective to establish a relationship with an agency that can deploy one health worker to respond to the care needs of various building residents on designated days each week. This type of arrangement can be cost-effective for residents living on a fixed income while providing the key to remaining in one's residence.

Accessory Apartments The use of an accessory apartment presents a practical way to remain safely in the community and close to family. With this housing option, the senior resides in a separate unit, maintaining his/her independence, usually in the home of an adult child.

Seniors' Programs—Day Care Programs Day care programs provide enrichment and stimulation for the senior and respite for the caregiver, supplementing a senior's life in the home. The programs are broken down into two models, the **social model** day care and the **medical model** day care. The social model, for which funding is available under the community Medicaid program, tends to provide entertainment, socialization and activities. The medical model, for which funding is available under the government sponsored long term home health care program

(known as the Lombardi program), provides a higher level of care.

3.3 Assisted Living

"Assisted living" refers to a housing option that includes a residential unit, meals, on-site activities, links to health care providers and assistance with activities of daily living.

The popularity of assisted living facilities is fueled by three particular features:

- (1) People often fear nursing homes; an assisted living facility is viewed as a more humane alternative.
- (2) Assisted living facilities promise more active and satisfying lifestyles for those able to enjoy them.
- (3) The cost of assisted living facilities is significantly lower than nursing home care. Nursing homes in the New York metropolitan region charge approximately \$350 a day or \$10,000 a month. Assisted living facilities in the same region charge a basic monthly rate between \$3,000 and \$5,000. Add-ons, however, including necessary individualized assistance, raise the cost of assisted living much closer to the cost of nursing home care.

New York "Assisted Living Program" The results of legislation that authorized an "Assisted Living Program" in New York are codified in the Social Services Law,¹ and matching regulations are found in the Social Services Regulations.²

Until recently, both New York and most other jurisdictions lacked adequate protection for the consumer. Historically, licensed assisted living facilities were rare. Such licensed facilities, known as "adult homes" or "enriched housing programs," were usually operated by a not-for-profit agency and were subject to significant regulation and inspections.

The larger, well-known facilities commonly regarded as assisted living facilities were not heretofore subject to license requirements. These are the so-called "look-alike" facilities or "assistive living" facilities. The absence of regulation created problems for the industry, including poor oversight. In addition, the facilities typically operated as two separate entities, a rental unit and a home care unit. This duality created confusion and lack of communication between the two parts.

On August 12, 2004, the New York Legislature passed assisted living legislation, adding a new Article 46-A to the Public Health Law.

The new legislation recognizes the importance of “congregate, residential housing with supportive services in a home-like setting.”³ The statute recognizes the basic philosophy of assisted living as an approach that “emphasizes *aging ‘in-place’* (emphasis added), personal dignity, autonomy, independence, privacy and freedom of choice.”⁴

The legislation defines an assisted living facility as “an entity which provides or arranges for housing, on-site monitoring, and personal care services, and/or home care services (either directly or indirectly), in a home-like setting of five or more adult residents unrelated to the assisted living provider.”⁵ The definition includes all of the so-called look-alikes, while also including the enriched housing and adult homes of previous law.

This legislation imports many concepts from federal legislation. For example, the facility must provide an ISP, or *individualized service plan*, for every resident and update the ISP on a regular basis. The ISP is developed with the resident, the resident’s representative and the operator, in consultation with the resident’s physician.

The legislation specifies that the needs of the resident must be met and that, if necessary, the resident’s home health agency and physician must certify that these needs can be met. It is in this circumstance that the gray areas appear. The statute says that a resident who requires 24-hour nursing care must be discharged. However, such discharge need not take place and the resident may remain if: (a) the resident hires appropriate nursing, medical, or hospice care; (b) the resident’s physician and home care services agency both determine and document that with the provision of such additional care, the resident can be cared for safely; (c) the facility operator agrees to retain the resident and to coordinate the care; and (d) the resident is otherwise eligible to remain at the residence.

The statute provides that an operator can apply for an *enhanced assisted living* certificate.⁶ In essence, the operator who qualifies as “enhanced” is permitted to keep a resident beyond ordinary discharge. The operator must show how it will meet these needs, including a written description of services, staffing levels, staff education and training, work experience and environmental modifications that will be made to protect the resident’s safety, health and welfare.

Many facilities hold themselves out as being able to deal with the special needs of persons with dementia or cognitive impairment. Facilities claiming to provide *special services* or *servicing individuals with spe-*

cial needs, must submit a plan setting forth how they will meet such needs.

Every resident is entitled to a clear admissions agreement that must contain certain minimum provisions. In addition, all residents must be presented with a statement of residents’ rights when presented with advertising brochures or an admissions agreement. The statute does not offer a basic standard form of agreement.

3.4 Continuing Care Retirement Communities (CCRC’s)

Continuing Care Retirement Communities offer shelter, care and services for a person’s lifetime.

There are three basic stages of care: independent living, assisted living and nursing home care. A resident is admitted at the independent living level. As the resident becomes unable to perform certain activities of daily living, he/she moves to the assisted living facility. Should a resident’s physical and/or psychological needs further increase, the facility, in consultation with the resident and the resident’s health care provider, may move the resident to the nursing center.

The three stages of care are often present at the same campus, although this is not necessary. Many of the owners of CCRC’s are also nursing home operators who offer a bed at a related facility nearby.

Payment Arrangements Payment arrangements for services vary. The simplest form is the fee for service contract in which the resident agrees to pay a daily rate for all personal services according to the level of care needed. The modified contract provides a limited amount of nursing care, after which the resident is responsible for payment. The extensive contract offers unlimited long term care at little or no substantial increase in monthly cost. The choice of contract affects who may apply.

The extensive contract offers long-term care at a level monthly cost. These CCRC’s seek healthy and mentally competent applicants, because well residents in effect subsidize the more frail residents, thereby reducing the facility’s average cost per resident over the long term. This approach enables CCRC’s to take a risk that the cost of care for a certain percentage of their residents will exceed the income generated by the average resident.

A fee for service contract allows a facility to manage its costs differently. Facilities that offer this option are far less restrictive and admit applicants with a significant level of physical or mental disability because each resident, in effect, pays for him/herself.

The extensive and modified contracts require a sometimes substantial up-front fee. In the case of the extensive contract, however, the facilities offer a continuum of care for a constant rate. That is, the resident pays the same fee whether in the assisted living unit or the nursing home.

Continuing Care Retirement Communities may require the residents to have long-term care insurance. Otherwise the CCRC itself applies a portion of the resident's payment to procure insurance on behalf of the resident.

Resources for Further Information In response to the explosive growth of these communities, two entities have been organized, and both have extensive web sites.

The American Association of Homes and Services for the Aging, AAHSA, offers advice on these communities, including definitions, a discussion of services provided and contract issues, as well as reference to other resources (*see* aaha.org).

The second group is CARF-CCAC formed in 2003 when the Commission on Accreditation of Rehabilitation Facilities acquired the Continuing Care Accreditation Commission. CARF-CCAC provides accreditation and reviews the credentials of continuing care retirement communities, aging services networks and other types of providers. Its web site (ccaonline.org) discusses standards and lists currently accredited facilities.

Given the volume of information and communities, why do most of us in New York know so little about continuing care retirement communities? CARF-CCAC lists nearly 400 CCRC's nationwide. California, a state with a population size and mix similar to that of New York, has 46 facilities on the list. Connecticut has 11; New Jersey has 8; Pennsylvania has 62. New York has but one. While there are facilities other than those on CARF-CCAC's list (and this is only one source of accreditation), the numbers raise the question of why New York State is not prominent in this arena.

3.5 Continuing Care Communities in New York State

The early models elsewhere in the country showed potential, but also generated problems and possible abuses. People paid large sums of money for the promise of life time care, but in many cases the facilities could not follow through on promises for life time care, because their limited financial reserves could not keep up with the health care demand of the resident mix. Likewise, in many such cases, the value of the resident's investment was severely compromised, and on occasion, totally lost.

New York lawmakers took note of these failures and drafted legislation with significant consumer safeguards that have resulted in a barrier to entry to potential operators.

New York law sets the bar high in terms of a facility's financial requirements. For example, it requires that a CCRC's liquid assets be maintained in a reserve sufficient to cover principal and interest payments for a year, operating costs for six months, repairs and replacements for a year and cash flow conditions as determined by regulation. Additional restraints apply to CCRC's funded with Industrial Development Agency (or IDA) bonds.

Add to this the high cost of land in New York, particularly in the New York metropolitan area, and the result has been a limited number of communities.

Equally daunting, New York law, prior to October 2004, permitted only the extensive and the modified contract, thus significantly limiting the number of CCRC's. At the same time, New York encouraged the development of "look-alikes," that is, arrangements that had much of what the fee-for-service arrangement provided, but were not labeled (or licensed as) CCRCs.

New Law Authorizes Fee-for-Service Communities A new statute, enacted in October 2004, authorizes up to eight fee-for-service communities. Only two of the licenses will be awarded to for-profit operators. These communities must be approved by the Commissioner of Health, the Public Health Council and the Continuing Care Retirement Community Council. Look-alikes are not affected by the new law.

Several important provisions address financing. Each community must establish a benevolent care fund to make assistance available to qualifying subscribers unable to pay certain fees. No guidelines are provided, however.

In addition, each fee-for-service continuing care contract must contain:

1. A description of all services to be furnished by the operator.
2. A statement of the fees charged.
3. The terms and conditions under which an operator or a resident may cancel a contract.
4. A statement requiring that a resident either (i) exhaust available resources, including funds from a refundable entrance fee, prior to applying for medical assistance or any other income-qualified state subsidy for long-term care, or (ii) purchase or maintain long-term care insurance, which would provide requisite

coverage for all levels of services offered at such continuing care retirement community. (Italics added.)

The impact of the statute has yet to be seen, but the availability of the fee-for-service model is welcome. The development of the look-alikes, which follow the fee-for-service model, is a testament to their attractiveness. In the absence of the fee-for-service model, facilities were looking primarily for applicants who enjoyed both substantial wealth and good health. The fee-for-service contract eliminates the risk to the facility and thereby expands the range of acceptable applicants.

What is disturbing, however, are the provisions regarding financial arrangements that appear to be inconsistent with federal law. What, for example, is intended by requiring each applicant to indicate that he/she will exhaust all resources (if the applicant has no long-term care insurance) before applying for Medicaid? If this is interpreted to prohibit what is commonly viewed as lawful Medicaid planning, then the statute violates federal law.

3.6 Recommendations

The burgeoning cost of long-term care cannot be solved by government programs alone. Yet it is clear that government programs may be necessary for a significant portion of the population.

The facilitation of non-institutional (that is non-nursing home) alternatives may offer a viable solution. Wealthy individuals have options other than nursing home care, but the options for less affluent seniors who need long-term care are typically more limited, essentially to home care or a nursing home with few alternatives in between. Middle class individuals also frequently face the same fate as the financially poor when the extraordinary costs of health-related care exhaust their modest resources.

Spending government dollars in different ways could contain costs and provide better care for more seniors in the long run. The following recommendations are based on the housing options outlined earlier in this chapter:

Home Modification Costs associated with retrofitting or otherwise modifying a home to accommodate the needs of its aging resident should be tax deductible to the homeowner. Tax deductions, tax credits or direct payments, would cost less than moving an individual to a nursing facility.

This approach could help to reduce the financial barriers that are now an obstacle to those of limited means. Opportunities might be made for projects

such as renovating a kitchen to make it barrier free, widening halls and door openings to allow wheel chair access, modifying a bathroom to add safety accessories, obtaining an alert system to reduce the need for the constant presence of an aide, and installing an elevator, lift or motorized chair to provide safe and convenient access to their homes.

Reverse Mortgages Programs to reduce the up-front costs and interest rates on insured home equity conversion loans would provide the elderly and their families with more flexibility in making difficult life-style decisions.

Home Sharing Rent (if any) from persons moving in and performing minor chores should be reportable but not subject to taxation as income. The cost of providing food, heat and utilities should be tax deductible.

Accessory Apartments Existing programs that encourage adult children to care for their parents should be expanded. The principal example today is Medicaid's "caretaker child exception" that allows parents to transfer their homestead to a child who has lived with and cared for them, without imposing a penalty that would make the parents ineligible for institutional Medicaid for a period of time based on the value of the property.

Tax breaks could be provided for adult children to encourage them to create accessory apartments for their parents. The costs could be amortized over a longer period of time to encourage the aging parent to remain at the home for an extended period. If an aging parent bears the cost for work done on property owned by the adult child, the expense should not be treated as a gift that would subject the parent to a period of ineligibility for institutional Medicaid coverage.

Apartment Living Encourage both landlords and boards for cooperatives and condominiums to employ professionals such as social workers and personal care assistants to coordinate services for frail elderly and other residents with disabilities. This applies to subsidized and market-rate housing alike.

Apartment buildings organizing the use of home-health care or personal care workers to address the needs of ten or more residents should qualify for a tax incentive.

Naturally Occurring Retirement Communities NORC's offer significant opportunities to provide care at a significantly lower cost, because the care can be offered to a large number of people in a central location. These communities often have common swimming pools or exercise facilities that can be expanded to accommodate rehabilitation.

Most importantly, it may be possible for those who need a higher level of care to share attendants with others in a similar situation and still be safely maintained.

Assisted Living Facilities The 2004 statute is a major step in the right direction. To enhance this newly enacted legislation, some form of government subsidy should be considered for the poor who often leave the assisted living facility because the only way to receive the Medicaid benefits they need is to enter a nursing home.

Appropriate Medicaid coverage should be devised for qualifying residents at assisted living facilities, because the cost of remaining at the assisted living facility could be less than half of the cost of the nursing home and represents a more efficient and appropriate use of the respective facilities.

Continuing Care Retirement Communities The 2004 statute, which now encourages the fee-for-service model, is also a major step in the right direction. However, it authorized the establishment of only such eight facilities, (six of which must be run by not-for profit entities), a total that should be increased.

Legislation is also needed to encourage the use of long-term care insurance by individuals in CCRC's. Medicaid planning should be available to avoid the need for moving those who can remain in CCRC's into nursing homes at a higher cost to the state.

Enforcement Building codes and specialized laws governing apartment buildings, CCRC's, assisted liv-

ing facilities and other group homes should be enforced.

Similarly, the Fair Housing Amendment Act and the Americans With Disabilities Act should be enforced to assure that the elderly are not needlessly forced to move into institutional settings.

3.7 Conclusions

This report is intended to open ideas and explore possibilities that will enable the older adult population to live longer with a better quality of life. We urge that studies be undertaken to measure the relative costs and benefits to the state of the approaches recommended in this report.

The recommendations in this chapter seek to foster compliance with the requirement in *Olmstead v. L.C.* (see Chapter 2) that the elderly not be unnecessarily institutionalized.

Endnotes

1. Social Services Law § 461-L.
2. 18 NYCRR § 494 with related sections throughout the 480's and 490's of Title 18.
3. Public Health Law § 4650)
4. *Id.*
5. Public Health Law § 4651(1).
6. Public Health Law § 4654.

Chapter 4

Long-Term Care Insurance

OVERVIEW: Insurance policies that will provide individuals with long-term care at home and in nursing homes are perhaps the most promising vehicle for reducing, or at least containing, the need for government financing of care for the elderly. Nevertheless, they cannot be regarded as a cure-all panacea.

The policies are not inexpensive. Dual policies that are taken out by a couple in their early 60s and provide four years of benefits at \$200 per day (with a rider to adjust the amount upward to account for inflation) typically require total yearly premiums in the \$4,000 range. Rates are higher for those with some ailments, and policies may not be available at all for individuals with life-threatening illness.

For those who can afford these policies, however, they provide a level of comfort regarding asset protection. If a policyholder ultimately develops health problems that will require expensive long-term care, a three-year coverage policy provides at least enough time to take steps needed to protect assets within Medicaid's "look back" period for penalties applicable to asset transfers. Those who purchase "Partnership" policies know that they will qualify for government benefits at the end of a three-year term without the need to divest themselves of assets.

Options to encourage further acceptance of long-term care policies include increased tax credits for premiums paid. Partnership policies might gain more popularity if they are permitted to lift the requirement that government benefits available at the end of the coverage period are available only if care is given in New York State.

By Bruce L. Birnbaum
with Gail Holubinka and Brian Andrew Tully

4.1 Long-Term Care Realities

Almost anyone who requires long-term health care risks impoverishment. At a cost per day that averages \$180 nationwide and \$269 in New York State,¹ long-term care rapidly becomes a race between time and the exhaustion of lifetime savings.

In New York, the \$269 daily average works out to \$98,185 for one year. In downstate metropolitan areas the figure is more likely to exceed \$109,000 for a year in a \$300-per-day nursing home, or \$145,000 at rates that are increasingly in the \$400-per-day range.

When savings are gone, Medicaid is the last recourse. This reality is particularly devastating for

those who believe they have "good health insurance" or that "Medicare will cover my medical expenses." Aside from limited coverage for a maximum of 100 days after a hospital stay, Medicare does not pay nursing home bills or the cost of extended in-home services. Some high-end private insurance policies provide longer coverage, but it seldom lasts more than a few months beyond the end of Medicare's 100 days. Even within the 100-day period, neither Medicare nor the typical health insurance policy covers strictly "custodial" services for those who have ailments such as arthritis, dementia or Alzheimer's disease but do not need skilled nursing care and will not benefit from rehabilitation.

Faced with these sobering realities, even those who have insisted, "I can pay my own bills," soon find that they have little choice but government assistance, either because they have very limited assets, or because they want to leave some type of modest inheritance for children likely to be faced with even greater inflationary pressures than they faced during their lifetimes.

It is not surprising, therefore, that Medicaid spending on long-term care almost tripled during the 1990s.²

Unless alternative sources of funding are found, the budgetary pressure on government can only increase as Baby Boomers reach age 65.

4.2 Basic Long-Term Care Concepts

Although long-term care insurance (LTCI) is now the subject of serious investigation by those who hope to slow the increase in the need for government funding, it was not created to answer the pressures of a growing elderly population, nor was it developed as a private alternative to public funding.³

In the late 1980s, however, insurers began to see the possibilities for LTCI. This realization coincided with the spiraling of Medicaid dependency, and even some states became interested, experimenting with "Partnership" policies that allowed policyholders who exhausted their policy coverage limits to qualify for government assistance without divesting their assets.⁴

Passage of the Health Insurance Portability and Accountability Act (HIPAA) in 1996 provided a framework that established ground rules advantageous to both the LTCI industry and consumers.⁵ HIPAA ended an era in which criteria for eligibility

and other coverage options had varied widely, establishing the principle that if policies contained certain provisions, they would be considered “Tax Qualified” and thus eligible for favorable tax treatment. Benefits, for example, would be exempt from taxation as income, and some or all of the premiums might be a deductible expense on tax returns. (See 4.14 for details on taxation issues.)

In 2002, the federal government acted to make long-term care insurance coverage available to federal employees, creating the Federal Long-term Care Insurance Program (FLTCIP). A side benefit was increased consumer awareness of the financial devastation that the need for long-term care could inflict.

