

1-1-2004

Back to the Future: The Future of Long-Term Care in Massachusetts

Deborah H. Thomson
University of Massachusetts Boston

John J. Ford
University of Massachusetts Boston

Follow this and additional works at: http://scholarworks.umb.edu/gerontologyinstitute_pubs

 Part of the [Family, Life Course, and Society Commons](#), [Geriatrics Commons](#), [Health Law Commons](#), [Health Policy Commons](#), and the [Public Health Commons](#)

Recommended Citation

Thomson, Deborah H. and Ford, John J., "Back to the Future: The Future of Long-Term Care in Massachusetts" (2004). *Gerontology Institute Publications*. Paper 5.
http://scholarworks.umb.edu/gerontologyinstitute_pubs/5

This Research Report is brought to you for free and open access by the Gerontology Institute at ScholarWorks at UMass Boston. It has been accepted for inclusion in Gerontology Institute Publications by an authorized administrator of ScholarWorks at UMass Boston. For more information, please contact library.uasc@umb.edu.

Back to the Future:

The Future of Long-Term Care in Massachusetts

Deborah H. Thomson, J.D.
John J. Ford, J.D.
Instructors

Students

Sybil Baer

Janet Benkert

Darleen Blood

Jeanne Bragg

Helen Buckley

Cathy Callahan

Loretta Epeneter

Kathryn Erat

Suzanne Gnospelius

Edna Staub

A Project with support from the College of Public and Community Service and the Gerontology Institute, University of Massachusetts Boston, 2003-2004 Academic Year

© Copyright, 2004, the Gerontology Institute, University of Massachusetts Boston.
For more information on the Institute and its publications, or to order additional copies
of this report, write to:

Publications, Gerontology Institute
University of Massachusetts Boston
100 Morrissey Boulevard
Boston, MA 02125-3393;
call: (617) 287-7300; fax (617) 287-7080
e-mail: gerontology@umb.edu

Back to the Future:

The Future of Long-Term Care in Massachusetts

Deborah H. Thomson, J.D.
John J. Ford, J.D.
Instructors

Students

Sybil Baer

Janet Benkert

Darleen Blood

Jeanne Bragg

Helen Buckley

Cathy Callahan

Loretta Epeneter

Kathryn Erat

Suzanne Gnospelius

Edna Staub

A Project with support from the College of Public and Community Service and the Gerontology Institute, University of Massachusetts Boston, 2003-2004 Academic Year

PREFACE

The genesis of this paper was a course taught at the University of Massachusetts Boston over the 2003-2004 academic sessions. The class, taught by attorneys Deborah Thomson and John J. Ford, was in partial fulfillment of the requirements for the Gerontological Social Policy Certificate, College of Public and Community Service. The class examined current issues in long-term care and developed recommendations to address the needs of the Baby Boom generation as its members approach retirement.

Students who contributed to this report are Sybil Baer, Janet Benkert, Darleen Blood, Jeanne Bragg, Helen Buckley, Cathy Callahan, Loretta Epeneter, Kathryn Erat, Suzanne Gnospelius and Edna Staub. The recommendations in this report are those of the students. All of them have had direct experience with our current system, either on a personal level or a professional one. The report was enriched by this store of knowledge. It is the hope of the students and the instructors that the report will help legislative leaders and policy makers in Massachusetts develop concrete proposals that will move us toward a comprehensive, affordable, and high quality continuum of long-term care services and supports.

Deborah Thomson is an attorney with a specialty in elder and health law and is the principal of The PASS Group, where she engages in administrative and legislative advocacy for non-profit organizations working on elder and health care issues. She has worked in Massachusetts for many years for various organizations, including the Massachusetts Law Reform Institute and the Massachusetts Chapter of the Alzheimer's Association. A recipient of numerous awards, Ms. Thomson has participated in many task forces and coalitions at both the state and national levels, addressing various long-term care and elder health issues. She is a graduate of the National Law Center. She can be contacted at The PASS Group, 151 Merrimac St., #660, Boston, MA 02144 (E-mail: bresdeb@charter.net).

Attorney **John J. Ford** has written and lectured extensively on elders= rights, especially with respect to incapacity and long-term care. Mr. Ford is a graduate of Boston University and the Boston University Law School. He was a Reginald Heber Smith Fellow 1970-1972, as staff attorney for Vermont Legal Aid, Inc., and Neighborhood Legal Services, Inc., (NLS) in Lynn, MA. He has been the Director of the Elder Law Project at NLS since 1977. Mr. Ford has been an instructor at the North Shore Community College Center for Older Adults and at the University of Massachusetts Boston Gerontology Institute. He is Chairman Emeritus of the Elder Legal Coalition, the former President of the Massachusetts Chapter of the National Academy of Elder Law Attorneys, and the former President of the Board of Directors of the South Boston Community Health Center. He can be contacted at Elder Law Project, Neighborhood Legal Services, Inc., 37 Friend Street, Lynn, MA 01902 (E-mail: jford@nlsma.org).

Table of Contents

Executive Summary.....	vi
Introduction.....	1
Overview of the System.....	2
Medicare	6
Medicaid	9
Delivery Systems.....	14
Long-Term Care Insurance	19
Work Force	22
Personal Responsibility	25
Conclusion	27
References.....	30

Executive Summary

The state of Massachusetts, like the rest of the United States, is facing an approaching crisis in long-term care. Over the next few decades the number of Massachusetts residents age 65 and older will soar. As these numbers increase, so will the need for long-term care.

Massachusetts is ill prepared to provide the services that will be needed. Our current system of health care benefits leaves many elders with gaps in coverage. Those individuals who need long-term services often impoverish themselves and their spouses before the state pays for their care. Others languish on waiting lists to receive services. Our current provider supply and direct care workforce is inadequate to meet the needs of today's elders, let alone cope with an increase in care needs. Although the state currently spends hundreds of millions of dollars on long-term care services provided by the MassHealth Program and the Home Care Program, providers are often reimbursed at below cost. We must reassess and plan for our future needs before the current problems in long-term care become a crisis.

Following is a list of recommendations to improve our long-term care system and to address the coming surge in elder demographics. The recommendations are grouped by subject area and address a wide range of systemic issues. The one overriding concern of the authors is the need for better public education about long-term care and the programs and services that are available to those in need. Until elders and their families have a better understanding of the system and its alternatives, it will not be possible for individuals to plan thoughtfully for their care needs.

Medicare

Medicare is the primary source of health care coverage for Massachusetts' elders. Although the program provides coverage for acute care and certain outpatient services, it does not cover chronic, long-term care needs. Because of the many gaps in its coverage, beneficiaries often purchase "Medigap" insurance at additional cost or enroll in a Medicare+Choice managed care plan.

Recommendations

- Educate the public about what Medicare does and doesn't cover.
- Expand Medicare coverage to include more long-term care.
- Mandate negotiation of prescription drug prices by Medicare.
- Increase the use of demonstration projects within Medicare.
- Increase funding for Medicare to meet the future needs of the elderly.

Medicaid

Low-income elders and institutionalized elders can qualify for coverage through the state Medicaid Program (MassHealth). The program covers a broad range of services,

including long-term care, and serves as a “wrap-around” benefit for elders dually eligible for both Medicare and Medicaid. Because Medicare does not pay for most nursing home care, Medicaid has become the default source of coverage for many middle-class elders who must exhaust their income and assets to qualify for nursing home care. Efforts by elders to plan for Medicaid nursing home eligibility and avoid impoverishment are controversial and have led to both federal and state efforts to prevent asset transfers. In recent years Massachusetts has concentrated on expanding community-based care options under Medicaid to keep elders at home and avoid or delay costly nursing home placement.

Recommendations

- Educate the public about Medicaid.
- Prevent the impoverishment of spouses of nursing home residents by implementing more generous asset and income rules.
- Expand the Home and Community-Based Waiver to keep frail elders at home.

Delivery Systems

Long-term care is provided by a range of providers and individuals in a variety of settings. Elders move throughout the system depending on their current health status and care needs. Due to increasing demand and limited reimbursement from government programs, the current provider network is not able to meet the needs of all who request services. Family caregivers provide a large amount of non-reimbursed care for frail elders yet receive minimal assistance in the form of care coordination or support services. These problems in the delivery system often result in premature institutionalization of elders at additional cost to the state.

Recommendations

- Expand the availability of providers and services delivering community-based care.
- Better coordinate care across the range of settings and payers.
- Provide increased support to family caregivers.

Long-Term Care Insurance

In recent years, the purchase of private long-term care insurance has become an alternative to Medicaid-financed long-term care. These insurance products comprise a modest share of current long-term care costs and are not suitable for all elders. The policies are expensive and are underwritten based on the age and health status of the purchaser. The policy premiums are subject to increase over time and may become unaffordable and subject to lapse. These product-design aspects limit the market potential of long-term care insurance.

Recommendations

- Pass state legislation establishing long-term care insurance standards.
- Expand the Medicaid Long-Term Care Partnership to allow more purchasers to shelter assets from Medicaid estate recovery.

- Subsidize the premium payments of long-term care insurance through the Medicaid Program

Work Force

There is currently a shortage of direct care long-term care workers that includes certified nurse aides, home health aides, and home care workers. These paraprofessional workers earn low wages, often go without health insurance benefits, and have a high rate of on-the-job injuries. In addition they often suffer from a lack of respect and control over their work. As a result, providers have difficulty attracting and retaining workers, which in turn impacts quality of care and increases the burden on family caregivers. As the number of elders in need of care increases, the number of workers available to supply this care will decrease.

Recommendations

- Improve the wages and benefits of long-term care workers.
- Improve workforce retention by respecting and empowering workers.
- Address diverse culture issues within the long-term care workplace.

Personal Responsibility

Many elders are threatened by confronting their future need for long-term care services. Faced with a potential loss of health and independence, many elders avoid financial planning to meet future care needs. This avoidance is compounded by ignorance of care and coverage options. Often this ignorance leads to catastrophic results such as ineligibility for needed care due to asset transfers or impoverishment of community spouses.

Recommendations

- Establish a public education program to encourage informed planning for the cost of long-term care.
- Help minimize long-term care costs by maintaining good health practices.

While all of these incremental changes would improve Massachusetts' long-term care system, they will not cure its problems. In the long run, we need a national overhaul of our health care system, including long-term care, to ensure that all residents receive comprehensive, affordable, high quality health care.

Introduction

The American population is aging, and Massachusetts is no exception to the rule. As the post-war Baby Boom generation approaches retirement age, policy makers are beginning to assess the increased demand for long-term care services over the next several decades. How to care for a larger elderly population and how to pay for that care are becoming increasingly urgent issues, both for individuals and society as a whole.

Until now, the lack of a coherent federal long-term care system has left states with the task of providing and financing care. The ability of states to do so varies based on their economic cycles and elderly demographics, but no state currently meets all of its residents' needs for long-term care. Family caregivers supply a large amount of care and support for their loved ones, and institutional care is often the only choice for elders without family supports or access to community care. Many elders are impoverished by their out-of-pocket health care costs, especially the cost of nursing home care. Long-term care providers are often paid less than the actual costs of care by public programs such as Medicare and Medicaid. Yet despite the bargain, states spend hundreds of millions of dollars to reimburse care. The system is under stress, and without effective planning an increased demand for services in the future may well strain it beyond its capacity to deliver care.