4.3 Coverage Components of LTCI

Although some initially find that understanding LTCI is a challenge, the basic principles are fairly straightforward. If eligibility rules are met, the policyholder is paid in accordance with the benefit selections made when the policy was purchased. Because the vast majority of policies sold today are “Tax Qualified” and therefore follow HIPAA guidelines, the following information applies only to products that meet the guidelines.

Maximum (Daily/Weekly/Monthly) Benefit Policies provide for a maximum amount of benefits that will be paid in a stated period. Some policies establish a daily maximum, others use a weekly or even a monthly figure. The amount selected by the policyholder reflects the anticipated expense—usually the amount billed by a long-term care facility in the area where the policyholder expects to reside, or a smaller amount equal to the difference between the charge by the facility and the amount the policyholder believes will be available from his/her own income.

Lifetime Maximum Benefit How long will benefits be paid—for 2 years, 3 years, 4 years, 5 years, 6 years, or even for an unlimited period? Related to this is the Policy Limit or Pool of Money. For example, if a policy will pay a maximum of \$300 per day for 5 years, that makes the ultimate pool of money \$547,500 ($\$300 \times 365 \text{ days/year} \times 5 \text{ years}$). But if the insured needs only \$150 per day, the same pool of money (the “Policy Limit”) will last 10 years, not 5 years.

Elimination Period Similar to a deductible, the Elimination Period reduces premium cost by establishing a period of self-payment. Usual options range from 0 to 365 days. Days can be counted on either a calendar day basis or only for those days when a qualified service is received.

Inflation Protection By definition, LTCI is intended to be used immediately after being pur-

chased, yet it must define the maximum amount that will be payable on a daily basis for specific services. At the time of purchase, a maximum benefit of \$300 per day may be adequate for the typical cost of a day’s care, but inflationary pressures are likely to increase that figure over time. Thus, it is normally wise to purchase a policy that provides for the maximum benefit to increase to keep pace with inflation. This option is especially important for younger purchasers.

Types of Coverage LTCI policies come in three types—Facility Only (Nursing Home, Assisted Living Facility, Adult Day Care, Hospice Care), Community Only (Personal Care, Home Health Care), and Comprehensive, which covers all qualified long-term care services defined in HIPAA.

Contingent Non-Forfeiture Most policies now include a form of Shortened Benefit Period coverage in the event premiums are increased over a certain amount. The increased percentage trigger is based on the age of the policyholder at purchase.

4.4 Optional Benefits

Options and Riders may not be available in all states. The following list is intended to give an idea of the various options, although it does not set forth all the available possibilities.

Shared Spousal Benefits Riders that give a husband and wife access to the same Lifetime Maximum are a recent development. A “Spousal Shared Benefit” usually means that both spouses can access the combined pool of money. This helps make the policy more affordable for larger amounts of coverage, while also increasing the likelihood that more of the benefits paid for will be used.

This option also addresses the frequent concern that only one spouse may ultimately need care but it is impossible to predict beforehand which one this will be. By electing to take this approach, each spouse will have access to the other’s pool of money if his/her own pool runs out. Options are also available to add more benefits if the entire pool of money is depleted.

A husband and wife in their early 60s who wish four years of coverage at \$200 per day for each of them, together with a rider allowing for the daily amount to be increased to keep pace with inflation, can expect to pay a yearly premium in the \$4,000 range. In the terminology typically used by the policy documents, such a plan has a maximum yearly benefit of \$73,000 for each of them and the combined Pool of Money is \$584,000.

Spousal shared benefits are available in New York State.

Multi-Generational Policies A “Multi-Generational Policy” permits other members of the policyholder’s family (e.g. parents, grandparents and children) to draw benefits from the collective Lifetime Maximum.

In structuring these policies, it is important that a sufficient pool of money be available to protect all of the affected parties. Contingent provisions should also exist for the procedures to be followed if policy benefits are exhausted before all the potential beneficiaries have died.

The premium reductions and psychology linked to multi-generational policies may encourage purchases by some individuals who would not otherwise obtain coverage for just themselves.

Policies of this type are not currently available in New York State.

Shared Waiver Rider If one spouse becomes eligible to receive benefits, and thus is no longer required to pay premiums, some policies also waive the premium for the spouse who is not claiming benefits.

Survivor Rider If one spouse dies, premiums are waived for the surviving spouse.

In general, many policies with a spousal option make the same benefit available to domestic partners.

Limited Pay Options Rather than paying premiums for the life of the policy, many insurers offer options that permit payment for a shorter period of time. Among the most popular are 10 annual payments or Paid Up at a specific age such as 65.

After this limited pay period, the policy becomes “non-cancelable,” which essentially is a guarantee that the premium will never reappear.

Non-Forfeiture and Return of Premium Options A shortened benefit period option can provide that if the policy lapses due to non-payment of premiums, the past premiums paid will not be forfeited but will be available to pay for services. A Return of Premium option provides that at the death of the Policyholder a named beneficiary may be eligible for a return of at least some of the premiums paid—the amount generally will be premiums paid less any benefits received, although a rider is available that provides a return of premiums without taking into account benefits received if the insured dies before age 65.

Restoration of Benefits This provision restores the Lifetime Maximum amount payable to the original figure, regardless of claims paid, provided that

the insured recovers, resumes paying premiums, and then needs no further care or treatment for a minimum period of time, generally, six months.

4.5 Built-In and Operational Features

Guaranteed Renewable All Tax-Qualified policies are Guaranteed Renewable. This means the insurer cannot alter any provision of the policy without the insured’s approval or cancel the coverage provided that premiums are timely paid.

Premiums LTCI premiums are meant to remain level for the life of the policy. Barring actuarial issues, premiums are set at the age the client purchases the coverage. Increases can only be made on a class basis (i.e. for all individuals who purchased comparable policies at age 61) and must be approved by the state, which generally requires that the insurer demonstrate hardship in paying future claims unless the increase is granted.

Indemnity vs. Reimbursement All benefit payments depend on meeting and maintaining eligibility requirements. However, benefit payments can be made in two ways:

- (1) Reimbursement Method: The benefits paid equal amounts actually paid for qualified LTC services, up to the daily, weekly, monthly or yearly “Maximum Benefit” chosen when the policy was purchased.
- (2) Indemnity Method: The benefits paid equal the daily, weekly, monthly or yearly “Maximum Benefit,” but no proof of payment for services or loss of income is required. The policyholder need only show that he/she met the policy criteria to be eligible for benefits. The indemnity method can provide for more flexibility than reimbursement, but the insured is generally required to file a monthly claim form, and the insurance company will generally send a claims examiner to see the insured every 90 days. In addition, the indemnity policy is more expensive than the reimbursement policy.

Waiver of Premium Premiums may be waived after a policyholder has been able to claim benefits for a specified period (e.g. 90 days). Alternatively, whenever benefits are payable, premiums are waived for as long as the claim remains open.

Underwriting The underwriting process typically involves answering routine medical questions, and authorizing the release of the prospective insured’s medical information to the insurance company. Medical exams may be requested (e.g. if the proposed

insured has not had a physical examination within the last 12 or 18 months) and the company can require personal interviews, particularly when the applicant is older.

Bed Reservation Days If a claimant residing in a nursing home or assisted living facility must be hospitalized, benefits will continue to be paid to reserve the individual's place at the nursing home or assisted living facility for a reasonable amount of time.

Alternative Care In some cases, payment may be allowed for services not directly stated in the contract if, on a case-by-case basis, such service is determined to meet qualified service standards and is in the best interest of the policyholder. Other plans may contractually provide for such alternative or additional plans of care. Examples are transportation, Meals on Wheels, caregiver training, durable medical equipment, home modification and assistive devices.

Care Coordination Some plans provide company-based care management services. Most also cover the cost of purchasing such assistance privately. Care managers help assess needs, develop a personalized plan of care, coordinate the delivery of the care services and monitor the services delivered.

Discounts Discounts are usually available to married and domestic partners as well as persons purchasing through plans "sponsored" by employers and association groups.

4.6 Long-term Care Insurance as an Answer

Increasing longevity in general and the aging Baby Boomers in particular, make it probable that the need for long-term care services and their attendant expenses will continue to grow. Concurrently rising expenditures for Social Security and Medicare serving this population will likely leave little room to expand public financing to include long-term care programs in the foreseeable future.

Growth in need and cost, coupled with static or shrinking public financial support places the burden of the problem on the individual. However, it is also true that among individuals who need some form of long term care the average amount spent in New York State is approximately \$250,000, a figure beyond the means of even the relatively comfortable middle-class.

If neither government programs nor the individual resources are expected to be able to support anticipated costs, one potential payment solution seems reasonably viable - insurance. Insurance allows individuals access to affordable protection for other major fiscal risks such as death, health care, or fire. Long-

term care is no different. However, insurance while "an" answer, is the not "the" only answer.

4.7 LTCI Issues

Although long-term care insurance is a promising prospect for many, it is not the answer in every case.

Suitability: Some individuals have nothing to protect. LTCI is only appropriate if someone has sufficient assets to protect. In some instances, it may be prudent to also protect income streams.

Affordability Affordability is a concept not easily defined. While there are some who cannot be expected to buy coverage, many, if not most, of the population could purchase if three factors are addressed:

- (1) Percentages of net income such as 5% or 7%, an approach favored by many researchers. Whether those figures are affordable to the consumer depends on a prospect's perceived need for the coverage. Unless a need is established, the purchase will lose priority in the individual's financial planning. Others have used percentages of assets as the basis for determining affordability.
- (2) Timing. Because the premium is age driven, and meant to be level, purchasing at a younger age broadens the potential market.
- (3) Subsidies. Two basic kinds of subsidy might be provided: premium and risk. A premium subsidy would give qualified purchasers a direct co-payment of premium. A risk-based subsidy would limit personal risk, the approach taken in Partnership programs that provide for government payment of expenses after the individual has exhausted a set level of insurance. The limits on personal risk may permit fuller coverage at a lower premium. Tax-favored subsidies can also be used (*e.g.* tax deductions and tax credits).

Quality of Company The quality of the company that stands behind the product is extremely significant. A company's premium rates should be based on realistic actuarial assumptions. Moreover, the company should have strong financial ratings and a proven track record of paying legitimate claims. As experience has already shown, companies that entered the market with unrealistically low rates were unable to continue to provide coverage.

Health Related Issues As with most insurance, eligibility for LTCI is health-related. However, in premium calculation, LTCI is akin to individual life insurance, not health insurance. There is no pool of

risk to absorb high probability purchasers and the expected pay-out is very high. A single LTCI episode, even for a modest policy, has an expected payment of more than \$100,000. While appealing on the surface, forcing the uninsurable into the program may be actuarially unsound at best. At worst it may lead to high premiums that drive the healthy out of the program, unless purchase becomes mandated so that there is no adverse selection.

Therefore, a single approach will not likely work. Resolution of the problem of financing long-term care should not be short-term and should not be a quick fix.

4.8 Possible Guidelines for Creating Change

LTCI may have limitations, but, realistically, it may be the only viable vehicle for change. The format of a program that balances the strengths and weaknesses of the insurance is outside the scope of this paper. Nevertheless, there are recommended guidelines that could help assure a successful design.

Issue While public spending is the impetus for change, the larger issue is how are we as a society going to accommodate the unavoidable expenditures to come. Placing the problem in a broader context could help avoid narrow, short-term solutions.

Goal Eliminating public LTC expenditures or even reducing them too much in too short a period of time is not reasonable. Set attainable, measurable goals.

Target Participants in a program based on private insurance must be healthy and able to afford premiums. Although affordability may be flexible, health status isn't. Consider dual programs: one for the insurables and one for the non-insurables.

Assessing Affordability and Expense Each of these concepts implies a different approach, as illustrated in the chart below.

Coverage Minimum coverage is enough insurance to delay or avoid public funding while allowing the consumer to retain assets. Policy options may permit lower benefit policies with commensurate asset protection equal to LTCI purchased.

Program The program uses insurance but does not need to create it. The LTCI market is at a point where product design is fairly mature.

Limitations There are limits, regulatory and/or financial, that limit the role insurance can play. A successful program design acknowledges the difference between insurance and public funding.

Psychology The program should not impose rules, requirements, or expectations that would not be acceptable to a reasonable person. This is the concept of "achievable morality." The notion of doing one's duty is not enough. Where the personal reward is deemed insufficient or unfair, people will seek other ways even at the expense of their society. On the other hand, if the personal reward appears to balance the duty, personal pride and community peer pressure can alter unacceptable actions.

Some have used the Medicaid spend-down rule as an example of a well-intentioned idea that may result in the circumvention of personal responsibility and has at times been perceived as detrimental to society. A client starting with \$10,000 and allowed to retain \$3,000 might feel the maximum asset limit reasonable. However, the person who expends \$300,000 might consider the requirement unfair and seek ways around it.

Tax Incentives Continuation and expansion of tax incentives to encourage consumers to purchase protection and employers to offer it as part of an employee benefit package.

4.9 Additional Insurance-Related Approaches

Life Insurance Accelerated Benefits These policies are not yet available in New York State, but

BARRIER	RESULTS	APPROACH
Perceived Need	Making personal LTC funding important	Education Inclusion in cafeteria plans Penalties
Expense	Premium cost beyond reasonable ability to pay	Employer and consumer tax incentives Concentration on younger buyers Government stop-loss protection Scaled down out-of-pocket options.

where they are, this approach permits holders of life insurance policies to receive a portion, or all, of the life insurance death benefit to use as long-term care insurance. This is a very attractive product because it may meet the needs of persons who want to protect against LTCI, but regard getting life insurance as a hedge against the possibility they won't need LTC. It is important when structuring these policies that most of the needs intended to be covered by the life insurance are appropriately addressed.

As part of the New York State 2004-2005 Budget, signed into law, the New York State Insurance Department is directed to study the advisability of offering such policy benefits to New York state residents.

Life Settlements and Viatical Settlements Viatical Settlements generally involve the sale of an existing insurance policy for less than the policy's death benefit when the insured is terminally ill.

Life Settlements, on the other hand, typically involve the sale of life insurance when the insured's life expectancy is longer than 12 months. The sale of a life insurance policy to a third party has raised concern to many people and companies. The concern is that it may be dangerous to give a third party an economic interest in having the death of the insured occur as soon as possible after the third party has made the purchase.

As part of their life insurance policies, some companies offer "accelerated death benefits" at little or no extra cost, an option that should be considered as an alternative to viatical or life settlements.

4.10 New York State's LTCI Regulations

New York has adopted many of the NAIC's model regulation provisions. The law dealing with LTCI requirements is embodied in Insurance Law Sec. 1117 and Regulation No. 62 (NYCRR, Title 11, Parts 52.12, 52.25 and 52.65).

Salient Regulations Some of the more salient provisions of New York State's LTCI regulations include:

- A minimum of 24 months coverage.
- Certain minimum coverage amounts depending on whether the policy is issued inside or outside the "metropolitan" area (e.g., at least \$100/day nursing home coverage in the metro area, or \$70/day outside the metro area).
- The requirement that individual LTCI be "guaranteed renewable."

- Limited rights to convert group policies to individual LTCI.
- Limitation to exclude pre-existing conditions for no more than six (6) months after the effective date of coverage, provided full disclosure was provided by the insured.
- Prohibition of condition coverage on prior hospitalization or a prior specified level of care in order for another level of care in a nursing home or at home to be covered.
- Options for coverage increases due to inflation must be offered.
- The consumer must be offered the "option" of purchasing a non-forfeiture provision such as a reduced paid-up policy.
- There are various disclosure requirements (e.g., outlines of coverage).

4.11 New York State Long-term Care Insurance Education Initiative

As part of the New York State final budget for 2004-2005, the New York State Department of Health is to establish centers to educate the public about LTCI.

This would be accomplished by the dissemination of audio, visual and printed material, the creation of media campaigns, workshops and other methods of providing this information to the general public. As part of this project, counseling and referral services are to be available.

4.12 The Robert Wood Johnson Project

The Public/Private Partnership New York is one of four states that have received federal waivers allowing them to participate in the Public/Private Partnership for Long-Term Care, an effort that originated with planning assistance from the Robert Wood Johnson Foundation. (The others are California, Connecticut and Indiana.)

This program, initiated in 1993, generally provides that New York citizens who purchase approved long-term care insurance policies (designated "Partnership Policies") can obtain Medicaid benefits after policy benefits are exhausted, yet not divest themselves of their assets. Partnership Policies must contain the following provisions:

- A minimum benefit period of three-years for institutional coverage. 11 N.Y.C.R.R. § 39.3(b)(1).

- A minimum daily benefit of at least \$180 (2005) per day for nursing facility care (indexed), and a minimum daily benefit for home care equal to half of the benefit for nursing home care. 11 N.Y.C.R.R. § 39.3(b)(1). Although there is some flexibility on providing a daily benefit higher than the minimum amount, in no case may the home care benefits paid for the month exceed an amount equal to the number of days in the month multiplied by the minimum daily benefit. 11 N.Y.C.R.R. § 39.3(b)(2)(iv).
- The policyholder must be permitted to substitute home care benefits for nursing home benefits on the basis of two home care days for one nursing home care day, regardless of whether the daily benefit for home health care is less than or equal to the daily benefit for nursing home care. 11 N.Y.C.R.R. § 39.3(b)(2)(ii) and (iii).
- Inflation protection that increases the daily benefit by at least 5% compounded annually if the insured purchases the policy prior to age 80. 11 N.Y.C.R.R. § 39.3(b)(5).
- An “elimination period” that imposes a wait of no more than 100 days between the onset of a need for services and eligibility for payment of benefits. 11 N.Y.C.R.R. § 39.3(b)(9).

This unique program has a number of downsides. For instance, after transitioning onto the NYS Medicaid Program, income above certain limits must be contributed toward the cost of care. So if an individual’s monthly income is high, most of it will still be spent for care, diminishing the attractiveness of the program, particularly if the individual’s core assets do not constitute a particularly large estate.

In addition, although the insurance coverage may be used in any state, when it ends, an individual generally must be physically present in New York State to receive the Medicaid portion of the program. New legislation provides, however, that reciprocal agreements can now be entered into with other states that have Partnership programs. This would allow purchasers of policies in those states that have comparable partnership policy benefits as New York, to be eligible for Medicaid coverage in New York as long as purchasers of policies in New York are eligible for Medicaid coverage in such other states.

At this writing, New York has not entered into such reciprocal agreements, but presumably options are being explored with states that offer Partnership programs comparable to New York’s. It is likely, however, that these reciprocal arrangements will provide only limited asset protection, because among the four states with partnership programs, New York is the

only one that permits unlimited asset protection when the policy benefits are exhausted.

The New York rules for this project (formally known as the Long-term Care Security Demonstration Program) are in Regulation No. 144 (NYCRR, Title 11, Part 39).

The program underscores the benefits of insuring against the financial risks of long-term care and may help to alleviate a rapidly growing Medicaid budget.