This report looks at a number of different components of the long-term care system, identifies its successes and shortcomings, and makes recommendations to strengthen it in future years. Among the many recommendations, the one that the authors found most critical is the need to educate elders about the long-term care system and their options in planning for the future. There was general agreement that most elders have little knowledge of the system and how to plan for their future needs. Hopefully, this report will reinforce the need for increased public discussion of these issues and how to address them.

Overview of the System

The Population – Characteristics and Trends

Massachusetts currently has approximately 831,000 elderly residents age 65 and older, roughly 13% of its total population.¹ This percentage is increasing as the Baby Boom generation ages; by the year 2020, elders in the Bay State will constitute almost 17% of the state's population.² Massachusetts' elderly population is also becoming more diverse. Almost 7% of elders belong to a minority group, an increase of more than 73% over the past decade.³ The fastest growing age segment of the elder population consists of individuals age 85 and older.⁴ This cohort is also the most likely to need long-term care.

Elders (65 and older) in Massachusetts are predominantly female and are often widowed and living alone.⁵ This population is frail; approximately 40% of elder residents have some form of activity limitation, including self-care, mobility, sensory and cognitive limitations, and approximately 12% of elder residents need help with at least one activity of daily living (ADL).⁶

Social Security is the primary source of income for Massachusetts' elders, who generally live on modest incomes. Approximately 15% have incomes at or below the federal poverty level (\$12,490 for a couple), and over 30% have incomes at or below twice the poverty level.⁷ Roughly 69% of elders own their own homes.⁸

Massachusetts' elders generally have health care coverage, but their coverage is often not comprehensive. The majority (730,000) is enrolled in Medicare and approximately 137,000 elders are enrolled in Medicaid.⁹ Most non-institutionalized elders have some form of private supplemental insurance, either through an employer plan or purchased individually.¹⁰ Prescription drug coverage is often lacking, although approximately 80,000 elders are now enrolled in the Prescription Advantage drug insurance program.¹¹ Approximately 22% of Massachusetts Medicare beneficiaries are enrolled in a Medicare+Choice managed care plan.¹²

The Provider Network – Services and Funding

Long-term care services in Massachusetts span a continuum of elder care needs ranging from institutional care to social support services. While many medical services are covered by Medicare and Medicaid, other state-funded programs provide extensive social support services. There are also significant levels of medical and social services that elders pay for out-of-pocket. Long-term care insurance provides only a small amount of coverage for long-term care.

Nursing homes provide a range of services to their residents, including room and board, medical care, and physical and occupational therapy. Massachusetts currently has 461 nursing homes serving approximately 45,000 nursing home residents. This is a significant reduction in capacity; since 1998 103 nursing homes across the state have closed due primarily to financial problems associated with low Medicaid reimbursement rates.¹³ Even with this reduction of roughly 6,000 beds Massachusetts ranks among the top ten states in nursing home beds per capita. Approximately 30,000 nursing home residents are Medicaid recipients and roughly 69% of nursing home care is paid by the Medicaid program. In contrast, Medicare pays approximately 11% of nursing home costs, since it only reimburses a highly skilled level of care for a limited period of time.¹⁴

While not providing health care services within the meaning of Medicare, assisted living residences (ALRs) fill a critical gap in the care continuum. By providing a combination of room, board, and personal care services, ALRs allow frail elders to avoid nursing home placement and remain in the community. Residents live in “independent” private units and pay a monthly fee that covers these basic services. Many ALRs offer additional services at an additional monthly charge, and many provide specialized dementia care.

There are currently 170 ALRs in Massachusetts, and the average monthly cost for a one-bedroom ALR unit is \$3,200.¹⁵ (In contrast, the average monthly cost for a nursing home bed is \$7,320). Neither Medicare nor Medicaid pays for the room and board portion of ALR costs, although Medicaid does pay for ALR services for residents enrolled in a “Group Adult Foster Care” program.¹⁶ The cost of ALRs prevents many elders from

accessing them, while other elders exhaust their savings paying for ALRs. If these residents do not have family members to subsidize their cost of care, they often end up entering nursing homes as MassHealth recipients.

Home health agencies and visiting nurse associations in Massachusetts provide the bulk of community-based nursing and home health aide care. These services are provided in the home and include observation and assessment of medical condition, skilled nursing care, physical therapy, and personal care. Like nursing homes, these agencies rely on Medicare and Medicaid as their primary payment sources and help prevent premature nursing home placement. A number of home health and visiting nurse agencies have closed or consolidated over the past few years due to financial difficulties; the Home and Health Care Association reports that their current membership of 100 agencies is down from a high of 165 members in 1997.¹⁷ Even so, Massachusetts ranks among the top ten states in per capita spending on home health care.¹⁸

Another important group of community providers are the adult day health programs. Over 100 adult day health programs in Massachusetts provide transportation, medical services, personal care, and social support at program centers to approximately 10,000 individuals, many of whom suffer from dementia. In addition to serving participants, adult day health programs provide respite for family caregivers. It is estimated that without adult day health services 50% of program participants would be institutionalized.¹⁹ Adult day health is not a Medicare-covered service and participants must pay privately or be Medicaid eligible. Like other providers who rely on Medicaid, adult day health programs struggle financially to meet the cost of care and a number of them have closed in recent years.