Partnership policies may now provide for less than three years of insurance coverage. They can provide as little as twelve months of coverage, with asset protection under Medicaid limited to the policy pool of coverage. For example, if the Partnership Policy pays two years at \$200 per day, the individual will be able to retain \$146,000 (\$200 x 365 days x 2 years) in assets when he/she applies for Medicaid. Any other assets would have to be transferred or spent down before the individual would become eligible for Medicaid. As of this writing, no Partnership Policies approved in New York provide for less than three years of coverage.

Effective April 1, 2005, New York State licensed agents must have completed a Mandatory NYS Partnership training course and be certified as a Partnership agent.

4.13 The Federal Employee Long-term Care Insurance Program

The Federal Long-term Care Insurance Program (FLTCIP) was created by the Long-Term Care Security Act of 2000 (P.L.106-265). This program makes approximately 20 million people eligible to apply for this LTCI, including federal and Postal employees and annuitants, active and retired members of the uniformed services, their qualified relatives and a few other eligible groups.

The U.S. Office of Personnel Management sponsors the Federal Program. OPM selected both John Hancock Life Insurance Company and Metropolitan Life Insurance Company as the insurers for the federal program. They jointly formed Long-term Care Partners, which exclusively serves the long-term care insurance needs of the Federal Family.

As with private LTCI plans, the FLTCIP provides long-term care insurance to help pay for costs of care when the insured needs help with activities of daily living, or suffers from severe cognitive impairment, such as Alzheimer’s disease. The Federal Program is designed to be a tax-qualified long-term care insurance coverage under Section 7702B(b) of the Internal Revenue Code of 1986, as amended. Therefore, the same Federal income tax advantages afforded to all

insureds who own tax-qualified LTCI are available to taxpayers who are in the FLTCIP.

The Federal Program offers four pre-packaged plans. The Facilities 100 plan covers care in nursing homes, assisted living and hospice facilities and respite services provided in a facility. The Comprehensive 100, 150 and 150+ plans cover everything in the Facilities 100 plan, plus home care, adult day care, respite services at home and home hospice care. Participants can also customize their plans by mixing and matching the available benefit options up to \$300 in daily coverage.

The Federal Program offers an Alternative Insurance Plan and a "Service Package." Some employees—members of the uniformed services and their spouses who apply for LTCI using the "abbreviated" underwriting application and are not approved to enroll in the insurance they originally applied for—will be offered the Alternative Insurance Plan. It offers nursing-home-only coverage with a 180-day waiting period and 2-year benefit period. The Alternative Insurance Plan also has higher premiums. This plan is not available to those who use the full underwriting application. If one applies for and is denied the standard insurance and is not offered the Alternative Insurance Plan, they will be offered a Service Package. The Service Package is not insurance. It is a package of services, including access to a care coordinator, general information and referral services, and access to a discounted network of long-term care providers and services. It costs \$59 per year, for an individual or a couple.

4.14 Taxation of LTCI

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) was signed August 21, 1996. Prior to HIPAA, the tax treatment of LTCI premiums and benefits was unclear.

LTCI Proceeds Qualified Long-term Care Policy benefits are generally excluded from gross income. See, IRC Sec. 7702B(a)(2). See too, IRC §§ 104(a)(3) and 105(b). Benefits paid from "indemnity" as compared to "reimbursement" or "non qualified" policies may trigger taxable gross income. If an LTCI payment from an indemnity policy exceeds \$240 per day for 2005, the excess may be included in gross income.

Premium Deductions for Individuals Individuals who itemize their deductions can add eligible long-term care insurance premiums to their medical expenses. Such amounts are deductible to the extent they exceed 7.5% of adjusted gross income. See, IRC Sec. 213(a). Eligible premiums are based upon age (subject to indexing) as follows:

Age	2005 Eligible Premium
40 and under	\$270
41-50	\$510
51-60	\$1,020
61-70	\$2,720
71 and over	\$3,400

Premium Deductions for the Self-employed Self-employed individuals can deduct 100% of the above eligible premium for themselves, for their spouse and dependents, without regard to the 7.5% floor and without regard to whether the taxpayer itemizes his or her deductions. As a general rule, members of LLC's, partners and more than 2% shareholder/employees of an S Corporation are treated as self-employed. See, IRC. §§ 162(1) and 1372.

Premium Deductions for C-Corporations A C-Corporation is entitled to a full deduction of the premium it pays on behalf of any of its employees, their spouses or dependents, as part of an accident and health employee benefit plan. IRC Sec. 162(a). Here, the deduction is not limited to the "eligible" premium component. The entire amount paid by the business may be excluded from the employee's gross income. See, IRC §§ 106, 7702B and 104(a)(3). This exclusion also applies to shareholder/employees in a C Corporation and to shareholders in an S Corporation who own 2% or less of the corporation.

Premium Deductions for Selective Benefit An employer can be selective in the classification of employees it elects to cover for LTCI. Nondiscrimination rules that apply to certain types of plans, Qualified Retirement Plans, for example, do not apply to LTCI benefits provided by employers. Consequently, participation in an LTCI accident or health plan may be limited to one or more key employees, as a class.

Proposals for Premium Deductions President Bush's 2005 Tax Proposal included enhanced tax incentives to further encourage the purchase of LTCI including an above the line tax deduction for the "full" premium. The government has generally been encouraging people to purchase LTCI. Examples of this are the Partnership policies mentioned above, the HIPAA legislation discussed above, the recent Federal legislation establishing a voluntary LTCI program for Federal employees and New York State's recently increased tax credit (discussed below) for LTCI premium payment.

Proposals have also included allowing tax-favored and penalty-free withdrawals from Individual Retirement Accounts, or similar types of invest-

ment vehicles, as well as allowing LTCI to be purchased pre-tax in qualified “cafeteria plans.”

New York State Tax Legislation As of January 1, 1996, New York State residents have been able to deduct their eligible LTCI premiums, provided the policies were qualified or grandfathered policies, without regard to the 7.5% floor.

As of 2002, however, there is now no longer a state tax deduction for the premium paid. Instead, New York Tax Law Sec. 606 permitted a 10% tax credit for the LTCI premium payment. As of 2004, New York Tax Law permitted a 20% tax credit for the LTCI premium payment. The credit amount is a dollar-for-dollar reduction in taxes that is subtracted directly from the amount that would otherwise be due as tax.

Endnotes

1. See, MetLife Survey of Nursing Home and Home Care Costs, April 2002).
2. See, Congressional Research Service, The Library of Congress, Long-term Care: What Direction for Public Policy? (Order Code RS20784 Updated Dec. 18, 2002).
3. Recognizable LTCI was first sold by a handful of carriers in the early 1960s. Initial policy limitations reflected its intended role as a niche market product. Nursing-home-only coverage and small, static benefits made the insurance almost as ineffective as coverage as it was invisible to the public at large.
4. Under the aegis of grants from the Robert Wood Johnson Foundation, eight states (California, Connecticut, Indiana, Massachusetts, New Jersey, New York, Oregon and Wisconsin) initiated research projects to determine whether this new insurance could help stem the tide of what seemed to be inevitable Medicaid dependency. Of these, four states (California, Connecticut, Indiana and New York) created what are now known as Partnership programs. While the success of these programs continues to be debated, one clear effect was they seemed to have helped jump-start both industry commitment and product refinement. The first LTCI products of the 1980s changed quickly and dramatically. A combination of consumer demand and the effect of the Partnership programs helped accelerate the industries’ improvement of the policies and understanding of the marketplace.
5. Prior to HIPAA, insurers had room to experiment. This was positive in many respects, although certain basic tenets of coverage, such as eligibility, varied dramatically from policy to policy.

Chapter 5

Near-Term Alternatives For New York State

OVERVIEW: The absence of a national program to finance long-term care has left Medicaid with the task of assisting not only the very poor but also members of the middle class. Long-term care expenses can rapidly exhaust the assets that seniors need to care for themselves at home or to assure that a “community spouse,” typically the wife, is not impoverished by the needs of the ill spouse.

Faced with ever-increasing obligations and the specter of even greater expenditures as more Americans enter their 60s, 70s and 80s, individuals who need near-term assistance inevitably turn to Medicaid. The lack of realistic data on current programs, however, has been a major obstacle to developing rational approaches to both present and future funding options.

Abrupt changes in eligibility criteria would bring undue hardship to those who have made good-faith plans to comply with long-established standards for assistance. In addition, federal statutes would preclude many often-discussed changes in eligibility rules, and the prospects for experimental “waivers” would be doubtful.

Too often, stereotypes about Medicaid recipients have poisoned efforts to engage in a rational debate on changes that might be made in the program. The mythical nature of these stereotypes is readily exposed by a simple review of the Medicaid application process and the options already available to the Medicaid program to pursue reimbursement for services it provides.

Before contemplating any wide-ranging changes in programs for the elderly, the Legislature and Medicaid administrators need to obtain reliable data to assess the potential impact of changes. Only then can they fashion new approaches that will maintain the financial viability of the program while continuing to meet Medicaid’s federally mandated obligation to serve those whose only realistic option is government assistance for their long-term care needs.

Meanwhile, options such as encouraging the use of “Partnership” policies, expanding assisted living options, and supporting community-based programs may lessen the demands on government funding.

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5.1 Myths vs. Realities

No realistic effort to address the near-term care needs of New York State’s elderly and disabled residents is possible until myths about current programs are dispelled and steps are taken to obtain data needed to assess the impact of possible changes in the Medicaid program.

Medicaid has evolved into the *de facto* safety net for members of the middle class when faced with expenses that routinely equal or exceed \$100,000 per year for nursing home care in many areas, and a like amount when an individual needs round-the-clock home care and no family members are available to provide uncompensated assistance.

Any abrupt changes in Medicaid eligibility rules could well result in the denial of necessary medical assistance for individuals who have attempted to make prudent plans for their declining years based on long-established state and federal guidelines.

Individuals likely to need assistance within a near-term range of approximately five years are unlikely to qualify for, or be able to afford, options such as long-term care insurance policies that may be practical for those whose needs may be a decade or more away.

Rational decisions can be made on changes that would not impose undue hardships only if the changes have a factual basis and are not the product of hasty mythological stereotypes. Similarly, seeking options that might reduce the need for nursing home admissions, the most expensive component of care for the elderly, will make sense only in the context of whether documented experiences point the way toward programs that are less expensive but provide appropriate levels of assistance.

Myth: *Medicaid planning involves the fraudulent sheltering of assets.*

Reality: Federal law specifically provides for estate planning that includes the possibility of eventual eligibility for Medicaid benefits if an individual requires an extended period of nursing home care. The choices made are subject to close scrutiny when a Medicaid application is filed.

Anyone in New York State who ultimately qualifies for Medicaid benefits signs a statement, subject to penalties for perjury if false, that his/her assets now total \$4,000 or less,¹ not counting funds set aside in a Pre-Plan trust to pay for a funeral.² Once eligible for Medicaid, an individual can retain \$50 in monthly income for personal needs,³ but the remainder of any income (the “NAMI”—Net Available Monthly Income) will be used to help pay the nursing home bill, reducing Medicaid’s total expenditure for the recipient of its assistance.

If the individual is married, his/her spouse is also required to disclose the full extent of his/her assets. This “community spouse” may then retain up to \$95,100 in assets (the “CSRA”—Community Spouse Resource Allowance) and is entitled to retain \$2,378 in monthly income (the “MMMNA—Minimum Monthly Maintenance Needs Allowance”).⁴ A home, condominium or cooperative apartment used by a community spouse is an “exempt asset” and not part of the CSRA calculation. (See the digest of applicable rules in Appendix C.)

Actuarially sound annuities are permitted, but the full amount of principal and interest payable each month must be included in computing both NAMI for an individual and the MMMNA allowance for a spouse. IRAs in “payout status” need not be depleted, but, again, all distributions must be part of the NAMI and MMMNA computations. The value of a spouse’s IRA is included in computing the spouse’s CSRA, however.

In certain hardship cases, a “community spouse” may apply for approval of a larger CSRA and/or MMMNA by demonstrating that he/she requires additional resources to generate income needed to reach the MMMNA figure. In cases where hardship can be demonstrated, it is also possible to seek a fair hearing to request a larger MMMNA, either by retaining additional assets to generate income or by obtaining approval to keep more of the income of the ill spouse.⁵ If approval is granted for a larger CSRA or MMMNA, the community spouse is then exempt from a spousal refusal lawsuit.

Reliable statistics are not publicly available, but it appears that approval for larger CSRA amounts is not extensive. Thus, in most cases a spouse who wishes to retain more than the standard amount must sign a “spousal refusal” that opens the possibility of a lawsuit by Medicaid to obtain full reimbursement for the amounts that Medicaid spends for the ill spouse. CSRA

An application for Medicaid requires disclosure of all financial transactions during the past three

years, together with any transactions in the past five years that have involved placing assets in a trust.

Depending on where an individual lives, each uncompensated asset transfer ranging from \$5,988 to \$9,612⁶ results in a “penalty period” of one month during which the person must pay privately for nursing home care if it is needed during the period after the transfer is made. Uncompensated asset transfers include, most often, gifts to an individual’s children or assets placed in a trust. For married couples, the penalty period calculations apply both to gifts made by the applicant and to gifts by the applicant’s spouse.

No penalty periods apply to eligibility for home Medicaid, but the individual must also have no more than \$4,000 in assets. After paying premiums for any supplemental health insurance the individual may have, a home Medicaid recipient may retain only \$667 per month⁷ to pay for food and housing expenses, the remainder goes to offset Medicaid’s cost of providing home aides and medical care not covered by Medicare or insurance. If the Medicaid recipient is married, the couple can retain \$5,850 in assets and \$975 in total income. A spouse who wishes to retain more income and/or assets must file a spousal refusal. (See the digest of applicable rules in Appendix C.)

Myth: Millionaires are receiving Medicaid.

Reality: Any current millionaire who is receiving Medicaid has probably filed a fraudulent application and is subject to penalties for perjury.⁸

If an asset was concealed, Medicaid’s “tape match” process provides a mechanism to find the asset. Periodically, the local agencies administering Medicaid receive tapes from the U.S. Internal Revenue Service listing interest on bank accounts and other assets. If the Social Security number on such a report matches the Social Security number of a Medicaid recipient, the Medicaid agency checks to see if the asset was disclosed on the application (and presumably depleted after the period covered by the tape). If it was not, the agency asks for an explanation.

If any Medicaid recipient has a spouse who is a millionaire, the spouse is subject to a lawsuit by Medicaid for reimbursement of the full amount paid for care of the ill spouse. If the Medicaid program ultimately shows a net loss from assisting the ill spouse, it is because Medicaid has not exercised its right to sue the spouse for reimbursement.

Myth: Medicaid Recipients Leave Large Estates

Reality: Medicaid is entitled to reimbursement for assistance it has provided to any deceased recipient who leaves an estate subject to probate or administration in the Surrogate's Court.

No statistics are available, but this recovery apparently exists most often against the proceeds from the sale of the house that a home Medicaid recipient lived in until death.

Aside from a home and any residue in an account that held the \$4,000 "personal needs account" a recipient was allowed to keep upon applying for Medicaid, it is unlikely that any other significant financial assets would be available at death. Any bank accounts the recipient held with a family member's name as a joint owner were subject to the asset review at the time of an application. Any funds given to the individual whose name appeared on the account were subject to inclusion in the computation of applicable "penalty periods."

In addition, as a precaution to assure that Medicaid does have an opportunity to make any claim that may exist against an estate, most local Medicaid agencies routinely send representatives to the Surrogate's Courts to research probate and administration files to match the Social Security numbers of decedents with those of individuals who have received Medicaid.

5.2 Insufficient Data

The current rules for Medicaid eligibility reflect a basic set of federal standards⁹ that establish parameters for eligibility. The limited flexibility given to the states to establish detailed guidelines for the individual programs is regularly the subject of discussions about whether the financial criteria should be changed.

The core difficulty in considering any adjustments to the program is a lack of data about the financial impact of current rules on the Medicaid budget. Without this information, it is impossible to gauge the extent of potential medical hardships for Medicaid recipients and whether any changes would, indeed, yield significant cost savings without a dramatic impact on availability of care.

The lack of information also makes it difficult to assess the potential viability of program changes such as different rules for home care coverage and a different approach to providing assistance to those who might be able to remain in assisted living environments rather than be left with no alternative except a nursing home.

Implementing changes without the benefit of reliable data and appropriate alternatives based on that data would put the most vulnerable members of our society at grave risk.

Following are examples of areas where more information is needed before government officials can reasonably propose changes and make realistic estimates of whether changes would produce significant savings for the Medicaid budget without compromising the level of needed care.

What is the effect of asset transfers on Medicaid costs?

Every application for institutional Medicaid requires disclosure of uncompensated asset transfers within the three years preceding the requested coverage date, and of transfers to trusts within the five years preceding the requested coverage date.

No figures are known to be available for the extent of asset transfers disclosed on institutional Medicaid applications in New York State.

In 1995, however, one national study estimated that if *every* older individual with a significant incentive to divest countable assets to become eligible for Medicaid actually did divest every penny, the amount transferred would equal about 4% of Medicaid nursing home expenditures.¹⁰

Among the thousands of residents in New York State nursing homes, the experience of elder law attorneys suggests that the vast majority who have qualified for Medicaid immediately upon admission did so with little or no advance divestiture of assets. No reliable figures are known to be available, however.

Experience also suggests that another significant portion of those who receive nursing home benefits from Medicaid did no advance planning until faced with an illness that required nursing home admission. For them, at a minimum, they had to spend at least half of their assets as private-pay residents while giving away no more than half of what they owned at the onset of their illness. But again, no reliable statistics are available.

How long do nursing home residents pay privately before qualifying for Medicaid?

No analysis of Medicaid applications is known to be available that would support even reasonable speculation on an answer to this question.

Yet every application for nursing home Medicaid requires information on when the individual was admitted to the facility and the extent of private-pay care given before the Medicaid "pick up date." A sur-

vey examining the extent of private pay coverage before Medicaid eligibility would provide a much clearer picture of whether Medicaid is truly being used as a last-resort option or whether, as some myths would suggest, it is becoming the payor of first resort.

Without violating any individual's privacy, this information should be made available to those who must make decisions on whether eligibility rules should be changed and, if so, when.

Are nursing homes the most reasonable and cost-effective care settings for all of their residents?

For an individual with extensive skilled care needs such as delicate medication regimens, feeding tubes and a lack of mobility that requires assistance from at least two persons for transfer to and from beds and wheelchairs, nursing homes are probably the most appropriate setting unless a dedicated family member is able to provide care and supervision at home.

Many other individuals with far less intense care needs now qualify for Medicaid coverage in nursing homes, however. Their "scores" on the "Patient Review Instrument" required for admission show that their needs are related primarily to "physical care" and some limited supervision of their medication. They are largely ambulatory, at least with a cane or a walker, and require little or no assistance transferring from beds and wheelchairs.

Every nursing home is subject to periodic audits of its residents' conditions, and reimbursement rates for each facility are effectively based on an overall average of the care level required for its residents. Thus, information is now being gathered on the range of needs being met in nursing homes. It should be made available to those who must make decisions on how Medicaid dollars should be spent.

Is the Medicaid program effectively administering the rules for spousal refusal?