A range of social support services is provided by the state Home Care Program through Aging Service Access Points (ASAPs), which assist approximately 36,000 elders on an average daily basis. Services provided include personal care, house cleaning, shopping and other less medicalized yet essential community services. Medicare and Medicaid do not reimburse these services unless they are provided via the Massachusetts Home and

Community-Based Waiver Program, under which Medicaid reimburses a broad range of care for approximately 4,500 individuals at risk of institutionalization.²⁰

Massachusetts is unique among states in that it has a network of Aging Services Access Points (ASAPs) that coordinate care and screen elders for Medicaid and Home Care Program eligibility. These 27 community non-profit agencies also provide information and referral services and contract with other agencies that provide direct care to elders. Most ASAPs are federally designated Area Agencies on Aging and serve as the local sources of funding distribution for Older Americans Act programs, including nutrition, transportation, and legal services. ASAPs also administer state supportive housing programs, protective services, and money management programs. ASAPs coordinate the work of local SHINE volunteers (Serving the Health Insurance Needs of Elders) and nursing home ombudsmen. As such they are an important community resource for elders.²¹

A final important group of providers in the long-term care system is the Councils on Aging (COAs). Located in towns and cities throughout the Commonwealth, COAs coordinate meals, transportation, social day care, counseling, and volunteer opportunities for elders. While they are not providers of medical services, COAs provide critical a link between elders and resources in the community. COAs serve over 425,000 seniors per year and are funded with a combination of state and municipal dollars.²²

In recent years, Massachusetts has seen a shift in its Medicaid long-term care funding away from institutional care and towards community-based services. This reflects elders' preference to stay in their homes as long as possible; it also reflects the perception that community-based care is more cost-effective. When the costs of younger persons with disabilities are included with elder costs, about 50% of Medicaid long-term care dollars pay for nursing home care, while approximately 42% of Medicaid long-term care dollars go to community-based services.²³ (Additional long-term care dollars are spent on Intermediate Care Facilities for the Retarded and mental health facilities.) State Home Care Program services add approximately \$120 million to the community care total, while

COAs receive approximately \$6.5 million in state dollars.²⁴ This trend towards increased community care funding and services is expected to continue in the near future.

Medicare

Medicare is the primary public health program serving elders in Massachusetts. The program is funded by the federal government through a combination of worker taxes, government revenues, and beneficiary co-payments and deductibles. Medicare has four component parts, Parts A through D. Part A covers hospital inpatient care, while Part B covers outpatient care. Together they reimburse a range of services, including hospital care, physician care, tests, skilled nursing home care, home health care, and medical equipment and supplies. Medicare does not pay for what is called “custodial care,” services that are not primarily medical in nature. It also reimburses only when a beneficiary is within a “spell of illness,” which is controlled by the length of time and severity of a beneficiary’s care needs.

While Medicare used to be a “fee for service” system, in recent years types of coverage available through Medicare have expanded. Elders can now choose traditional fee for service coverage, or they can enroll in a Part C Medicare+Choice/Medicare Advantage managed care plan. Federal law changes in the last year have added additional coverage options, including Health Savings Accounts (HSAs) and a new Part D drug benefit option. Individuals who are dually eligible for Medicare and Medicaid can enroll in the federal PACE program of managed care or the Massachusetts Senior Care Options (SCO) program of managed care.

In addition to the services it does cover, Medicare is noteworthy for what it omits. Medicare does not cover chronic long-term care services. Because Medicare was designed to reimburse beneficiaries in need of acute and skilled medical care for fixed periods of illness, it generally reimburses long-term care services for short periods of time if at all. So, for example, an otherwise healthy elder with Alzheimer’s disease who needs constant supervision and help with daily tasks would not qualify for Medicare coverage of his or her care needs. Seniors must purchase “medigap” coverage at additional cost or enroll in a

Medicare+Choice plan to reduce their out-of-pocket costs and expand their coverage. Even then, prescription drugs and other care needs may not be covered. Most long-term nursing home care is not paid for by Medicare, as it generally covers short periods of intensive skilled care after a hospitalization.²⁵

Recommendations

- **Educate the public about what Medicare does and doesn't cover**

Most Americans, including elders, do not know what benefits are covered by Medicare. More importantly, they do not know what Medicare does not cover. The absence of such understanding results in elders failing to anticipate their future health care costs. It can result in significant financial distress, particularly if an elder needs nursing home care that is not reimbursable by Medicare. Both the federal and the state governments should increase public education efforts in this regard. The SHINE program, a federally funded program of insurance counseling, should be expanded to provide additional education services to elders. The Executive Office of Elder Affairs should increase its use of media, online resources, speaking engagements, and other forms of communication to ensure that Massachusetts' elders are fully informed about the scope of Medicare benefits.

- **Expand Medicare coverage to include more long-term care**

Medicare is the primary source of medical coverage for most elders, yet it is riddled with holes in coverage. Its original design as a mechanism to cover distinct spells of acute illness and recovery is no longer adequate to meet the needs of today's elders, let alone the future needs of the Baby Boom generation. The failure of Medicare to cover chronic care results in elders deteriorating in the community and being hospitalized or prematurely placed in nursing homes, at additional cost to elders and to state Medicaid programs. Unless the program is restructured to include chronic care services, the long-term care system and those it serves will continue to suffer.

- **Mandate negotiation of prescription drug prices by Medicare**

The Medicare Prescription Drug Improvement and Modernization Act of 2003 (MMA) does not allow the Medicare Program to negotiate uniform drug discounts for Medicare beneficiaries. This failure to capture cost savings contributes to continually escalating prescription drug costs for beneficiaries. The federal law should be amended to require the federal government to negotiate comprehensive drug price discounts on behalf of Medicare beneficiaries.

- **Increase the use of demonstration projects within Medicare**

Many of the recent good innovations in the Medicare Program began with demonstration projects as allowed under federal law. For example, the PACE Program of All-Inclusive Care for the Elderly began as a demonstration project. Likewise, coverage of many new benefits and new payment methodologies have begun as demonstration projects. The MMA contains a number of demonstration projects, including projects to improve the quality of care provided to beneficiaries with chronic conditions. This allows the testing and adjustment of a new provision on a trial basis before expanding it to the whole Medicare population. All such demonstrations are subject to a report to Congress with appropriate recommendations based on outcomes. Medicare should encourage future demonstration projects.

- **Increase funding for Medicare to meet the future needs of the elderly**

The United States currently spends about \$295 billion per year to fund Medicare coverage.²⁶ It is one of the largest appropriations in the federal budget, yet it does not meet many of the long-term care needs of today's elderly and disabled beneficiaries. In the next two decades, we will experience a number of factors that will further the Medicare shortfall: an increase in the number of Medicare-eligible individuals; a continuing increase in health care cost inflation; expensive new drugs and technologies; and an increased shortage of health care workers. Federal funding increases must begin now if the current level of Medicare coverage is to be expanded. At a minimum, elders' long-term care needs must be carefully monitored over time and sufficient funding appropriated to provide necessary, high quality long-term care. To the extent that Medicare assumes a greater role

in reimbursing long-term care services, states will shoulder less of a burden on their Medicaid programs, and elders will not be forced to impoverish themselves as quickly to access care.

Medicaid

Medicaid (MassHealth) is a program of health care coverage designed to serve low-income families and disabled and elderly individuals. Funded by a combination of state and federal dollars, it is the insurer of last resort and serves as “wrap-around” coverage for individuals dually eligible for Medicare and Medicaid. The program covers a broad range of acute and long-term care services, some of which are mandatory, some of which are a state option, and some of which are available through waivers. States often try to get Medicaid to cover as much state-funded health care as it can, since “federal financial participation” results in a significant amount of the cost being reimbursed by the federal government.²⁷

Medicaid eligibility is determined based on a combination of income and asset criteria and a finding of “medical necessity” for particular services. To complicate matters further, income and asset criteria for institutional long-term care and community-based care differ in significant ways. An elder who lives in the community can qualify for Medicaid if he or she has income at or below the federal poverty level of \$9,310 for an individual and \$12,490 for a couple. In addition, he or she must have countable assets at or below \$2,000 for an individual or \$3,000 for a couple. These stringent eligibility criteria preclude all but the poorest elders from accessing community-based Medicaid benefits. On the other hand, an elder in a nursing home qualifies for Medicaid at a much higher income level and can allocate a significant portion of marital income and assets to a community spouse. Because nursing home care is expensive, Medicaid has become the default insurer for middle-class elders who exhaust their assets paying for care and have income that is less than the monthly cost of the nursing home.²⁸

In recent years, the federal government has imposed strict penalties on individuals who transfer assets for less than fair market value prior to entering a nursing home.²⁹ The intent

of these rules is to prevent elders from giving away assets in order to qualify for Medicaid nursing home reimbursement. The rules can be a trap for unsophisticated elders who give gifts to family members only to find themselves ineligible for Medicaid after they enter a nursing home and spend down their assets. Because of the complexity of the Medicaid rules, many elders seek legal advice on planning for long-term care. Effort to order their affairs responsibly are often condemned as using “loopholes” to qualify for long-term care.

Due to the high cost of nursing home care and the preference of elders to remain at home, states in recent years have tried to reduce reliance on institutional care and expand availability of community-based long-term care. This has resulted in the expansion of waiver programs that provide more comprehensive services to very frail elders.³⁰ In Massachusetts, the SCO program of managed care for dually eligible elders is one such waiver program. Community Choices is another.³¹

Although Medicaid spending comprises almost one-third of the state budget, the federal government reimburses approximately 50% of its cost. This makes it an attractive alternative to state-only funded programs. In addition to garnering federal dollars, Medicaid generates jobs in the health care industry, supporting employment throughout the care continuum.³² With increased use of federal waivers, Massachusetts has been able to include a broad range of individuals and services within its Medicaid program.

There is a tremendous amount of misinformation about the Medicaid Program, both among elders and among the public at large. Because it is a complex program, it is easy to mischaracterize Medicaid, the population it serves and the services it covers. Because it is expensive, it is easy to dismiss it as a “budget-buster” without acknowledging the vital role it plays in providing health care and stimulating the economy. Because it is publicly financed, it is easy to dismiss recipients as “gaming the system” to receive benefits. These perceptions need to be corrected if Massachusetts wants to develop a rational system of long-term care

Recommendations

- **Educate the public about Medicaid**

Massachusetts should develop an ongoing system of education about long-term care and the role Medicaid plays within it. Families should be informed about the types of long-term care available and the likely costs of such care. Medicaid income and eligibility criteria should be part of such a curriculum, as should the availability of alternative options such as long-term care insurance. This education campaign could be coordinated by the Executive Office of Elder Affairs in concert with the ASAPs and COAs. Providers, insurers, employers, financial planners, advocates, and state bureaucrats could play a part in designing the curriculum and producing written materials and media products. If a successful education campaign is designed and implemented, elders may view Medicaid as one possible choice in a range of options to pay for long-term care. It will prevent the inadvertent impoverishment and institutionalization that often results from lack of knowledge of the long-term care system.

- **Prevent the impoverishment of spouses**

One of the worst consequences of chronic illness is the impoverishment of a well spouse. This occurs in several ways. Spending income and assets to pay out-of-pocket for community-based care that Medicare does not cover is a common occurrence. Spending down income and assets to pay for nursing home care is also a common cause of impoverishment. In both cases, spouses can be left with severely reduced income and assets with which to support themselves.

Federal Medicaid law attempts to ameliorate such impoverishment by allocating a portion of marital income and assets to the community spouse of a nursing home resident at the time the resident applies for Medicaid.³³ The law gives states a range of options in this process. While Massachusetts formerly opted to allow the maximum level of assets and income to a community spouse, in recent years it has opted for the federal minimum asset allowance and a more stringent method of computing the spousal income allowance.³⁴ These changes have drastically reduced the financial resources of community spouses.

The impoverishing effects of Medicaid nursing home care places a heavy burden on spouses, many of whom are elderly and frail themselves. It can result in premature nursing home placement of the community spouse, who cannot afford alternatives to institutional care such as assisted living residences or community-based services. It can also result in community spouses qualifying for Medicaid themselves after their spouses die and their assets are exhausted. This makes no sense in terms of economic or health policy.