Efforts by local Medicaid agencies vary greatly in regard to following-up on Medicaid's right to reimbursement from community spouses who have invoked the spousal refusal option.

Data should be made available on matters such as the number of Medicaid recipients whose spouses have filed spousal refusals, the reported extent of the spouse's assets, and whether the local Medicaid agency has taken steps to pursue appropriate reimbursement.

At least two factors may have influenced Medicaid's apparent decisions not to pursue spousal refusal actions in some cases.

One factor may be a simple realization that such lawsuits would be harsh in the home Medicaid context where a community spouse is at risk for a suit if his/her assets exceed \$5,850. The figure, far below the \$95,100 CSRA threshold for suits in the context of Medicaid payments for care in a nursing home, is unrealistic in most areas of New York State. It may also reflect a realization that the Medicaid program may incur even greater long-term costs if the community spouse who has spent down his/her assets must later look for assistance that would otherwise have been financed with private funds. And, judging from the experiences of many elder law attorneys, it could also reflect a concern that some of these couples could simply give up on home care and both apply to the nursing home, particularly when one spouse has extensive care needs and the other spouse meets at least the minimum requirements for nursing home coverage.

Results from appropriate studies focused on analyzing this factor might well lead to a realistic revision of the spousal refusal rules, adjusting those that impose undue burdens on community spouses and providing clear guidelines on when spousal refusal lawsuits are genuinely appropriate.

A second factor may be that some county officials have little incentive to pursue the lawsuits, even when the assets of a spouse significantly exceed the allowable maximums. Under the reimbursement rules applicable to Medicaid funding, it appears that many counties do not find it is cost-effective for them to bear the costs of lawsuits likely to be more financially beneficial to the state than their own counties.

Some counties do pursue these suits, but others take little or no action. Counties that do institute lawsuits do not follow uniform practices. Nassau County, for example, has adopted a policy of not settling for less than 100%, while New York City has been willing to settle cases for amounts well below 100% under certain circumstances.

Centralizing the administrative process for these lawsuits could provide Medicaid with recovery revenues that it is already fully authorized to obtain. It could also lead to the development of better criteria for assessing spousal liability by establishing a consistent, structured framework to determine when the circumstances of a community spouse genuinely require the retention of income or resources beyond the standard limits. The result would make administration of the program more fair to everyone affected.

Are community spouses whose incomes exceed \$2,378 per month contributing 25% of the excess over that amount?

When the personal income of a community spouse exceeds the “minimum monthly maintenance needs allowance” (MMMNA) of \$2,378, Medicaid “asks” for 25% of the excess as the “voluntary contribution amount.” Even if the contribution is made, however, the spouse, typically a wife, remains subject to the risk of a spousal refusal lawsuit.

No statistics are available on the frequency with which spouses voluntarily remit these payments, but it is likely to be rare. And the experience of elder law attorneys suggests that the community spouse in these circumstances, usually a woman, may need the income for her current expenses, and/or may have few assets available for her own long-term needs in the community.

Reliable information on this subject might also lead Medicaid to conclude that those who make these “voluntary” contributions should otherwise be exempt from spousal refusal lawsuits focused on their remaining income. And that result might well encourage those who are not now making the contribution to do so.

5.3 Past Attempts to Address Near-Term Concerns

Past attempts to address near-term issues illustrate the effect that lack of valid data has had on efforts to chart a reasonable course for changes in financing the care needed by aging and disabled residents of New York State.

Notable among previous efforts was the 1996 report, “Securing New York’s Future: Reform of the Long-term Care Financing System,” adopted by a 10-to-1 vote of the New York State Task Force on Long-Term Care Financing.¹¹ It recommended that the state pursue three strategies to decrease reliance on Medicaid to pay for long-term care:

- (1) Promote the development of affordable long-term care insurance products, by tax incentives for traditional insurance, and to enhance the New York State Partnership program;
- (2) Expand the transfer of assets rules to home care, eliminate the doctrine of spousal refusal, and broaden the rights of the state to recover Medicaid benefits paid for long-term care from the patient or the estate of the patient’s spouse.
- (3) Create a “Defined Private Contribution” amount program for the uninsurable and the elderly over a certain age designed to protect a

certain percentage of net worth before qualifying for Medicaid under less restrictive rules similar to those that apply in the Partnership program.¹²

Implications Regarding Insurance The task force correctly identified insurance as a hopeful prospect for the future, but its near-term value is limited. In addition, the task force report failed to acknowledge that long-term care insurance is not a panacea—many who might eventually benefit from it have been uninsurable for many years before their illnesses grow worse, and those with limited incomes and assets are simply unable to afford the coverage.

The Legislature subsequently approved some income tax incentives for the purchase of long-term care insurance, but that action did not address the needs of those currently faced with extensive bills for the care they and their spouses need.

Nor did the tax changes provide a breakthrough change in the affordability obstacle that still discourages many middle-class New Yorkers. Premiums vary widely based on coverage options and the age of applicants, but for a healthy couple in their early 60s who purchase a policy that would provide approximately \$200 per day in benefits and an inflation rider, the typical annual premium exceeds \$4,000. Among those whose finances might allow them to consider coverage, many in their 50s and 60s would either be ineligible due to their medical status or be forced to pay extraordinarily high premiums if they suffer from high-risk ailments such as diabetes or advanced heart disease.

An extensive discussion of the potential future benefits of long-term care insurance is provided in Chapter 4.

Implications Regarding Eligibility Rules Ultimately, careful review of the changes in eligibility rules that were recommended by the 1996 task force showed that many of the suggestions would have been inconsistent with mandated federal standards and contrary to the intent of Congress as reflected in the Medicare Catastrophic Coverage Act of 1988.

In addition, although adequate figures on the impact of the changes were not available, it became clear from the widely known experiences of the elderly that the burden would have fallen most heavily on married couples without insurance who sought to keep an impaired spouse at home. Allowing couples to keep only \$975 of their joint monthly income and \$5,850 in resources does not leave sufficient resources to pay household expenses and provide the caregiving spouse with any kind of financial security for the future. Only the spousal refusal option, permitting the caregiving spouse to refuse to contribute his/her

own income and resources toward care for the ill spouse, has made it possible for many couples to pay reasonable household expenses while the ill spouse remains at home and receives care through Medicaid. Without this option, a caregiving spouse would have no other option except to have the ill spouse admitted to a nursing home, where the cost to the state could easily be twice the cost of home services.

The community spouse, typically the wife, faces a gut-wrenching choice in these circumstances. She can send her husband to a nursing home, retain \$95,100 in resources and \$2,378 in monthly income, or she can keep him home, retain only \$5,850 in assets between them and try to get along on income of \$975 a month for both of them. Even if she elects the home care option and files a spousal refusal statement, there are cases on record in which community spouses with as little as \$40,000 in assets became the subject of Medicaid lawsuits for reimbursement.

Regardless of which choice the wife makes, she is also likely to face a financial crisis at her husband's death. Instead of having adequate resources for her support, she faces the likely prospect of significantly diminished assets and a reduced income stream. Unless she has significant income of her own, she has inevitably relied on income from her husband. Even if her husband was in a nursing home and \$2,378 a month was available to her, at his death that figure is likely to be lower. Only one Social Security payment (the larger of her monthly Social Security amount or her late husband's monthly amount) will be available her, and other benefits such as her husband's pension may either disappear or be greatly reduced.

In short, without spousal refusal, rules that permit an ailing spouse to transfer his/her own assets to the community spouse without incurring a "penalty period," and the other federally approved transfer of assets rules, the middle-class, and especially surviving spouses, would have faced financial ruin.

Implications of the Defined Contribution Concept This approach may be worth considering (see Chapter 6 for an example of a possible technique). It has been impossible to assess its true worth, however, because adequate financial data on current trends in Medicaid spending has not been available.

Carefully implemented with adequate advance notice, such a program might encourage advance planning so the aged and disabled could comply with Medicaid rules applicable to options that would allow them to retain assets that might otherwise be given away. These aged and disabled individuals would then have a larger stream of income from their assets during both their healthy years and when the need arises for increased care services. For those who

need nursing home care, that continuing stream of income would result in higher "Net Available Monthly Income" (NAMI) payments to the nursing home and thus reduce how much Medicaid must pay. For those who remain home, that income might postpone the day when Medicaid assistance would be needed. When Medicaid home care assistance did become necessary, the income still available to these individuals would reduce the burden on Medicaid.

The potential benefits and downsides of such an approach can only be analyzed, however, with adequate data that should be available from Medicaid's experience in dealing with Medicaid applications and providing benefits.

5.4 Partnership Policies

Among the more successful past efforts has been New York's decision to obtain a federal waiver that permitted it and three other states (California, Connecticut and Indiana) to offer "Partnership" policies to pay for long-term care.

These policies (covered more extensively in Chapter 4) seek to encourage individuals to purchase long-term care insurance by having the state guarantee that, after the private benefit period has been exhausted, the policyholder will be eligible for Medicaid benefits regardless of the extent of the policyholder's assets other than any continuing stream of income.

Anecdotal evidence suggests that these policies may well have resulted in savings for the Medicaid program, but, again, no attempt is known to have been made to assess their impact and analyze whether they could be expanded in any way to provide greater benefits to the elderly insured and diminish the drain on the resources of the Medicaid program.

It appears, for example, that incentives to purchase these policies would be greater if their terms (1) allowed for the portability of the policies between all states, (2) protected income as well as resources, and (3) removed restrictions that limit amounts payable for home care benefits to half the amounts available for institutional care.

As described more fully in Chapter 4, recent legislative changes have opened the possibility that policyholders will no longer be required to return to New York State to receive Medicaid benefits after the policy benefits are exhausted.

The changes suggested in items (2) and (3) above could encourage more individuals to purchase these policies. The current requirement that income be used for care needs after the policy period ends discour-

ages purchases of the insurance, especially by those who would wish to remain at home and would need income to maintain their households and pay other non-care expenses. The regulation limiting the home care benefit payable on a monthly basis to half the monthly amount payable for institutional care¹³ apparently is designed to assure that Partnership benefits on a three-year institutional policy will last for six years if used exclusively for home care.¹⁴ This needlessly limits the Partnership's usefulness for those who might otherwise benefit, for example, from five years of home care service at a daily reimbursement rate slightly higher than 50% of the benefit for institutional coverage.

Quantification of the results is hampered by the lack of statistics, but anecdotal evidence suggests that a substantial amount of the benefits provided by Medicaid go to individuals who do not live more than three years after the start of benefits. If this observation is supported by appropriate research, it would then be reasonable to conclude that every year an individual is covered by a policy is one less year that the Medicaid program must provide benefits.

To accurately gauge the potential economic impact offered by greater use of Partnership policies, it would be instructive for the state Legislature to ask the New York State Health Department to prepare an analysis of how much the Medicaid program could save if it were relieved of paying benefits for the first three years of an individual's need for assistance.

5.5 Expansion of Assisted Living Options

The experiences of elder law attorneys and geriatric care managers point to the inevitable conclusion that a significant segment of the nursing home population in New York State consists of elderly individuals who could benefit from assisted living but cannot afford costs that typically range from \$2,000 to \$5,000 per month.

Because no government subsidy is available for assisted living, many of these individuals whose needs go beyond the basic housing and meals provided by assisted living facilities are left with few choices except entering a nursing home, where, even at the discounted rates the Medicaid program pays to facilities, the cost to Medicaid typically exceeds \$5,000 each month.

One potential alternative that may merit expansion is the "Assisted Living Program." (See also 3.3.) Now in effect on a limited basis in New York State, this option is available to facilities that are prepared to go beyond the basic housing/meals services and provide on-site physicians and nurses who attend to daily health care needs such as the supervision of

medication. The result is an alternative to a nursing home admission for those who are generally mobile but require assistance with medications and only limited help with activities of daily living.

In a typical program, an individual with \$1,000 in monthly income can qualify for a waiver from Medicaid to retain that amount as a house/room-board payment to the facility, which provides meals and lodging in a three-person room and a wide variety of daily activities that encourages him/her to leave the room during the day. Medicaid then pays \$2,200 per month for the medical component of services. If the individual has more than \$1,000 in monthly income but lacks resources to make full payment for the medical component, Medicaid receives the balance of the monthly income and applies it toward reducing its contribution to the monthly \$2,200 charge for the medical services. Individuals with less than \$1,000 in monthly income may qualify for SSI that supplies the difference between their incomes and the \$1,000 monthly charge, and the SSI-related qualification for Medicaid pays for the medical services.

For individuals who can pay privately, the monthly cost in a two-bed unit is approximately \$2,700 and the medical component is \$2,200. The total cost of approximately \$4,900 is more affordable than the private rate in a nursing home and postpones the day when these individuals must turn to government assistance.

The recently enacted New York Assisted Living Statute provides standards to assure that care in assisted living facilities truly meets the needs of their residents. Programs expanding options for limited government assistance could have the effect of reducing the need for many individuals to enter more costly nursing homes while assuring that their needs are met properly.

5.6 Home Care and Community-Based Programs

The desire of most seniors and the disabled to remain at home has been endorsed by the U.S. Supreme Court in *Olmstead v. Zimring*,¹⁵ a decision covered more fully in Chapter 2.

The financial benefits of the following suggestions are difficult to quantify, but taken together they have a clear potential to reduce an otherwise inexorable trend toward greater government subsidization of long-term care needs.

Informing the Public New York and its counties need to commence an immediate and aggressive campaign to better inform the public of the variety of home care and community based programs available

to seniors and the disabled. In doing so the programs need to effectively use the services of community outreach programs and not-for-profit organizations that are in a unique position to communicate information on viable alternatives to institutional care directly to seniors and the disabled who belong to their organizations.

Options in the Freedom Initiative New York needs to take advantage of the initiatives in the 2001 Freedom Initiative, 2002 Independence Plus Medicaid waiver program and President Bush's 2005 federal budget. In general, these would temporarily allow states more flexibility in their Medicaid payment systems without having to seek waivers from CMS so they can provide assistance in the community or at home. Another proposal, "Money Follows the Individual," would allow money to follow the preferences of recipient seniors and the disabled, while giving them greater flexibility and control over the services they receive. President Bush has authorized \$1.75 billion in funding for this initiative.

Incentives to Encourage Long-Term Care at Home New York needs to provide financial incentives to seniors and the disabled that opt to receive long-term care at home or in the community. These would include significant reductions and/or elimination in local property taxes, or their postponement until the homes of recipients are sold.

Income Taxes New York and the federal government need to significantly reduce the income tax burdens of seniors and the disabled who opt to receive long-term care at home or in the community. Tax credits could help to accomplish this objective.

Caregiver Participation by Families New York needs to encourage caregiver participation by family members. Options include incentives such as the expanded availability of respite and caregiver support services for caregiver spouses and other family members.

Financial Incentives to Families New York and the federal government need to provide financial incentives to family members who provide full-time care to seniors and the disabled. Examples include tax credits and/or income and property tax reductions. Family involvement will significantly extend the amount of time that seniors and the disabled can remain in the community, saving the government the higher expense of institutional care.

Incentives for Employers New York and the federal government need to create incentives for large employers and corporations to provide paid leave to family members who provide care to family members.

Consumer-Directed Home Care New York needs to improve awareness of and access to its Consumer Directed Home Care Program, which allows self-directing disabled and chronically ill adults to supervise and authorize payment for their own service plan. It should also implement demonstration programs to show how meeting the diverse non-medical needs of seniors can encourage them to remain at home.

Care Management Services New York needs to expand and improve case management services for home care, with greater emphasis on thorough and effective discharge planning for those who are leaving hospitals or have completed stays at rehabilitation centers.

Reverse Mortgages With the significant increases in home values during the past decade, many New York seniors have significant untapped equity in their homes that could be used to allow them to remain at home and pay for the care they need. Reverse mortgages are a vehicle to tap this unused equity, but their use has remained limited due to lack of public understanding and significant up-front costs.

Programs to better promote and educate the public about these mortgages would address the first issue.

Tax and financial incentives could address the financial issues. Closing costs and mortgage insurance can easily exceed \$10,000 on a \$200,000 loan. See also Chapter 3.

Assistance to Faith-Based Groups Among more than 350,000 religious congregations in America, a growing number are supporting programs that provide screening, detection, and prevention of disease. These efforts vary in degree of formality and scope, ranging from occasional health fairs and periodic wellness seminars to highly organized health ministries run by full-time congregational nurses.

These programs represent opportunities for congregations to channel their faith toward prevention, fitness, health education, and patient advocacy among members and the local community. Congregational nurses in Alabama, Ohio, Michigan, Montana and Florida have recorded accomplishments in these areas that illustrate the potential for similar success in thousands of congregations in other states.

The U.S. Department of Health and Human Services and private organizations such as the Robert Wood Johnson Foundation have funded initiatives of this type. The goals generally are to reduce or delay the institutionalization and hospitalization of the elderly, to link health and social services providers with faith communities to enhance the provision of care to

the elderly with unmet needs, to provide opportunities for healthy seniors to contribute to their community and to promote a multi-generational model of care.

Several federal initiatives, such as the Return to Home Legislation, Charitable Choice and the Housing and Urban Development's Center for Community and Interfaith Partnerships demonstrate an awareness and acceptance of these programs.

Florida, with elderly residents who constitute a population percentage significantly higher than most other states, has actively begun to encourage state-faith community healthcare partnerships. In 1992, the state adopted the Florida Health Care Access Act, which eliminated the threat of malpractice lawsuits to programs treating the working poor and indigent. The act provides that professionals cannot be sued while volunteering their services, except in cases of willful or wanton negligence.

Existing Adult Day Care Center Programs New York needs to expand and improve existing adult day care programs and public awareness of them.

Home Sharing and Informal Care Giving New York needs to encourage home sharing with seniors and informal care giving by family members and friends.

Senior Wellness and Disease Prevention A healthy senior can live independently and in the community for a longer time than an unhealthy senior. Increased state funding to promote senior wellness and disease prevention could delay the day when seniors have no choice except admission to a nursing home.

Endnotes

1. These and other eligibility figures for Medicaid in 2005 are available at <http://www.brookdale.org/iol/index.html>. Click on "2005 Medicaid Only Income Exemption and Resources Levels" and "2005 Medicaid Regional Rates for Calculating Transfer Penalty Periods."
2. Individuals may set aside any amount they wish for a funeral, but if the full amount is not used for the funeral, any remaining balance is payable to the Medicaid program as reimbursement for services provided.
3. If the individual has been paying for a Medicare supplementary insurance policy, an amount sufficient to pay for that insurance may also be retained. This works to the advantage of the Medicaid program, because it will then not be liable for the co-payments required for services not entirely covered by Medicare.
4. The relevant standards are found in 18 N.Y.C.R.R. § 360-4 *et seq.* The figures shown were recently announced for applications filed in 2005. The 2004 figure for the CSRA was \$92,870 and the MMMNA was \$2,319. When computing the MMMNA, Medicaid allows applicants and spouses to deduct from their gross income any amounts they pay for supplemental medical coverage such as Medicare Part B insurance. Technically, the CSRA for a refusing spouse is one-half of the couple's assets (not counting the value of the home where they live) at the start of the illness that has precipitated the need for care assistance. The minimum amount is approximately \$74,820 regardless of the value of pre-illness assets, and the maximum is \$95,100 for those whose pre-illness asset total was \$190,200 or more. In practice, however, most local Medicaid agencies allow the spouse to retain a full \$95,100.
5. Situations that may lead to a finding that a larger MMMNA is necessary include a finding that a community spouse has extraordinary expenses for medical needs. A spouse who does not have a car might also ask for an increased allowance to pay for transportation costs to visit an ill spouse who is in a nursing home many miles away.
6. The 2005 figures by region:

Central Region	\$5,988	Northern NYC Suburbs:	\$8,332
Western Region	\$6,181	New York City:	\$8,870
Northeastern Region	\$6,501	Long Island:	\$9,612
Rochester area	\$6,981		

Medicaid bases these figures on an annual survey of the average cost of one month's nursing home care in each of these regions.