The Legislature and the Administration should work together to restore the income and asset allowances of community spouses of nursing home residents to the federal maximum level and method of calculation. This will support the ability of elders to provide for themselves and delay their entry into institutional care.

- **Expand the Home and Community-Based Waiver**

Massachusetts currently has a Medicaid waiver program to provide community-based services for individuals at risk of nursing home placement. This “home and community-based waiver” is authorized to provide a broader range of Medicaid- reimbursed services than is normally covered, including social support services.³⁵ The waiver also disregards spousal income and assets in determining an applicant’s financial eligibility. Currently the waiver serves about 4,200 elders, with an additional 450 “slots” reserved for a demonstration project called Community Choices. Community Choices serves a subset of the waiver population “at imminent risk” of nursing home placement and allows a higher dollar expenditure than the waiver.

Enrollment in the waiver is limited by authorizing only a fixed number of slots.

Although this number has increased over time, further expansion of waiver slots would allow more elders to benefit from expanded community-based care. In addition, waiver eligibility is determined by using the Medicaid community income limit of 100% FPL. A provision in the FY2005 State Budget directs the Medicaid Program to apply for federal authorization to increase the waiver income limit to 300% of the federal SSI payment level (approximately \$1,700 per month).³⁶ If approved, this will allow many more elders access to community-based services.

- **Repeal authorization of a waiver to increase transfer of asset penalties**

In its FY2004 Budget, the Massachusetts Legislature directed the Medicaid Program to seek a waiver of federal rules governing the imposition of penalties for transfer of assets for less than fair market value prior to entering a nursing home.³⁷ The current federal provisions require state Medicaid Programs to “look back” 36 months for impermissible transfers when an individual enters a nursing home or applies for Medicaid, whichever is later. In the case of transfers to a trust, the look-back period is 60 months. If an individual has given away assets during that period, he or she will be assessed a period of ineligibility for Medicaid-reimbursed nursing home care. The penalty period varies based on the amount of assets given away and begins running as of the date the transfer is made.³⁸

The proposed waiver would look back 60 months (5 years) in the case of real estate transfers and 120 months (10 years) in the case of transfers to or from a trust. Just as significantly, the penalty period would not begin running until the individual enters the nursing home and applies for Medicaid. This ensures that the individual will be in the nursing home during the penalty imposition. If the individual has exhausted his or her assets and does not have family members to assist him or her, there will be no source of payment for his or her care. A nursing facility may lawfully discharge a resident for non-payment of the costs of care.

The proposed waiver assumes that elders anticipate 5 or 10 years in advance that they will enter a nursing home and make transfers to avoid payment. This is untrue and unfair. Most elders with the ability to give gifts to their children and grandchildren do so for reasons independent of Medicaid eligibility. For instance, paying for a child’s wedding or paying a grandchild’s college tuition is considered a socially responsible act on behalf of family members. Furthermore, barring otherwise indigent nursing home residents from eligibility for Medicaid could result in discharge for non-payment, placing the elder’s health in serious jeopardy. It could also result in financially strapped nursing homes swallowing the cost of care because they are unable or unwilling to discharge the resident to an unsafe situation or environment.

Rather than punish elders for unwitting rules violations, the Administration should vigorously pursue a long-term care education campaign to teach elders and family members about the options for long-term care coverage, including an explanation of Medicaid and the rules governing transfers of assets. This will encourage responsible planning while eliminating the trauma of unanticipated transfer penalties.

Delivery Systems

Long-term care services in Massachusetts are delivered by a variety of entities and individuals and span a range of medical and social services. Individuals in need of long-term care generally receive a combination of services from different providers, often with different reimbursement sources, with the level of services varying over time. Unlike the “spell of illness” model in the Medicare Program, most chronically ill elders do not neatly progress from acute care to rehabilitation services to home health care to full independence. The successful treatment of such individuals depends on a flexible system of care that is responsive to the individual’s needs and is carefully managed over time.

In recent years, Massachusetts has moved away from heavy reliance on institutional care and has increased the level of community services available for long-term care. State Medicaid spending on community-based care, as opposed to nursing home care, for all recipients now accounts for almost half of Medicaid long-term care dollars.³⁹ Yet issues remain regarding the adequacy of payment for providers and the availability of services across the state. Service availability is further constrained by a limited supply of long-term care workers in sectors such as nursing homes, home health, and adult day health programs. For very frail elders living at home, the provision of services requires an ongoing level of care management and supervision. Often this burden of coordination falls on a family caregiver, who may find the system confusing and difficult to navigate or simply overwhelming.

Massachusetts is fortunate to have a state Home Care Program that pays for a range of support services not normally covered by Medicaid or Medicare and provides limited care

management. ASAPs contract with providers of home care services as well as plan and manage care for their clients. Yet the demand for such services far outweighs the dollars available to provide care. As a result, ASAPs are often forced to deny care to all but the frailest elders in the community and to restrict approved services for those individuals receiving services. This results in an increasing burden on family caregivers, who provide a significant amount of unpaid long-term care.

The increasing prevalence of Medicare+Choice managed care plans has created new challenges for service delivery. Medicare plans do not cover the full range of long-term care services, often resulting in a beneficiary transitioning to Medicaid or to private payment if he or she needs non-Medicare covered services. The process of moving from managed care plan services to another system is not well coordinated and often confusing for frail elders. It is also difficult for providers who must juggle different payment systems and different eligibility criteria for individuals moving from one system to another. Individuals with chronic illnesses who lose home health and other home-based care when Medicare coverage ceases are at risk of deteriorating health and subsequent rehospitalization, regression, or increased morbidity.