See also the digest of applicable Medicaid rules in **Appendix C**.
7. An additional \$20 unearned income credit is allowed without affecting eligibility for Medicaid coverage.
8. An unmarried millionaire could not receive Medicaid without committing fraud by failing to disclose the extent of his/her assets. In addition, even an individual with a million or more in an irrevocable trust and/or IRAs would be likely to have monthly income from those assets, plus payments from Social Security and any pension plan that would be sufficient to pay a monthly nursing home bill.
9. 42 U.S.C. § 1396a.
10. Korbin Liu and Marilyn Moon, "Recovering Hidden Assets: The Magic Bullet for Medicaid savings?" *The Urban Institute, Policy Bites*, No. 23, September 1995.
11. Created by New York State Law, Chapter 81 of the Laws of 1995.
12. 1996 Task Force Report, at page 22.
13. 11 N.Y.C.R.R. § 39.3(b)(2)(iv).
14. 11 N.Y.C.R.R. § 39.3(b)(2)(iv).
15. 119 S. Ct. 2176 (June 22, 1999).

Chapter 6

A Proposal for a New York State LTC Compact

OVERVIEW: This chapter proposes the creation of a New York State Compact that would consist of an agreement between the state and its chronically ill citizens to share the risks associated with paying for long-term care, an undertaking that market forces have proved unable to address.

Instead of frantically giving away assets when diagnosed with a chronic illness, citizens would have the option to “pledge” that they would use a defined amount of their then-existing assets to pay for their long-term care needs. The pledged amount would be a set maximum (perhaps \$300,000 as the average three-year cost of facility care), or up to one-half of their assets, whichever was smaller.

Until they spent the pledged amount, Compact members would pay entirely for their own care without Medicaid assistance. They would have full access to all their income and assets, rather than the current practice in which Medicaid recipients are reduced to a poverty level of assets and a net income (after the contribution required by Medicaid) that is seldom adequate to meet the needs of those who remain at home.

Once they spent the pledged amount, Compact members would have two options—regular Medicaid coverage requiring them to turn over most of their income, or an option to retain “private pay” status in which they would keep 75% of their income while Medicaid subsidized their long-term care obligations by paying 90% of what it would otherwise have paid to their providers.

Regardless of which option they chose, Compact members would not be “impoverished,” because they would retain the unpledged portion of their assets. Portions of the assets could be used for needs that Medicaid has never covered such as private duty aides in a nursing home or geriatric care managers to do errands, etc.

As shown by the illustrations, the program would be unlikely to increase Medicaid’s liability for providing services, and could significantly reduce its outlay as individuals paid for a greater portion of their care, particularly in the first years after they began to suffer from chronic illnesses.

In short, rather than being the “first resort” for individuals scared that they will outlive their resources, Medicaid would serve as a true “safety net” for those who live many years after being diagnosed with a chronic illness.

By Gail Holubinka

6.1 Design Parameters

The subject of this proposal is financing—not services. There are many issues related to the development of better and more efficient long-term care services, but without a viable payment source, concerns about the quality of service are moot.

At present, 80% of long-term care expenses in New York State are paid by Medicaid. The goal is to privatize as much of that expense as possible. Privatization of up-front coverage would address a dilemma that has faced public officials for years—how to avoid harm to the truly needy while controlling the costs of long-term care.

The majority of total long-term care expenses occur in the first 1 to 3 years after an individual is diagnosed with a chronic illness. Rather than frantically divest themselves of assets upon learning of a chronic illness, Compact members would initially retain all their income and use assets to pay the remainder of their costs for long-term care. At the same time, they would have the security of knowing that, under terms of the Compact, they would qualify for Medicaid assistance once they had used a “pledged” amount—never more than half of the assets in their names when they were diagnosed with a chronic illness—to pay for their long-term care needs.

Those who must come to grips with the realization that they have a chronic illness would be able to retain the dignity and self-reliance they crave, but they would also have the reassurance that if their illnesses lingered for an extended period, Medicaid would be a true “safety net.” Even after qualifying, however, they would retain access to a significant portion of the assets that are now often given outright to their children or placed in irrevocable trusts until they die.

A well-designed Compact program could foster the type of cooperation that is best achieved by creating a sense of shared responsibility and fairness. Its approach would not involve “look back” periods, complex rules and requirements, or expectations that would be unacceptable to a reasonable person or entity. A person seeking Medicaid after spending the pledged amount would simply provide evidence that the assets had been spent on long-term care.

The potential viability of any program is first measured in expense and complexity. Therefore, in so far as possible, it should use products, systems, processes, and people already in place and explainable in one sentence. No new procedures or operational expenses would be required. Administration economies would be possible through use of current resources.

Options Beyond Medicaid and Medicare The problem to be addressed is not about Medicaid or Medicare. The crisis in public financing is an effect, not a cause, and is driven by demographics. While these public programs are important, they are only two options available in responding to needs.

Current and future Medicaid or other government program eligibility rules are not applicable to a private pay solution, even if that solution involves such programs.

Joint participation with government does not automatically imply government rights, oversight, or controls greater than would be in place outside the program.

The manner in which public funding is delayed is not important. The issue is how to avoid or delay it for as long as possible without imposing undue burdens on the chronically ill.

6.2 A Compact Between State and Its Citizens

The proposal is to create a compact between the citizens of New York and their government. The focus of the compact would be an agreement that there would be a limit to the liability of both parties. What that limit may be would be subject to consumer choice and based on personal risk tolerance and need.

Rationale Statements The following basic concepts underlie the approach to be taken.

- Long-term care can be extremely costly. For all but a few, eventual impoverishment is unavoidable given sufficient amounts and lengths of need.
- Impoverishment is neither a desirable nor a rational societal expectation.
- Forced impoverishment leads to avoidance of reasonable private contribution.
- Avoidance leads to increased reliance on public funding.
- Increased reliance on public funding is unsustainable.
- Neither the individual nor the public sectors are capable of managing the anticipated cost of long-term care on their own.

- Medicaid remains a resource if prolonged long-term care services are eventually necessary.

6.3 Design Summary

Eligibility Participation would be limited to chronically ill New York residents residing within the state at the times they apply for and participate in the program.

The Compact option would not be available to persons eligible for or currently receiving Medicaid benefits.

Program The New York State Compact would permit participants to protect assets and in some cases income, by agreeing to pay a “pledged” amount equal to a maximum of the cost for three years of facility coverage at the average daily rate, or up to one-half of their assets, whichever was smaller if the two figures were not the same.

Assume that the maximum pledge amount was \$300,000 (based on the \$98,185 yearly average cost of facility care cited in 4.1). An individual with \$400,000 in assets could pledge a maximum of \$200,000, an individual with \$600,000 in assets could pledge \$300,000, and the maximum pledge for an individual with \$800,000 would also be \$300,000.

Assets would include all funds and property, including the homestead, as defined in Medicaid rules and regulations. Where the amount to be protected exceeded the value of liquid assets, the consumer could still participate by signing a lien against the value of real property, agreeing that the home could not be sold without repaying the state as a creditor.

Participants could make payments out of pocket, through insurance or reverse mortgages. Individuals with some other funding such as a long-term care policy might be able to satisfy their pledge amount without agreeing to have a lien placed against their property.

General Rules Once participants paid their “pledge” amounts, they would have two choices for assistance from Medicaid—a Medicaid Option providing coverage essentially similar to the current Medicaid programs, or a Subsidization Option in which they would continue to be “private pay” clients and would retain 75% of their income, but Medicaid would subsidize their long-term care expenses with payments equal to 90% of its rate for those services.

Thus, if the Subsidization Option was chosen and Medicaid’s normal reimbursement rate for the facility was \$150 per day, Medicaid would pay \$135 per day. Assuming the facility’s private pay rate was \$165 per

day, the Compact participant would pay the remaining \$30 per day, most likely from the 75% of the monthly income the participant was retaining. Medicaid would pay only the \$135, it would not pay for any of the other expenses it now bears for Medicaid recipients.

In general, those with relatively small incomes would be most likely to choose the Medicaid Option, because it would mean that the need to dip into their remaining assets would be minimal, particularly if they were in a nursing home. Those with relatively high incomes would be most likely to choose the Subsidization Option. The 75% of their monthly income that they would retain would be likely to pay all or most of their remaining daily obligation to a facility, together with the cost of services not covered by Medicaid. Assets would need to be tapped only for special needs such as private duty aides not covered by Medicare or Medicaid.

Those who chose the Subsidization Option would not be required to use providers contracted with the NYS Medicaid program. Even those who ultimately chose the Medicaid Option would not be required to use Medicaid providers until they actually applied for Medicaid.

6.4 Compact Definition of Expenses

Any New York State resident who had expended the amount pledged when he/she signed up for the Compact would be eligible for coverage upon demonstrating that the pledged amount had been spent. In no case would the amount exceed the cost for three years of nursing home care as computed by using the average statewide cost of such care.

To count as an expenditure under the Compact, an expense for Qualified Long-term Care Services made by or on behalf of a participant who had been assessed as eligible would need to be documented by proof that the expense had been paid (not incurred).

The definition of what was a Qualified Long-term Care service and what constituted eligibility would be in accordance with HIPAA rules and regulations.

6.5 Applying for the Compact Benefit

Resident consumers (or their representatives) who believed they would qualify as individuals requiring long-term care could contact their insurer, or in the case of cash payments, go directly to a state-approved assessment organization. Assessments would be at the expense of the applicant or their insurer where appropriate.

The consumer would contact the Compact office to arrange participation and sign appropriate agreements.

Proof of payment for Qualified Long-term Care services would have to be submitted to the Compact office. Qualified Long-term Care services would not need to be covered by or paid at the rates of Medicaid to count toward the agreed obligation.

6.6 The Compact Benefit

Participants who had met their agreed upon obligation could choose one of two Compact options, the Medicaid Option or the Subsidization Option.

Medicaid Option Those electing the Medicaid option would be entitled to all the benefits available under the Medicaid program and be subject to all its restrictions, with the exception of rights of recovery from assets protected by the Compact agreement.

Services would be those provided under the Medicaid program and would be paid at the Medicaid rate.

Income would be applied to the cost of care, and spousal obligations would be enforced.

Subsidization Option The Subsidization option would apply only to Qualified Long-term Care services. Participants could use any Qualified Long-term Care service they wished.

Where that service was covered by Medicaid, a participant would receive a subsidization amount equal to 90% of what Medicaid would have paid. However, Medicaid rules or restrictions would not apply. Participants would be required only to contribute 25% of their income to receive subsidization payments.

Persons receiving payments by Medicaid under this program would not be subject to Medicaid rules governing assets, recovery, or eligibility. Persons receiving payments from Medicaid under this program would not be required to use providers contracted with the NYS Medicaid program.

Participants in the subsidization program would be considered to be on private pay status, and would be charged a Compact Rate 10% higher than the Medicaid rate. (As indicated earlier, the Compact Rate at a facility would be \$165 if the Medicaid reimbursement rate at the facility was \$150.) The participant would be responsible for any difference between the subsidization from Medicaid (\$135 in the example) and the Compact Rate.

Income, annuities, insurance and reverse mortgage arrangements would be likely sources of payment for the variance between Compact and subsidization rates. Should the participant find it impossible to maintain the cost of the difference, he/she could apply for regular Medicaid coverage. The asset protection shall be honored.

Medicaid waivers from the federal government might be required for approval to use funds to finance the subsidization program.

6.7 Operations/Expenditure

Use Current Resources The current Partnership program has staffing and funding. Most of its efforts are directed toward maintaining an unnecessarily cumbersome program that served a fledgling industry but is no longer necessary.

In addition, the program is modeled on Medicaid, again making the goal of privatization difficult. These staff could form the foundation of the Compact.

The program would best be administered under the aegis of a neutral agency. Neither Medicaid, DoH, DoI, nor SoFA has the focus, expertise, or sufficient stake to manage the proposed program.

Use Commonly Accepted Vendors/Regulations Long-term care insurance is highly regulated by both state and federal rules and regulations. There would be no need to recreate a new infrastructure to support the Compact.

6.8 Examples of Potential Compact Outcome

Mrs. Jones is 78-year-old widow, frail but in relatively good health. She has an income of \$24,000 a year and assets of about \$300,000, consisting of a home valued at \$150,000 and savings of \$150,000. Insurance is not an option because coverage would be too expensive and it is doubtful she could pass underwriting.

Mrs. Jones wants to remain home as long as possible. She and her family currently engage an aide who is not a Medicaid provider, but Mrs. Jones is comfortable with the aide. The cost of the aide is \$200 a week for 10 hours of service. Their concern is the potential future need for help with multiple activities of daily living. With the higher level of need, at \$20 per hour, she would quickly expend her savings. She considered a reverse mortgage, but the amount she could get would not be sufficient.

At age 80, Mrs. Jones falls and the result is a need for substantial health care support. The uncovered expenses amounted to \$2,000. Her condition progresses to the point where she requires substantial assistance in bathing, dressing, and transferring to and from her bed. She wants to stay at home, but knows she needs help.

Present Options At present, the 78-year-old Mrs. Jones would have essentially two options to plan for her long-term care needs:

- (1) She can give her home and her savings to her children so she can qualify immediately for Medicaid home care. If she later needs nursing home care before the penalty period resulting from the gifts (approximately 36 months for gifts totaling \$300,000), she needs to feel confident that her children will use the funds she gave them to pay her nursing home expenses. There are two downsides: she is likely to lose the aide unless she can qualify for a consumer-directed home care program under Medicaid, and she will lose the income she would have received on her \$150,000 in liquid assets.
- (2) She can pay privately for home care, at least until her liquid assets run out (her \$2,000 in monthly income gives her an advantage unavailable to many whose income is not that high), and she can postpone any divestiture of her assets until a need arises. If she needs nursing home care, she can take the “rule of halves” approach, giving the house to the children and using the \$150,000 in liquid assets to pay her nursing home bill until the penalty period for the gift is satisfied.

Assumptions The examples that follow make the following assumptions about Mrs. Jones’s financial circumstances and her likely needs for long-term care:

- Her care needs at home are constant at 10 hours per week for two years.
- Home health aides under Medicaid cost \$18/hour; the private rate is \$19.80/hour.
- Medicaid’s rate at the nursing home is \$150/day; the private-pay rate is \$165/day.
- As a home Medicaid recipient, Mrs. Jones would be allowed to retain income of \$700 per month (rounded up from the current \$667 figure), and \$150 for a Medicare supplementary insurance program), thereby requiring that \$1,150 of her \$2,000 income be paid to Medicaid to offset its costs for her care.
- If, instead of liquid assets of \$150,000 and a house worth \$150,000, the actual breakdown was \$100,000 in liquid assets and a house worth \$200,000, she would agree to have Medicaid place a lien for \$50,000 on her home, to be repaid if the property is sold during her lifetime, or by the heirs to the property after her death.

Charts illustrating the Compact’s principles begin on the next page.

Scenario #1—Standard Medicaid Mrs. Jones decides to divest today and apply for Medicaid.

Mrs. Jones lives 5 years

Mrs. Jones lives 7 years

Estimated Cost to Mrs. Jones

Home health aide, 2 years ¹	\$0	Home health aide, 2 years ¹	\$0
Nursing home, 3 yrs @ \$150/day ²	\$0	Nursing home, 5 yrs @ \$150/day ²	\$0
Total (before contribution)	\$0	Total (before contribution)	\$0
Income contributed while home ³	\$27,600	Income contributed while home ³	\$27,600
Income contributed while in nursing home ⁴	\$64,800	Income contributed while in nursing home ⁴	\$108,000
Total Mrs. Jones Cost	\$92,400	Total Mrs. Jones Cost	\$135,600

1 - 104 weeks @ \$180/week

2 - 1,095 days (3 yrs) @ \$150/day Medicaid rate.

3 - 24 months (2yrs) @ \$1,150/month. (Monthly income of \$2,000 less \$150 Medicare supplementary insurance premium and \$700 retained income.)

4 - 36 months (3 yrs) @ \$1,800/month (\$2,000 less \$50 personal needs allowance and \$150 if used to pay the premium for a Medicare supplementary insurance policy. If no policy is purchased, the \$150 is also payable to Medicaid, which will be responsible for prescription drugs and hospital co-payments not covered by Medicare.

1 - 104 weeks @ \$180/week

2 - 1,825 days (5 yrs) @ \$150/day Medicaid rate.

3 - 24 months (2 yrs) @ \$1,150 /month. (Monthly income of \$2,000 less \$150 Medicare supplementary insurance premium and \$700 retained income.)

4 - 60 months (5 yrs) @ \$1,800/month (\$2,000 less \$50 personal needs allowance and \$150 if used to pay the premium for a Medicare supplementary insurance policy. If no policy is purchased, the \$150 is also payable to Medicaid, which will be responsible for prescription drugs and hospital co-payments not covered by Medicare.

Estimated Cost to Medicaid

Home health aide, 2 years ¹	\$18,720	Home health aide, 2 years ¹	\$18,720
Nursing home, 3 yrs @ \$150/day ²	\$164,250	Nursing home, 5 yrs @ \$150/day ²	\$273,750
Total (before contribution)	\$182,970	Total (before contribution)	\$292,470
Income contributed while home ³	-\$27,600	Income contributed while home ³	-\$27,600
Income contributed while in nursing home ⁴	-\$64,800	Income contributed while in nursing home ⁴	-\$108,000
Total Medicaid Cost	\$90,570	Total Medicaid Cost	\$156,870

Scenario # 2—First Compact Option Mrs. Jones pays for an assessment. She is found eligible and pledges half of her assets.

Under the Compact rules, her first of two choices is to protect half of her assets (\$150,000) with the understanding that virtually all of her income will go to Medicaid once she has spent \$150,000 on long-term care.

She will immediately become eligible for Medicaid to pay for her prescriptions and other medical expenses not covered by Medicare or her supplementary policy.

She will pay for home care herself (easing her concerns about losing the trusted aide) until her home care expenses for her health aide total \$150,000.

If she needs to enter a nursing home before she has spent \$150,000 on her long-term care, she will pay privately until her combined payments for home care and nursing home care total \$150,000.

Once she has spent \$150,000 for long-term care, she will pay Medicaid \$1,150 monthly from her \$2,000 income if she is still at home, all but \$50 monthly if she is in a nursing home.

<u>Mrs. Jones lives 5 years</u>		<u>Mrs. Jones lives 7 years</u>	
<i>Estimated Cost to Mrs. Jones</i>			
Home health aide, 2 years ¹	\$20,592	Home health aide, 2 years ¹	\$20,592
Nursing home, 785 days @ \$165/day ² *	*\$129,408	Nursing home, 785 days @ \$165/day ²	*\$129,408
Total (before contribution)	\$150,000	Total (before contribution)	\$150,000
Income Contribution ³	\$18,000	Income Contribution ³	\$46,800
Total Mrs. Jones Cost	\$168,000	Total Mrs. Jones Cost	\$196,800

1 - Mrs. Jones pays \$20,592 (104 weeks @ \$198 /week).

2 - After Mrs. Jones pays \$165/day 785 days (26 mos), she has fulfilled her commitment to spend \$150,000 on her care, Medicaid pays for her final 310 days in the nursing home at its \$150/day rate.

3 - 10 months @ \$1,800/month (\$2,000 less \$50 personal needs allowance and \$150 if used to pay the premium for a Medicare supplementary insurance policy. If no policy is purchased, the \$150 is also payable to Medicaid, which will be responsible for prescription drugs and hospital co-payments not covered by Medicare.

1 - Mrs. Jones pays \$20,592 (104 weeks @ \$198/ week).

2 - After Mrs. Jones pays \$165/day for 785 days (26 mos), she has fulfilled her commitment to spend \$150,000 on her care, Medicaid pays for her final 1040 days in the nursing home at its \$150/day rate.

3 - 34 months @ \$1,800/month (\$2,000 less \$50 personal needs allowance and \$150 if used to pay the premium for a Medicare supplementary insurance policy. If no policy is purchased, the \$150 is also payable to Medicaid, which will be responsible for prescription drugs and hospital co-payments not covered by Medicare.

<i>Estimated Cost to Medicaid</i>			
Home health aide, 2 years ¹	0	Home health aide, 2 years ¹	0
Nursing home, 1040 days @ \$150/day ²	\$46,500	Nursing home, 310 days @ \$150/day ²	\$156,000
Total (before contribution)	\$46,500	Total (before contribution)	\$156,000
Income Contribution ³	-\$18,000	Income Contribution ³	-\$46,800
Total Medicaid Cost	\$28,500	Total Medicaid Cost	\$109,200

* - The exact figure, \$129,525, has been adjusted downward to provide rounded figures.

Scenario #3—Second Compact Option Mrs. Jones pays for an assessment and is found eligible. She pledges half of her assets and elects to have Medicaid serve primarily as a source of a subsidy after she has used \$150,000 of her assets to pay for long-term care.

She will receive no assistance from Medicaid until she has spent \$150,000 on her long-term care. Medicaid will then subsidize her long-term care by paying 90% of what it pays for regular Medicaid recipients. She will pay Medicaid 25% of her income, and keep the other 75% to pay the balance of her long-term care bill and for personal and medical needs.

Mrs. Jones lives 5 years

Mrs. Jones lives 7 years

Estimated Cost to Mrs. Jones

Home health aide, 2 years ¹	\$20,592	Home health aide, 2 years ¹	\$20,592
Nursing home, first 785 days @ \$165/day ² *	\$129,408	Nursing home, first 785 days @ \$165/day ²	*\$129,408
Nursing home, last 310 days @ \$30/day ³	\$9,300	Nursing home, 1040 days @ \$30/day ³	\$31,200
Total (before contribution)	\$159,300	Total (before contribution)	\$181,317
Income Contribution ⁴	\$5,000	Income Contribution ⁴	\$17,000
Total Mrs. Jones Cost	\$164,417	Total Mrs. Jones Cost	\$188,317

1 - Mrs. Jones pays \$20,592 (104 weeks @ \$198 /week).

2 - Because Mrs. Jones has spent \$20,592 for home care, she must spend \$129,408 to reach the \$150,000 threshold for Medicaid long-term care assistance. At the \$165 private pay rate, she will spend a fraction more than \$129,408 in 785 days.

3 - Once Mrs. Jones becomes eligible for Medicaid, she remains responsible for the \$30 difference between the private rate of \$165 and Medicaid's \$135 payment. For the last 310 days that make up her three-year stay, the works out to \$93,000. During that time, Medicaid pays \$135 a day, or 10% below its normal \$150 rate.

4 - 10 months @ \$500/month (after retaining 75% of monthly \$3,000 income). The \$15,000 she retains during the 10 months will be available to pay the premium for a Medicare supplementary insurance policy if she wishes, or for prescription drugs and hospital co-payments, which will not be covered by Medicaid. It may also be the source of funds for extra needs such as an occasional private duty aide in the nursing home.

1 - Mrs. Jones pays \$20,592 (104 weeks @ \$198 /week).

2 - Because Mrs. Jones has spent \$20,592 for home care, she must spend \$129,408 to reach the \$150,000 threshold for Medicaid long-term care assistance. At the \$165 private pay rate, she will spend a fraction more than \$129,408 in 785 days.

3 - Once Mrs. Jones becomes eligible for Medicaid, she remains responsible for the \$30 difference between the private rate of \$165 and Medicaid's \$135 payment. For the last 1040 days that make up her three-year stay, the works out to \$93,000. During that time, Medicaid pays \$135 a day, or 10% below its normal \$150 rate.

4 - 34 months @ \$500/month (after retaining 75% of \$3,000 monthly income). The \$51,000 she retains during the 34 months will be available to pay the premium for a Medicare supplementary insurance policy if she wishes, or for prescription drugs and hospital co-payments, which will not be covered by Medicaid. It may also be the source of funds for extra needs such as an occasional private duty aide in the nursing home.

Estimated Cost to Medicaid

Home health aide, 2 years ¹	0	Home health aide, 2 years ¹	0
Nursing home, first 785 days ²	0	Nursing home, first 785 days ²	0
Nursing home, last 310 days @ \$135/day ³	\$41,850	Nursing home, last 1040 days @ \$135/day ³	\$140,400
Total (before contribution)	\$41,850	Total (before contribution)	\$140,400
Income Contribution ⁴	-\$5,000	Income Contribution ⁴	-\$17,000
Total Medicaid Cost	\$36,850	Total Medicaid Cost	\$123,400

* - The exact figure, \$129,525, has been adjusted downward to provide rounded figures.

Comparison of Totals for Each Scenario

Scenario #1—Standard Medicaid

Mrs. Jones lives 5 years

Total Mrs. Jones Cost \$92,400

Total Medicaid Cost \$90,570

Mrs. Jones lives 7 years

Total Mrs. Jones Cost \$135,600

Total Medicaid Cost \$156,870

Scenario # 2—First Compact Option

Mrs. Jones lives 5 years

Total Mrs. Jones Cost \$168,000

Total Medicaid Cost \$28,500

Mrs. Jones lives 7 years

Total Mrs. Jones Cost \$196,800

Total Medicaid Cost \$109,200

Scenario #3—Second Compact Option

Mrs. Jones lives 5 years

Total Mrs. Jones Cost \$164,417

Total Medicaid Cost \$ 36,850

Mrs. Jones lives 7 years

Total Mrs. Jones Cost \$188,317

Total Medicaid Cost \$123,400

Chapter 7

Beyond 2015: Long-Term Alternatives For Long-Term Care Reform

OVERVIEW: As the United States looks to provide support services needed by its aging population, the essential goals are to respect the individual dignity and autonomy of its citizens, avoid treatments that are unnecessary, ineffective or harmful, facilitate changes in the training of healthcare professionals, and finance new initiatives to help refocus the use of healthcare dollars.

It is in putting these goals into effect that problems and distortions arise. Development of new, more appropriate services has been slowed by cost concerns and the conflict with the medical model of care that is the focus of the insurance programs. There is much we do not know about medical diagnosis and interventions. Chronic conditions and aging-related ailments are among the least well understood.

By Anthony H. Szczygiel and Valerie J. Bogart

7.1 Goals

Long-term care needs do not fit the medical model of a professional care-giver assisting an otherwise healthy person through a short-term acute care episode. Uncertainty about how to proceed leads to significant practice variations.¹

The long-term health problems may be debilitating but incurable. Medical providers find little glamour in the work of slowing down deterioration in the patients they serve. Nevertheless, appropriate medical, health and social care can avoid or cure complicating medical conditions, and also improve the quality of life for individuals with long-term care needs.

7.2 Restraining Spending

Despite these promising areas for reform, the most pressing concern in health care reform has been restraining the growth of medical care spending by government and business.

Limited government initiatives are generally designed to displace more expensive care with less expensive care. Increasingly employers are avoiding health insurance liability for their employees, and even more so for their retirees.² Third-party payers, both public and private, have been careful not to displace “free” home care from family members with insurance benefits. We are just beginning to under-

stand the true cost this puts on the individual and the caregivers.³

Incentives to shift long-term care costs from one insurer to another are endemic to our multi-payer system. At best, these efforts result in cost-shifting between the programs with little positive effect on the over-all cost of the delivery system or the quality and continuity of care for those in need. Other stratagems deprive individuals of intended benefits or access to care they need. This suggests that part of the solution is to provide an umbrella of funding, under which providers can work with individuals to handcraft a workable plan of care, that cuts across the disciplines.

We need to be more creative in the methods of paying for the needed care. The complexity of the current long-term care payment systems wastes limited administrative energy and resources and perplexes those in need of care. Care providers must be allowed to devote more time and attention to quality of care and quality of life rather than to arcane reimbursement systems awash in forms and technical denials.

7.3 Evolving Trends

Addressing the health and social problems of long-term chronic conditions is a relatively new phenomenon in the United States. A variety of factors—including major improvements in the public health system, improvements in the individualized medicine system, and other changes we don’t fully understand—have caused a steady increase in life expectancy, and in other measures of overall health.

Life Expectancies In 1900, life expectancy at birth in the United States was 47 years. For 2002, life expectancy in the nation reached an all-time high of 77.3 years. There has been a marked decline in the rate of sudden deaths. This has led to an increase in the aging population, and an increasing need to deal with long-term states of disability.

The first half of the 20th century can be seen as the era of public health. The needs of an increasingly industrial and urbanized society included safe supplies of drinking water, improved sanitation and sewage systems, safer working conditions and protection from outbreaks of infectious diseases. In

response, government resources were invested in local public health systems, emphasizing such approaches as immunization programs, public water and sewer systems and occupational safety and health efforts.

In the second half of the 20th century, the emphasis shifted to individualized medicine, especially the episodic treatment of acute diseases. Advances in techniques, technology and drug therapy allowed for very sophisticated medical interventions to treat immediate medical threats. Employer-provided health insurance grew to cover two-thirds of the U.S. population. Due to favorable selection and limitations on coverage, this private insurance pays for only one-third of the nation's medical care costs. A variety of categorical government programs, headed by Medicare and Medicaid, developed to improve access for the elderly, the poor and other populations with limited access to medical care.⁴

Chronic Care Needs The first half of the 21st century promises to be the era of chronic care. In part, this results from a decline in sudden deaths. Two of the three leading causes of death, heart disease and stroke, have been declining significantly since 1960. The age-adjusted death rate from diseases of the heart has been more than halved, while the 2001 death rate from cerebrovascular disease was about 30% of the 1960 rate.⁵ Continuing efforts in public health have also fueled this trend. Between 1970 and 2001, death rates from motor vehicle-related injuries fell by nearly one-half.⁶ The one-third decline in cigarettes smoked between 1960 and the late 1990s is reducing cancer rates as well as heart disease, and strokes.

Conversely, the death rate for chronic lower respiratory diseases, Alzheimer's disease and diabetes continues to rise.⁷ Cancer, the second-leading cause of death, has had a promising, but not precipitous decline. From 1993 to 2001 cancer mortality rates dropped 1.1% per year.

An estimated 125 million Americans had at least one chronic condition in 2000. The prevalence of chronic conditions is projected to increase to 157 million Americans by 2020. The proportion of individuals with multiple chronic conditions will increase over the same time period.⁸

Many of these individuals, especially those with multiple chronic conditions, have difficulty performing activities of daily living (ADLs). Similarly, people with chronic conditions use more hospital care, physician services, prescription drugs and home health visits than people without chronic conditions. And again, those with multiple chronic conditions have the highest needs. For example, people with five

or more chronic conditions average 15 physician visits and fill almost 50 prescriptions in a year. These chronic conditions include arthritis, asthma, congestive heart failure, diabetes, heart disease, hypertension, cancer and cardiovascular disease.

There are positive developments that will allow the nation to adapt to this new reality of chronic care. First, the rate of disability is falling, even as the total number of disabled elderly increases.⁹ Findings based on the National Long-term Care Survey (NLTCS) showed dramatic declines (by as much as 15%) in the age-adjusted disability and institutionalization rates for the elderly U.S. population from 1982 to 1994. The National Nursing Home Survey (NNHS) and the National Long-term Care Survey (NLTCS) showed nursing home use rate for persons age 65 and over declined by over 10% in roughly the same time period.¹⁰

More recent studies have shown that the rate of disability continued to decline in the 1994 to 1999 period, and that the decline was greater in the 1990s than in the 1980s. In 1982, the disabled older population totaled 7.1 million, then increased to 7.5 million in 1994 as disability rates declined but the older population grew, according to the age-standardized analysis. By 1999, however, with the acceleration in the reduction in the rates of disability, the number of older people with disability was actually fewer—7 million—than it was 17 years ago. Between 1982 and 1999, the share of the elderly with severe disabilities, measured roughly as the ability to function independently with ease, declined from 26.2% to 19.7%. The cumulative reduction in disability was 25%, or 1.7% per year.

Aging Better In short, we are aging better. Scientists have suggested that the improvements so far may be related to public health measures over the last century, the progress in medicine and behavioral science that has resulted in improved health and function, and possibly social factors such as increases in education.

Finally, disability reduction may reflect a change in the disease environment over time. Increasing evidence documents that infectious diseases encountered early in life influence health later in life. Older generations of elderly were more exposed to these diseases and conditions as children than were younger generations, which may partly explain the change in disability over time.

The reasons for the decline in disability rates are especially important when we seek to forecast future needs. Some factors will have a temporary effect on the disability rates, while others have a long-lasting effect.

7.4 Subgroups With Differing Needs

Within the U.S. population, researchers have discovered sharp differences in Americans' health status, and in the starkest measure of overall health, life expectancy. Studies at the Harvard School of Public Health revealed sharp differences in Americans' life expectancies of the sort found between poverty-ridden and wealthy nations, not the type predicted within United States.¹¹ Significant variations have been observed even within the boroughs of New York City.¹²

Poverty is not conducive to good health. Neither is being uninsured. A rational long-term care system must account for the long-term effects of these disadvantages, as well as the immediate barriers to access to care.

Individuals who have achieved higher levels of education have a disability rate equal to only about half that of those with little education.¹³ The United States has had a large increase in the share of elderly with high school and college degrees. Between 1970 and 2001, for example, the percentage of the older population that completed high school rose from 28% to 70%. This may help to explain why we are, overall, aging better.

Still, disparities remain. One important question is why education is related to disability. Education can influence disability in many ways: by enhancing earning power, thus buying greater access to medical care resources; by increasing knowledge about appropriate health behaviors; and by the direct impact of mental stimulation on cognitive functioning.

7.5 Medical, Health and Supportive Services From the Individual's Point of View

The United States has not distinguished itself when compared with other developed countries in both overall life expectancy and in still-developing measures of the overall health of a country.

These measures include the Years of Healthy Life or the Disability-Adjusted Life Expectancy (DALE) system.¹⁴ To calculate DALE, the years of ill-health are weighted according to severity and subtracted from the expected overall life expectancy to give the equivalent years of healthy life.¹⁵

In 2000, the World Health Organization ranked the United States 24th in healthy years of life among the developed nations, at 70.0 healthy years overall. U.S. female babies could expect 72.6 years of healthy life, male babies just 67.5 years. Dr Christopher Murray, director of WHO's Global Programme on Evidence for Health Policy, commenting on the 2000 report, concluded: "Basically, you die earlier and

spend more time disabled if you're an American rather than a member of most other advanced countries."¹⁶

The challenge is to direct our expensive, in many ways excellent, but imperfect U.S. healthcare system to provide a better quality of care for everyone, and specifically for the growing number of individuals with chronic conditions. Despite advances, the current system of health care is failing to provide the full promise of the public health and individualized medicine advances of the 20th century. The 2004 shortage of flu vaccine drew attention to a fragile system of supplying life-saving medicines in the United States.¹⁷ Outcome studies have questioned the effectiveness of a number of aggressive medical interventions, such as open heart surgery.

Unresolved Questions There are many unresolved questions regarding the developing area of long-term care. Gerontologists, health planners and advocates are not at all sure what is the right mix of services.¹⁸ Long-term care service availability and capacity vary widely from state to state and, often, within the state.¹⁹ Existing services may not be available at the time and place they are needed. Further, researchers have noted that there has been a communication gap between medical care providers and other support services.

Historically, health-care providers have devoted little time to assessing a patient's functional ability, providing instruction in behavior care or self-care, or addressing emotional or social distress. Care is often fragmented, with little communication across settings and providers.

People who need supportive services often delay seeking care until some acute exacerbation of their condition occurs, a crisis that might have been avoided if the person had sought assistance earlier.²⁰

Despite these observations, researchers have identified some fundamental steps that can reduce the overall need for long-term care and improve the quality of care that is provided.

7.6 Preventive Care

Coverage of clinical preventive services—including screening tests, counseling, and immunizations—has increased in the United States during the past decade. Medicare, as the primary insurance for most elderly individuals, has slowly expanded its prevention and early detection services coverage. For example, Medicare covers a small list of vaccines.²¹ The list of early-detection tests has expanded to include Pap smears, pelvic exams, mammograms, colorectal cancer screenings, digital rectal exams, bone mass meas-

urements, and diabetes monitoring. Effective January 1, 2005, Medicare has covered an initial preventive physical exam for persons beginning Part B coverage on or after 1/1/05, cardiovascular screening tests, including cholesterol level and diabetes screening tests, and a fasting plasma glucose test. Nevertheless, many groups and individuals still fail to receive effective preventive services.

The Public Health Service's (PHS's) Healthy People 2000 project developed a nationwide plan to improve Americans' health and quality of life with specific, measurable objectives. This process produced three overall goals: (1) to increase the span of healthy life for Americans, (2) to reduce health disparities among Americans, and (3) to improve access to preventive services. A total of 300 objectives linked to health promotion, health protection, and preventive services were developed.

The nation did not attain all objectives for improving delivery of clinical preventive services outlined in Healthy People 2000.²² For example, rates of delivery of preventive services to older adults, such as colorectal cancer screening and pneumococcal vaccination, are low nationwide and vary by locality.²³ In 1997, one in five women reported not having had a Pap smear in the preceding three years, and one in four women aged 50 and older reported not receiving a mammogram in the preceding two years. Healthy People 2010 has a new set of health objectives for this decade.