Recommendations

- **Expand the availability of providers and services delivering community-based care**

Although no comprehensive survey has been done, it is clear that Massachusetts long-term care providers cannot meet the needs of all who request services. The Division of Medical Assistance has identified areas of critical shortages of nursing home beds, including Fitchburg, Lynn, and Northampton.⁴⁰ The Massachusetts Adult Day Services Association (MADSA) estimated in 2002 that an increase of 78 additional adult day care programs was required to meet current need adequately.⁴¹ To meet the projected increase in long-term care needs over the next decades, Massachusetts must begin now to shore up its deteriorating long-term care provider network.

One obvious way to do this is to increase Medicare and Medicaid reimbursement rates. Medicare reimbursement at the federal level is beyond the scope of state direction, but

Medicaid reimbursement rates are determined by the state Division of Health Care Finance & Policy under the direction of the Office of Health Services.⁴² Rates are funded by appropriations from the state budget as directed by the Legislature and the Governor. Efforts to look at improving the health care system in recent years have acknowledged payment inequities, but little action has been taken to remedy the problem.

Unless payment inequities are addressed, providers will be limited in their ability to attract, recruit, or adequately compensate their workers. Poor wages and benefits contribute to worker shortages and high turnover rates, which contribute to a diminution in the quality of care provided to long-term care patients.

One creative approach to generating additional funding for providers is the “user fee” proposed and implemented by the nursing home industry.⁴³ This mechanism requires nursing homes to pay a fee based on its number of non-Medicare beds. This fee is then matched by federal Medicaid dollars and returned to providers via the nursing home Medicaid rate. This mechanism generated \$288 million in the most recent budget year, and has been used in part to increase worker wages. This mechanism could be replicated to expand reimbursement for other provider groups.

- **Better coordinate care across the range of settings and payers**

Ideally, a chronically ill elder would have one individual coordinating his or her care regardless of service needs and payment source. This individual would be familiar with the elder’s diagnoses, medications, medical history, treatment preferences, and living situation and would work with the patient to determine how best to meet his or her needs.

Unfortunately, this dedicated care management model almost never occurs. Each sector of the provider network has its own method of patient assessment, care authorization, patient notification, and patient discharge. Discharge planning, key to successful transitions among providers, varies among providers. ASAP care management is limited by available resources and does not result in day-to-day involvement for the vast majority of clients.

Private geriatric care managers are often helpful in arranging transitions, services, and family support, but their cost may be beyond the reach of families.

Massachusetts must invest more resources in ongoing care management for chronically ill individuals. This need has been recognized in the Senior Care Options (SCO) Program. The SCO model blends Medicare and Medicaid funding to provide consolidated reimbursement and managed care across the continuum of services for dually eligible elders. Currently, three health care entities are certified as SCO providers and have begun enrolling members across the Commonwealth.⁴⁴ Although the SCO model is too new to measure its success, it offers a creative solution to coordinated and integrated long-term care service provision. If it proves successful, it should be supported and expanded.

Another new model that emphasizes care management for frail elders is Community Choices. Community Choices is a demonstration program within the Massachusetts Home and Community-Based Waiver Program.⁴⁵ It targets 400 elders at imminent risk of nursing home placement and provides a more intensive mix of community services with a higher average cost per individual than other Waiver enrollees. Services provided to Choices enrollees are Medicaid-reimbursed and include a range of services not normally covered by Medicaid. Like the SCO Program, this model should be evaluated and expanded if it provides cost-effective, high quality care.

- **Provide increased support to family caregivers**

Family caregivers play a significant and critical role in providing long-term care services to chronically ill individuals. Family caregiving is the sole support for approximately 78% of individuals receiving community-based care, and family caregivers provide substantial assistance to institutionalized individuals as well.⁴⁶ Often, the caregiver forgoes paid employment to provide care and juggles childcare responsibilities as well. It is not surprising that many family caregivers suffer from financial, physical, and mental stress.

Given the increasing proportion of elders in Massachusetts and the declining birth rates nationally, the supply of family caregivers may lessen dramatically in the next few

decades. It is therefore important to develop creative means of support for their caregiving. A number of models of caregiver support have been implemented in recent years to lessen the caregivers' burden.

On a national level, Congress has funded the Family Caregiver Support Program. Starting with a small federal appropriation of \$125 million in 2001, the program allows states to fund information services, counseling, support groups and training, respite care, supplemental services, and assistance in accessing services.⁴⁷ This program's funding should be substantially increased to provide an adequate base of support for all family caregivers.

A number of states have experimented with paying family caregivers to provide care. Often such payment is provided in connection with "Cash and Counseling" demonstration programs or the Personal Care Attendant Medicaid benefit.⁴⁸ In these programs, Medicaid recipients choose how to spend money for their in-home care. A significant number of these individuals have chosen to pay family care providers for their services.

Massachusetts should consider paying family members, either through a Cash and Counseling program, its Medicaid Personal Care Attendant Program, or its state-funded Home Care Program.

Respite care is another essential support for family caregivers. Respite care enables a family caregiver to take a break from caregiving duties, to rest or accomplish other tasks. Respite care can be provided on a daily basis or can be provided for a longer period to allow family trips or vacations. In Massachusetts respite care is provided via the Home and Community-Based Waiver or the state Home Care Program. Adult day care can function as respite for a caregiver, and institutional care can also provide respite during caregiver crises such as unanticipated hospitalizations of the caregiver. Massachusetts should strengthen its financial and programmatic support of respite services.

Long-Term Care Insurance

One of the more recent developments in long-term care coverage is the offering of private long-term care insurance. These products generally offer fixed dollar amounts of coverage for a range of services, including home-based and institutional medical care and assistance with activities of daily living. Often such policies have deductibles and elimination periods before coverage begins, and individuals must meet a disability standard before the benefits can be used.