A recent study by the Partnership for Prevention, funded by the Centers for Disease Control (CDC) found that fewer than half of all Americans receive the "most beneficial, cost-effective and disease preventing services in medicine."²⁴ The study prioritized 30 preventive health services recommended for the average-risk patient by the U.S. Preventive Services Task Force. The study found that tobacco cessation counseling for adults, vision impairment screening for older adults, colorectal cancer screening for adults over age 50, and flu shots for seniors were services that ranked high on the list but reached fewer than half of Americans.

Other experts have estimated that simple, cost-effective public health measures could add about six years' healthy life expectancy in most developed regions.²⁵ In richer countries, the five key killers are tobacco, alcohol, high blood pressure, high blood cholesterol and obesity.

Thus, one component of a plan for long-term care would be to maximize the benefits from cost-effective preventive care. State government should continue to work with health plans to ensure that these services are available, affordable and easily accessible.

7.7 Improving the Overall Quality of the Care and Treatment

The development and implementation of practice guidelines holds great promise for improving future health care.

The federal Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Health Care Policy and Research, supports the National Guideline Clearinghouse (NGC), a database of evidence-based clinical practice guidelines and related documents. Until 1996, AHRQ had directly developed clinical practice guidelines, targeted to widespread practices where there is a diversity of responses, and the possibility of significant cost savings by the use of best medicine. Several major guidelines on long-term care were released, including guidelines on incontinence, pressure ulcer prevention and treatment and post-stroke rehabilitation.

There remains a gap between identified "best medicine" practices and medical practice. State governments and state-supported medical education play central roles in supporting effective continuing medical education.

7.8 Expanding and Improving Non-Institutional Care and Services

Individuals with disabilities can benefit from social and supportive services such as adult social day care, Meals on Wheels and a wider range of barrier-free housing, often with congregate meals. Many of the services fall into the category of assistance with activities of daily living, and do not need to be provided by medical professionals.

Assistive devices for people with chronic health problems have helped them compensate for some loss of function. Canes and walkers help the elderly infirm stay out of nursing homes; walk-in showers and grab bars prevent hip fractures and allow those who have had a fracture to live independently; microwave ovens make it easier for the frail elderly to cook; and telephones with larger keypads enable the visually impaired to communicate.

The Centers for Medicare and Medicaid Services (CMS) has a number of planned and ongoing care coordination and disease management demonstrations and programs. The Medicare Prescription Drug, Improvement, and Modernization Act of 2003²⁶ authorized several demonstration projects intended to test potential future improvements in Medicare coverage, expenditures, and quality of care. For example, the Care Management for High-Cost Beneficiaries demonstration is the first effort to focus specifically on high-cost fee-for-service Medicare benefici-

aries. The goal is to compare how various case management models may be able to reduce costs while improving the quality of care and quality of life for beneficiaries.²⁷

CMS also publishes home health quality measures for home health agencies.²⁸ The Home Health Quality Initiative (HHQI) derives performance information from the Outcome and Assessment Information Set (OASIS). The report lists 11 measures related to improvement in getting around,²⁹ meeting the patient's activities of daily living,³⁰ patient medical emergencies³¹ and improvement in mental health.³² State support for these efforts is critical.

7.9 Institutional LTC Treatments and Care

Long-term institutionalization can debilitate a patient, both mentally and physically. Federal law sets conditions of participation for nursing homes that accept Medicare and/or Medicaid payments.³³ Revised nursing home quality standards set by the Nursing Home Reform Act of 1987 were phased in as of July 1, 1995.³⁴ The statute sets the lofty goal that each nursing home "provide services and activities to attain or maintain the highest practicable physical, mental, and psycho-social well-being of each resident in accordance with a written plan of care."³⁵

Compliance with the nursing home standards, however, is uneven. Sub-standard care is caused in part by an inadequate number of staff providing care in nursing homes. A 2000 federal study reported that nursing home residents need about three hours of nurse aide time per day to maintain their peak functioning.³⁶

New York Experience In New York, 98% of the nursing homes fell short of this standard. Organizations such as the Long-term Care Community Coalition of New York State have worked for many years on efforts to (1) enact minimum staffing ratios in nursing homes; (2) improve working conditions and wages for nursing home direct care staff; (3) fight federal proposals to reduce certification and training requirements for nursing aides who feed residents.³⁷

The State Department of Health has the lead role in surveying and inspecting the quality of care in nursing homes. It should move to an outcome-based evaluation process.

7.10 Reducing Unnecessary, Ineffective and Harmful Treatment

New York State must redouble its efforts to protect the public from unnecessary, ineffective and harmful treatment.

According to a 2000 report by the Institute of Medicine (IOM), preventable health care-related injuries cost the economy from \$17 to \$29 billion annually, of which half involved health care costs. The IOM report estimated that 44,000 to 98,000 people each year die from medical errors. Even the lower estimate is higher than the annual mortality from motor vehicle accidents (43,458), breast cancer (42,297), or AIDS (16,516), thus making medical errors the eighth leading cause of death in the United States.

Use of Prescription Drugs As the January 2006 implementation date for Medicare coverage of prescription drugs approaches, it is ironic that many elderly patients receive either too few prescription medications, or too many.

Studies have shown that patients very often do not comply with the full regimen of medication prescribed by their physicians. The full benefits of these medications cannot be realized at current levels of compliance. Methods of improving medication adherence for chronic health problems are mostly complex, labor-intensive, and not predictably effective.³⁸

On the other hand, the CDC determined in 1999 that more than 600,000 hospital admissions and 700,000 emergency room visits were the result of correctly administered medications that produced adverse side effects and even death. The elderly, because they take the most medications, have the greatest risk of such drug events.³⁹ Systematically reviewing patients' medications to avoid such consequences should be standard procedure.

The Institute of Medicine estimates that medication errors, occurring either in or out of the hospital, account for more than 7,000 deaths annually.⁴⁰

Bed Sores The 1987 Nursing Home Reform Act sought to establish minimum standards for skilled nursing facilities. The need to comply with the Act led to a practice guideline developed by the nursing home industry designed to prevent the occurrence of pressure sores.⁴¹ Nursing homes developed and implemented the techniques that help to prevent the development of bed sores. They are not complicated or technologically advanced. They require that patients be turned so that pressure is not placed on one part of their skin for more than two hours at a time if the patients cannot turn themselves, that patients be kept clean and dry and not left to sit in their own urine, and that various cushioning devices be used.

This has led to improvements, but bed sores remain a problem and an indicator of poor quality of

care. In 2002, 16.4% of all nursing homes nationally received citations for deficiencies regarding residents with pressure sores (bed sores). New York State was one of the 10 states with the highest number of violations regarding pressure sores—26.7% of its facilities were cited for deficiencies. Other common types of code violations were food sanitation (33% of all facilities), accident prevention (22.6% of all facilities nationally, 23.3% of facilities in NYS), quality of care (25.2% of all facilities nationally, 35.5% of facilities in NYS).⁴²

Restraints The NHRA more closely regulated the use of physical and chemical restraints on nursing home residents. Concurrent amendments to the Medicare and Medicaid statutes stopped nursing homes from using chemical or physical restraints on residents “for purposes of discipline or convenience.”⁴³ The only restraints allowed are those ordered by a physician for physical safety.

Compliance with these requirements may be improving, but is still lagging. In 2002, 9.9% of all facilities nationwide were cited for improper use of physical restraints. New York had a higher rate of violations, with 14.1% of all nursing homes cited for violations in 2002.⁴⁴

Fraud and Abuse Medicare and Medicaid fraud and abuse costs federal and state governments tens of billions of dollars per year.⁴⁵ The federal government has made significant efforts to address this problem, using such statutes as the Civil False Claims Act, 31 U.S.C. § 3729-33. However, the state government also can play a significant role in combating fraud and abuse by health-care providers.

7.11 Pioneering Models for Long-Term Care

The most promising models for providing long-term care address a central problem, the fragmentation of the service delivery system. On the provider’s side, support services are divorced from medical services. On the consumer side, the dizzying array of categorical programs prevents all but the most capable of understanding what’s available and at what cost.

The Medicare Payment Advisory Commission states bluntly: “There are few incentives and little infrastructure to support the coordination of care for beneficiaries in fee-for-service payment systems.”⁴⁶

Medicare is commencing a new Chronic Care Improvement Program (CCIP).⁴⁷ This demonstration program joins several others, including an ongoing Intensive Case Management controlled trial and a new capitated disease management demonstration.⁴⁸ These programs share the goals of seeking to insure

coordinated care across care settings and among service providers, teaching patients how best to care for themselves, and promoting the provider’s use of evidence-based treatment guidelines.⁴⁹

One program that has been providing a comprehensive service delivery system for disabled individuals is the Program of All-Inclusive Care for the Elderly (PACE), which integrates Medicare and Medicaid financing. The Balanced Budget Act of 1997 established the PACE model as a permanently recognized provider type under both the Medicare and Medicaid programs. As described on the CMS webpage, participants must be at least 55 years old, live in the PACE service area, and be certified as eligible for nursing home care by the appropriate State agency. The PACE program becomes the sole source of services for Medicare and Medicaid eligible enrollees.

An interdisciplinary team, consisting of professional and paraprofessional staff, assesses participants’ needs, develops care plans, and delivers all services (including acute care services and when necessary, nursing facility services) which are integrated for a seamless provision of total care. PACE programs provide social and medical services primarily in an adult day health center, supplemented by in-home and referral services in accordance with the participant’s needs. The PACE service package must include all Medicare and Medicaid covered services, and other services determined necessary by the multidisciplinary team for the care of the PACE participant.⁵⁰

Researchers face significant challenges in evaluating the impact of care coordination programs, and generalizing these results. We are still in the early stages of designing and evaluating such systems. Even the labels are still under construction. “Care coordination,” “case management” and “disease management” represent different visions and ranges of services.⁵¹

Care-management services can range from a care manager simply reminding people to take their medicines to figuring out what care they need (assessment and care planning), helping them to get it (coordination), and making sure it is working (monitoring).⁵²

Nevertheless, we are beginning to develop a set of standardized measures for evaluating outcomes of various models of care coordination. The state should support this research and the demonstration projects that put these models to the test.

Endnotes

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6. *Id.*, Table 44, p. 180.
7. Kochanek, et al., *Deaths; Final Data for 2002*, 53(5) National Vital Statistics Reports (October 12, 2004). See also, National Center for Health Statistics, *Health, United States, 2003* (Hyattsville, Maryland: Public Health Service. 2004), Table 38, p. 165.
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12. Steve Sternberg, "Study Finds Major Gap in U.S. Life Spans," *USA Today*, and Associated Press, "Surprises in a Study of Life Expectancies," *New York Times*, both December 4, 1997.
13. Manton and Gu, 98 *Proc. Natl. Aca. Sci. USA* 6354, 6359 (2001).
14. The concept of "health adjusted life expectancy" was first presented in 1964. Hillery, Sanders, 5 *Demography*, 354-361 (1968). For years researchers worked on developing an effective measure and source of data. In 1991, the US Department of Health and Human Services featured a "Years of Healthy Life" measure in the *Healthy People 2000* document.
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 28. See, Home Health Compare website on www.medicare.gov. The reports on individual home care agencies are updated each calendar quarter.
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 30. Four measures—Percentage of patients who get better at bathing, at taking their medicines correctly (by mouth) , at getting dressed and who stay the same (don't get worse) at bathing.
 31. Two measures—Percentage of patients who had to be admitted to the hospital and who need urgent, unplanned medical care.
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Chapter 8

Long-Term Alternatives: Public Financing

OVERVIEW: As public officials look toward future funding needs for long-term care, a major challenge is to develop alternatives that will slow the likelihood that government spending will otherwise increase many times over.

Rather than focus solely on controlling Medicaid expenditures, planners need to build a consensus on incentives and programs that will diminish the “institutional bias” toward nursing homes that has often characterized thinking since the government began to help pay nursing home bills in 1965. The overall objective should be to foster options such as insurance that can provide a viable first response to the needs of all but the chronically poor, leaving Medicaid as the safety net when a prolonged need for long-term care exhausts the means of even middle class individuals.

Realistic assessment must also be made on the burdens that long-term care services place on the taxing resources available to local governments.

Funding is not the only issue, however. As early as 2015, the pool of both family members and paid professionals may not be sufficient to provide needed care. Innovative programs such as aid to family members and scholarships will be needed to assure that there is an adequate supply of both family caregivers and paid workers to meet the long-term needs of the elderly.

By Michael D. Cathers

8.1 The Government’s Role

Public financing of long-term care in New York State and the nation is, in some ways, a victim of its own success.

Government funding assured access to services by elderly and disabled persons who would otherwise have been unable to afford quality long-term care, but the funding choices the government made and its decisions on eligibility for coverage shaped the market place in ways that are often a detriment to those who need long-term care now and in the future. The cumulative result is seen in the services provided, the workforce available, the quality of care and the extent of alternative sources of funding.

Many long-term care analysts have concluded that the better job the government does in providing long-term care services, the less incentive people have

to pay for their own long-term care and the more the elderly find ways to access the ‘free’ services by intentionally impoverishing themselves.

The result is most noticeable in the unintended “institutional bias” the government appears to have created in the public’s perception of long-term care when its early efforts in 1965 focused almost exclusively on funding high-cost nursing home care. More cost-effective and privately financed alternatives to nursing home care did not develop. Services such as home care, assisted living, adult day care, respite services and geriatric care management did not become readily available until long after they might otherwise have been if extensive public financing had not been provided for nursing home care. In addition, these conditions delayed the development of long-term care insurance for all levels of care.

As one leading consultant concluded:

The best hope we have to improve long-term care for all . . . is to find new sources of private financing to supplement the public resources which seem always to be scarce and limited. [The Heartland Model for Long-Term Care Reform: A Case Study in Nebraska]

Although this statement is largely true, there is little doubt that government will retain a significant role in the financing of long-term care—both directly, by funding services for elderly and disabled unable to afford quality long-term care, and indirectly, by providing incentives for private financing, workforce development, caregiver supports, and assurance of quality care.

8.2 Expanding Current Programs Is Not Enough

More money (either through increased funding or improved efficiencies) might be viable in the short-term, but in the long-term, increased government financing alone would only increase the likelihood that the majority of individuals needing long-term care will simply become dependent on Medicaid or other government-financed programs rather than explore private financing alternatives.

Without changes to the current government programs, in 30 years the impact of the Baby Boom gen-

eration would require government spending on long-term care services for the elderly to increase at least 2½ times beyond current levels. In constant dollars, spending could nearly quadruple, to \$379 billion by 2050, according to GAO estimates.

GAO projections estimate that, without changes in the federal health and retirement programs, spending for net interest, Social Security, Medicare, and Medicaid would consume nearly three-quarters of federal revenue by 2030. Similarly, Citizens For Long Term Care have estimated that without change “the current government services which provide for society’s most fragile, the aged and those with disabilities, will not be able to meet their obligations; in fact by 2030, unless reform is enacted, most if not all services will be bankrupt.”

Effect in New York The impact on local governments and their taxpayers in New York State could be ruinous. Funding in New York is based, in part, on a retrogressive taxation system that places the burden upon local governments and upon their poor and middle class citizens.

Local governments in New York State (56 counties and the City of New York) contribute 50% of the non-federal share of financing for most Medicaid services and 10% of most long-term care services. To meet this burden, county governments have just two revenue sources: sales taxes and real property taxes. Both taxes are retrogressive—that is, they have a disproportionate impact on low-income New Yorkers and place a heavier burden on those less able to afford it.

At present, all but a few of New York’s counties devote their entire real property tax collection to the funding of the local share Medicaid services.

In 2002, Senator Hillary Rodham Clinton released a report showing how rising costs of Medicaid had created a fiscal crisis for New York’s counties, forcing many to either raise property taxes or cut important services to balance their budgets. In her words: “Medicaid has become the single largest appropriation in many New York county budgets. With a struggling economy and a decrease in revenues, many local governments have been forced to either increase taxes, cut services, or do both in order to balance their budgets.”¹

Examples cited in the report included the following:

- Tioga County is considering raising property taxes to offset a jump in Medicaid expenses from \$4.5 million to as much as \$7 million.

- Albany and Rensselaer counties now pay more for Medicaid than they collect in property taxes and are finding ways to increase property taxes and cut services.
- Chautauqua County’s Medicaid expenses have increased 80% since 1998 and are projected to consume 71% of the county’s tax levy in 2003.
- Westchester is contemplating a 10% increase in property taxes due to a projected \$28 million increase in Medicaid spending.”

A county-by-county budget survey of the New York State Association of Counties showed that “73% of counties increased their real property tax levies in 2002, many for the first time over the past several years . . . thirty-six counties outside New York City collected less sales tax in 2001 than they did in 2000 . . . every county is reporting that over the past 12 months that Medicaid caseloads have increased by an average 7% and that in 2002 counties are budgeting an average 10% caseload increase.”²

Assemblyman Bob Sweeney, D-Lindenhurst, chair of the Assembly Committee on Local Governments, in introducing legislation to address the impact of Medicaid costs on county government,³ noted, “New York’s Medicaid program, as it is structured today, can no longer be supported at the local level, especially through regressive property and sales taxes . . . As a result of the growth of Medicaid in recent years, local taxpayers are struggling every year with higher taxes and a reduced level of county services, with no end in sight. A cap on Medicaid costs . . . could put an end to the double-digit property tax increases we have witnessed statewide.”⁴

The financial impact on local government of the Baby Boom generation coming of age for long-term care will be unsustainable. It will virtually eliminate the ability of local governments to function, and increased real estate taxes could make it impossible for many low-income and elderly New Yorkers to retain ownership of their homes.

In this regard, the state and federal governments, with their largely progressive system of taxation (income taxes) and ability to create additional progressive revenue streams, must assume the local share of Medicaid funding.

Work Force Issues Nor is funding the only critical issue. Steps must be taken to assure that a work force is available to furnish the care that surely will be required. Current programs have been ineffective in encouraging the development of this workforce.

As early as 2015, the number of persons likely to need long-term care will be increasing substantially

faster than the number of persons available to provide that care, either as family members or as paid caregivers. Families will need more support to supplement their efforts, and more paid caregivers will be necessary to provide this support.⁵

8.3 Rethinking the Role of Government in Financing

Various analysts who have reviewed state Medicaid programs have offered ideas on the government's role in financing long-term care.

Some have suggested that public financing of long-term care be viewed as analogous to public financing of retirement security. They ask not just whether public dollars are now being leveraged in a way that is most effective to satisfy the public's long-term care needs, but also whether steps are being taken to promote the development of complementary private resources to satisfy the needs that demographic realities identify.

In this view, government would continue to satisfy individual needs for assistance with the expenses of long-term care and maintain its societal responsibility for caring for those unable to care for themselves. The government would continue to provide a safety net, including a full continuum of long-term care services, for those having the greatest need. That is, "a good safety net, better than we have today, but not so strong that it discourages each individual from thinking about his/her own role in meeting future long-term care needs."⁶

AARP and others support the development of a broader, social insurance program that would form the basis of long-term care financing. Under this model, individuals would pay into the program and be entitled to benefits defined in law, including cash payment options, when they need services. Government's role would be extended beyond providing a safety net. The government mandate would include a mandatory social insurance program providing long-term care to broad groups of beneficiaries using eligibility standards based on functional criteria and social needs that take into account cognitive, physical and social limitations and the need for support, supervision or training.

8.4 Financing Options

Suggested financing options include alternatives ranging from tax incentives to an expanded Medicare program insuring all Americans against the risks of the need for long-term care. These options include:

Tax Incentives Purchase of long-term care insurance would be encouraged by creating a refundable credit for the payer's costs of this insurance.

Subsidies Those who purchase long-term care insurance would be eligible for subsidies provided under an income-scaled tax-credit arrangement or extended to all purchasers through tax deductibility of premiums.

Required Coverage The public would be required to carry long-term care insurance, just as car owners are now generally required to carry automobile insurance. Elements of this process would include:

- (1) A requirement that all adults either carry a specified amount of long-term care insurance or self-insure their own long-term care;
- (2) Premiums for those with low and moderate incomes would be paid through income-scaled tax credits, or
- (3) A tax credit system would be created so that the out-of-pocket cost of the insurance would not rise as people aged.

Social Insurance Institute a program of universal, compulsory social insurance under which:

- (1) Long-term care would be an earned right.
- (2) All of the benefits of an insurance model—most important, pooling—would come to the fore if the insurance were social in nature, just as they do if the insurance is private.

Front-end Coverage Public funding would be limited to "front-end" coverage (through social insurance or subsidized private insurance) with the following provisions:

- (1) Social insurance at the front end would serve as a continuing base of support.
- (2) After a specified period, people would have to pay for long-term care out-of-pocket, with private resources providing a supplement, or as a last—not first—resort, they would turn to Medicaid.

Back-end Funding Public funding would be limited to "back end" coverage (through social insurance or subsidized private insurance) that would:

- (1) Provide "catastrophic" coverage.
- (2) Specify that social insurance or subsidized private insurance would kick in only after a specified time such as six months or a year,
- (3) Place explicit responsibility for long-term care on society as a whole rather than on those relatively few individuals unlucky enough to require expensive care at the end of their lives.

A New Blend A new blend would be created for a mix of programs.⁷ Its essential elements would include:

- (1) The integration of front-end care into Medicare, creating a Medicare Part C, building on the Medicare practice of reimbursing care following acute illness. Medicare would reimburse the disabled elderly for the first six months or a year of home or institutional care, ending the artificial distinction that now exists between rehabilitation after an acute illness and the kind of care required by a chronic condition.
- (2) Back-end insurance coverage would be mandated. It would be supported by income-scaled tax credits. The income scaling would make long-term care insurance affordable, minimize use of public money for estate protection, and target subsidies appropriately. Moreover, even if heavily subsidized, insurance that is private would be fully funded, an especially important feature because of the unfavorable demographics on the horizon.
- (3) Cutbacks would be made in Medicare reimbursement for routine health care, freeing Medicare funds to provide front-end long-term care coverage. The financial stress that Medicare faces as Baby Boomers age is an opportunity to rethink the scope of the care it finances. Some scaling back of Part A and Part B benefits for the routine care of middle- and high-income beneficiaries would offer scope for a Part C. A shift to more catastrophic coverage would make the program as a whole more consistent with the logic and purpose of insurance.
- (4) Standards for Medicaid eligibility would be tightened. The object would not be to deny needed support to the disabled elderly, but to make it more difficult for people to turn to Medicaid first.

8.5 A System of Social Insurance

True long-term care reform, in the long term, requires a reevaluation of the traditional federal, state and local financing roles to better ensure an equitable distribution of public funds for older persons and individuals with disabilities. The current financial pressure on Medicaid must be alleviated, and that program's ability to help the poor must be enhanced.

There is a need for multiple sources of funding: a continuing need for a governmental role, as well as a role for individuals to contribute to meeting their own needs in the way they prefer.

There will continue to be a need for the government to maintain its role in providing a strong safety net for those unable to afford the costs of long-term care while assuring that the full range of long-term care services are available to all, according to their individual needs and circumstances.

It is essential that government should have an equally important role in encouraging personal preparedness for long-term care beyond basic social insurance. This should be done by encouraging, and financing, public policies that divert the middle and upper-middle class to private long-term care financing sources and public-private partnerships.

The only way to fully assure minimal coverage for long-term care services appears to be through a system of social insurance that provides basic long-term care without relying on the government safety net. This is *not* an economically feasible alternative for the American worker, however. A report published by the Brookings Institution⁸ has estimated that funding a comprehensive social insurance plan by means of payroll taxes to provide nursing-home coverage and to expand access to home care would require a tax rate, without a ceiling on taxable wages, of almost 3% today and almost 4% by 2018. It would rise sharply after 2018 to reach almost 8% by 2048 when the demand for long-term care would peak.

8.6 Recommendations

The government must provide financial incentives to enhance the individual's ability to obtain private financing for long-term care, while also maintaining its direct financial support for quality long-term care services needed by the poor elderly and disabled who must turn to the government as provider of last resort.

Government funding for the following activities and programs would encourage individual preparedness.

Education Educate people about their personal responsibilities for assuring their own future health care and long-term care needs, the true risks of long-term care and the options available to meet those risks through Health Department and Office for Aging outreach programs and public service announcements.

Private Insurance Assure the availability of sound private long-term care insurance policies through strict regulation of long-term care policies and establishing stringent policy standards and developing a government re-insurance program.

Consumer Protection Ensure that consumers are adequately protected when purchasing insurance

through mandated disclosures and provision of independent policy comparisons.

Incentives for Private Insurance Create incentives for the purchase of long-term care insurance through a refundable credit for the costs of insurance and by subsidizing the premiums under an income-scaled tax-credit arrangement.

Support for Caregivers Create incentives and supports—such as expanded respite services, in-home and out-of-home, and day care options—to enable informal caregivers to continue providing assistance.

Work Force Programs Provide incentives (such as scholarships, student loan forgiveness, employer subsidies) for the development of a sustainable long-term care work force, assuring that a work force is available to furnish the care that surely will be required.

New Approaches Provide research grants and public institutes of health programs designed to encourage new technologies and the evolution of new paradigms for organizing and delivering long-term care in both homes and in institutions.

Safety Net Government must continue to provide a safety net, including a full continuum of home and institutionally based long-term care services, for those who have the greatest need. As described in

Chapter 5, options are available to tighten Medicaid eligibility that would not deny support needed by the poor disabled and elderly, but would diminish the tendency to turn to Medicaid as the first source of assistance.

Endnotes

1. Clinton Report: Increased Medicaid Costs Threaten Financial Health Of New York's Counties, NYSAC Weekly Wire, November 22 2002.
2. (NYSAC Releases Findings Of "The State Of The Counties" Budget Survey, NYSAC WEEKLY WIRE, February 1, 2002.
3. A.9924, Local Taxpayer Relief Act of 2004.
4. Sweeney Introduces Local Taxpayer Relief Act of 2004; Bill Would Cap Local Share of Medicaid, NYSAC WEEKLY WIRE, March 5, 2004.)
5. See, Caregivers and Long-term Care Needs in the 21st Century: Will public policy meet the challenge? by Robert B. Friedland, Issue Brief, July 2000, Georgetown University Long-Term Care Financing Project (ltc.georgetown.edu).
6. See, Long-Term Care And The Policy Agenda by William Scanlon, Conference Remarks, March 2004, Georgetown University Long-Term Care Financing Project (ltc.georgetown.edu).
7. See, Financing Long-Term Care by Walter M. Cadette, Public Policy Brief No. 59 2000, The Jerome Levy Economics Institute of Bard College.
8. See, Wiener, Joshua M., Laurel Hixon Illston, and Raymond J. Hanley. 1994. *Sharing the Burden: Strategies for Public and Private Long-Term Care Insurance*, Washington, D.C.: Brookings Institution.

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APPENDIX A

(See Chapter 2)

LIST OF Members of Most Integrated Setting Coordinating Council as of July 2004

<p>Antonia C. Novello Commissioner NYS Department of Health</p>	<p>Thomas A. Maul Commissioner NYS Department of Mental Retardation and Developmental Disabilities</p>
<p>Sharon Carpinello Commissioner NYS Office of Mental Health</p>	<p>Joseph H. Boardman Commissioner NYS Department of Transportation</p>
<p>Judith A. Calogero Commissioner NYS Division of Housing & Community Renewal</p>	<p>John A. Johnson Commissioner Office of Children & Family Services</p>
<p>Richard Mills Commissioner NYS Education Department</p>	<p>William A. Gorman Commissioner NYS Office of Alcoholism & Substance Abuse Services</p>
<p>Richard Warrender State Advocate Office of the Advocate for Persons with Disabilities</p>	<p>Neal Lane Acting Director NYS Office for the Aging</p>
<p>Gary O'Brien Chairperson Commission on Quality of Care for the Mentally Disabled</p>	<p>Karen Oates, Mental Health Association of Rockland County</p>
<p>Henry M. Sloma Executive Director Our Lady of Peace Skilled Nursing Residence</p>	<p>Harvey Rosenthal NYAPRS - NY Ass'n of Psychiatric Rehabilitation Services</p>
<p>Kathy Bunnell Director Broome County Office for Aging</p>	<p>Patricia L. Fratangelo Executive Director, Onondaga Community Living, Inc., an OMRDD-funded agency</p>
<p>Constance Laymon Director, Consumer-Directed Choices, Inc. Albany (Consumer-Directed Personal Assistance Program contractor in five upstate counties)</p>	<p>Michael Parker, Ph.D. Expert on Disabilities of all Ages</p>
<p>Kimberly T. Hill Consumer</p>	<p>Carol Raphael President and Chief Executive Officer The Visiting Nurse Service of New York</p>

APPENDIX B

(See Chapter 2)

NEW YORK STATE MEDICAID PROGRAM EXPENDITURES ON LONG-TERM CARE: FEDERAL FISCAL YEARS 2001 - 2003

	Expenditures by Fiscal Year				No. of Recipients served in Fiscal year (fewer are served at any one time - many are short-term users)			
	2001	2002	2003	% change 02-03	01	02	03	% change 02-03
Institutional LTC (not w/ICF-DD, OMR inpatient)	5,256,638,114	5,658,437,929	6,014,953,363	6.3%	146,914	148,949	144,783	0.6
Non-Instit'l TOTAL (with nursing, hospice)	2,828,828,749	2,974,039,023	3,248,346,846	9.0%	194,805	198,247	196,647	(0.8)
- Personal care	1,552,590,150	1,589,924,504	1,765,670,979	11.1%	88,427	88,281	87,678	(0.7)
- LTHHC (waivers - TBI, Lombardi, etc.)	457,146,017	483,808,697	520,625,928	5.4%	27,407	27,747	28,111	1.7
- Home Health (CHHA)	623,305,115	650,137,875	704,235,427	6.7%	91,906	92,715	89,844	(3.1)
Nursing - private duty	156,515,421	157,231,733	155,327,858	(1.2%)	9,278	10,723	11,339	5.7
Hospice	31,206,308	29,381,514	54,256,887	37.8%	4,137	4,874	5,585	14.6
ICF-DD	1,212,434,364	1,220,069,788	1,191,112,422	(2.4%)	20,683	19,924	17,463	(12.4)
OMR Inpatient	1,271,493,413	1,349,740,983	1,523,128,341	12.8	2,394	2,292	2,198	(4.1)
TOTAL MEDICAID SPENDING)	27,024,682,735	30,014,625,513	33,899,594,589	12.9%	3,032,007	3,437,188	4,087,253	18.9

Source: NYS Dept of Health Office of Medicaid Mgt., On-Line SURS Information Retrieval System (November 2004)

APPENDIX C

(See Chapter 5)

BASIC RULES—ELIGIBILITY FOR MEDICAID IN A NURSING HOME

Unmarried Persons

Resources: A person who is not married may retain \$4,000 in assets.

The person may also have arranged for a pre-paid funeral by placing money in a special irrevocable account, generally one maintained by the “Pre-Plan” Trust based in Albany. There is no limit on the amount that may be set aside. After death, however, if the entire amount is not spent, any remaining balance is payable to Medicaid if it provided assistance while the person was alive.

Income Allowed: The person is also allowed to retain \$50 per month from her/his Social Security payment as a “personal needs allowance.”

If the person has Medicare supplemental insurance, Medicaid allows it to be continued. Money from the Social Security payment each month is used to pay the premiums.

Otherwise, after subtracting the \$50 allowance and any money used for a supplemental insurance plan, all of the person’s remaining Social Security, pension and other income go to the nursing home to help pay the monthly bill. This amount is the “Net Available Monthly Income (NAMI).” Medicaid then pays the remainder of the amount due to the nursing home.

Married Persons

(For simplicity, the assumption is made here that the man is the one who needs nursing home care. The same rules apply, however, if the wife is the one who needs care in a nursing home.)

Husband’s Resources: He may retain \$4,000 in assets in only his name. He may also have a pre-paid funeral if the money is in an irrevocable account. Any amount not spent at death is payable to Medicaid if it provided services during his lifetime.

Couple’s Income: The man may retain \$50 from his Social Security account as a “personal needs” allowance.

The premium for any Blue Cross or similar supplement to Medicare coverage can also be paid with Social Security funds.

His wife is entitled to a minimum of \$2,378 per month in income after paying the premium for any Medicare supplemental coverage. If her own personal income is not this high, she is entitled to as much of her husband’s income as needed to reach that level.

- If the wife’s monthly Social Security payment, pensions and other income total \$1,550 per month, she is entitled to \$828 from her husband. If his total income from Social Security and other sources is \$1,858 per month, he gets to keep \$50, his wife gets \$828 from him, and the \$980 that remains goes to reduce the amount that Medicaid must pay on his behalf at the nursing home.
- If the wife’s income from Social Security and other sources is \$2,378, her husband still gets to keep \$50 from his monthly income, but all the rest of his income from Social Security and other sources goes to reduce the amount that Medicaid must pay on his behalf at the nursing home.
- If the wife’s monthly income is more than \$2,378, she is “asked” to contribute 25% of the excess toward her husband’s care. Thus, a wife whose monthly income was \$2,578 would be asked to contribute \$50 monthly toward her husband’s support.

Wife’s Resources: In addition to their home, coop or condominium, if they have one, the wife may retain in her own name, or in her name and her husband’s, a minimum of \$74,820 in assets and a maximum of \$95,100, an amount that Medicaid describes as the “Community Spouse Resource Allowance (CSRA).”

The precise CSRA amount depends on the extent of the couple’s resources when the husband developed the illness that forced him to enter a nursing home:

- If the couple had less than \$149,640, the wife is able to **retain \$74,820**, no matter how much less they had.
- If the couple had more than \$149,640 but \$190,200 or less, the wife may **retain half** of what they had.
- To **retain \$95,100**, the couple’s assets must have totaled \$190,200.

Wife’s Total Income Allowance: If the wife’s income and the husband’s income together total less than \$2,378, the wife may ask to retain more than \$95,100 in resources so that the interest on these additional assets can raise her income level to \$2,378.

- A woman with a monthly income of \$2,278 might ask to retain \$135,100. The additional \$40,000, invested at 3%, would yield \$1,200 per year, or \$100 per month. That interest would then raise her total monthly income to \$2,378. Medicaid generally approves requests to retain additional resources in these circumstances.

Spousal refusal: Once there is enough income available for the wife to receive \$2,378 per month, she must sign a *spousal refusal* if she wants to retain more than the allowable maximums for income and assets. Her husband must sign an *assignment of support*, a document that authorizes Medicaid to step into his shoes and file suit in court to force his wife to provide him with the financial support that is rightfully his.

Once Medicaid has processed a spousal refusal, it has the option to go into court and sue the woman to obtain reimbursement for the funds it has spent on her husband's behalf. It is never possible to predict when Medicaid may sue and when it may not. In general, however, the greater the assets the wife has retained, the more likelihood that a suit will be filed.

GIFTS AND "PENALTY PERIODS"

Many have heard about the *three-year look back rule*. To understand how the rule works, it is necessary to know how Medicaid reacts when a potential recipient of nursing home assistance has made gifts.

For every \$8,870 that a New York City resident gives away, the person is ineligible for nursing home Medicaid for one month. This is referred to as a "penalty period," and it begins on the first day of the month following the month when the gift was given.

- Someone who gave away \$8,870 in June 2003 would not be eligible for Medicaid nursing home coverage until August 1, 2003, *even if the person met all the other eligibility requirements for nursing home Medicaid*.
- Someone who gave away \$88,700 in June 2003 would not be eligible for nursing home coverage for 10 months—until May 1, 2004.
- Someone who gave away \$266,100 (30 x \$8,870 = \$266,100) in June 2003 would not be eligible for Medicaid nursing home coverage for 30 months—until January 1, 2006.
- Someone who gave away \$319,320 (36 x \$8,870 = \$319,320) in June 2003 would not be eligible for Medicaid nursing home coverage for 36 months—until July 1, 2006.

But even if someone gave away \$350,000 in June 2003, the earliest eligibility date for Medicaid nursing home coverage would still be July 1, 2006. ***This is the significance of the "three-year look back rule."*** Medicaid only "looks back" at someone's financial records for the past 36 months. The oldest bank statement that would have to be produced for someone seeking Medicaid as of July 1, 2006, would be one for July 1, 2003. Thus, Medicaid would not know about the \$350,000 gift made in June 2003, and it would not have the information necessary to enforce a penalty period.

Bottom line: Anyone who wants to give away more than \$319,320 needs to be sure that at least \$319,320 is available to pay a nursing home bill for 36 months, and then give the rest away. (The \$8,870 figure used to compute penalty periods was chosen as the "average monthly cost" of private care in a nursing home, and if the actual amount is greater, Social Security and other income generally will make up the difference.)

BASIC RULES—HOME MEDICAID

No "penalty periods" apply when home Medicaid is sought. Applicants who have divested enough assets to be down to the required maximum by the end a month can be eligible for home Medicaid at the start of the next month.

Unmarried Persons

To be eligible for home Medicaid, an unmarried individual may retain a maximum of \$4,000 in assets, not counting the value of a "homestead"—a house, condominium or cooperative apartment.

A home Medicaid recipient may also have set away funds for a funeral in a "Pre-Plan" or similar account.

After paying premiums for any supplemental health insurance, the individual may retain \$667 per month to pay for food and housing expenses, plus \$20 as an "unearned income credit."

The remainder of the individual's monthly income is used to pay for long-term care, with Medicaid supplying the balance of the funds. (In practice, the income over the \$687 total is generally sent to Medicaid, which then pays the agency responsible for the care.)

If the individual owns a homestead, Medicaid places a lien on the property. When it is sold, Medicaid seeks recovery from the proceeds for the amount it paid on the individual's behalf.

Married Couples

When a husband or wife seeks home Medicaid, the total assets of the couple may not exceed \$5,850, not counting the value of a "homestead."

After paying premiums for any supplemental health insurance, their combined total income may not exceed \$975 per month.

A couple with assets and income above these amounts typically places the assets in the name of the healthy spouse, who then files a spousal refusal. The refusal applies only to the income of the healthy spouse. Thus, a Medicaid recipient with \$1,075 in monthly income would still be required to pay \$100 toward care.