In Massachusetts, the state Division of Insurance regulates the content and marketing of such policies, setting minimum coverage requirements and specifying disclosure information.⁴⁹ Under certain circumstances, individuals who carry long-term care insurance may be able to preserve assets from recovery by Medicaid after the death of the recipient.⁵⁰ Under federal rules, premium payments for policies meeting certain standards qualify as federal tax deductions.⁵¹

Long-term care insurance policies currently play a minor role in paying for long-term care. In 2001, approximately 8.3 million policies had been sold nationally, with approximately 5.8 million still in force.⁵² These policies paid for approximately 10% of long-term care costs in 2002.⁵³ The reasons for limited product purchase are many. Premiums vary based on the age of the insured, but in general they are expensive and many elders cannot afford them. Policies are also underwritten based on health, and chronically ill individuals may be barred from purchasing a policy. In addition, premiums can increase over time as the cost of health care goes up. Fixed-dollar coverage amounts that are adequate at the time of purchase may provide relatively little coverage by the time benefits are utilized. Individuals who purchase long-term care insurance at a younger age will pay lower premiums but may be forced to let their policies lapse if they cannot keep up with premium increases. They may also be impoverished by the cost of long-term care because their fixed-dollar coverage is inadequate to meet the actual cost.

Recommendations

- **Educate the public about the pros and cons of long-term care insurance**

Most elders do not understand long-term care insurance and how to evaluate its suitability for their individual circumstances. As a result, elders are vulnerable to sales techniques that may misrepresent the purpose and benefits of the product. For example, some insurance brokers stress the fact that long-term care insurance may shelter an elder's assets from estate recovery if he or she enters a nursing home on Medicaid. While this is true, an elder with minimal income and assets may not need this protection or might be better advised to make different arrangements for his or her estate. If an elder with minimal income purchases a long-term care insurance policy and the premiums increase over time, he or she may have to let the policy lapse and lose the benefit of the premiums already paid. On the other hand, long-term care insurance might be an excellent option for individuals with substantial assets and adequate income. But without the information needed to evaluate the suitability of a particular policy for the elder's circumstances, informed decisions cannot be made.

The Division of Insurance in collaboration with the Executive Office of Elder Affairs has produced a consumer guide to long-term care insurance titled "Financing Long-Term Care: Your Guide to Long-Term Care Insurance." This publication contains a wealth of information about long-term care insurance and is available on line.⁵⁴ To reach elders who are not computer-literate, the guide should be made available throughout the Commonwealth at Councils on Aging and other senior sites. In addition, the SHINE program should be strengthened with a combination of training and staffing increases to advise elders about long-term care insurance. EOEA should encourage presentations on long-term care insurance from experts such as responsible insurance brokers and estate planning attorneys. If necessary, additional state funding should be appropriated for this purpose.

- **Pass state legislation establishing long-term care insurance standards**

Currently, Massachusetts does not have product-specific statutory authority over the offering and sale of long-term care insurance. In recent legislative sessions, legislation has

been introduced that would define policy contents, set standards for policy sales, set forth consumer protections, and specify disclosure requirements for prospective buyers.⁵⁵ This legislation has yet to pass. The Legislature should make a concerted effort to pass legislation regulating this product in the next legislative session.

- **Expand the Medicaid Long-Term Care Partnership**

Massachusetts is one of four states that have in effect a “long-term care partnership.” Under the terms of this arrangement, Medicaid will forgo recouping the cost of medical care from the estate of an institutionalized recipient if the recipient has in effect long-term care insurance meeting certain standards and does not intend to return home.⁵⁶ Medicaid will also forgo counting the home of an institutionalized recipient as an asset if the individual has appropriate long-term care insurance and does intend to return home.⁵⁷

Federal legislation passed in 1993 precluded additional states from implementing long-term care insurance partnerships and mandated estate recovery against deceased recipients in other states. In the past year, Congress has indicated its willingness to consider removing the partnership ban. Legislation has been introduced to accomplish this and the Senate Special Committee on Aging has held hearings on the bill.⁵⁸ Massachusetts should support the passage of this legislation to encourage the purchase of long-term care insurance nationally and to help control the public program cost of long-term care.

- **Subsidize the purchase and premium payments of long-term care insurance through the Medicaid Program**

Currently, Medicaid does not pay for the cost of long-term care insurance unless an individual is in a nursing home and is a Medicaid recipient. In that circumstance, Medicaid will allow the premium costs to be deducted from the resident’s “Patient Paid Amount.”⁵⁹ The Administration should investigate the subsidization of long-term care insurance premiums for individuals below a certain income and asset level who also meet age and disability requirements. Given the likelihood of such individuals to need Medicaid-reimbursed long-term care when their income and assets are exhausted, a subsidy could be cost-effective over the long run.

- **Expand the available tax incentives for purchase of long-term care insurance**

Tax incentives for the purchase of long-term care insurance exist at the federal level. The premiums of “federally qualified” policies can be deducted from federal tax liability in the same manner as a medical expense deduction. However, the deduction is capped based on the age of the taxpayer.⁶⁰ Treating premiums as a tax credit would improve the attractiveness of such policies. A lesser improvement would be to remove the cap on premium deductions.

Work Force

The long-term care workforce in Massachusetts is composed primarily of nurses, certified nursing assistants, home health aides, and home care workers. These workers perform the majority of paid, hands-on care for elders across the care continuum. Each job category has its own education and training requirements, which are mandated by state and federal laws and regulations.

Over the past several years, there has been an increasing shortage in the number of long-term care workers. The reasons for this are complex. Long-term care work is physically and emotionally demanding, with a high rate of on-the-job injuries. The hours are long, and worker shortages often require existing staff to work overtime. The pay scales are low, particularly for paraprofessional workers, and job-related benefits such as health insurance are either not offered or are too expensive to purchase. In addition to these issues, paraprofessional workers often are frustrated by a lack of support and respect in their jobs and their perception that their input into patient care is not valued. All of this contributes to a relatively high turnover rate and a chronic shortage of staff in nursing homes and home health care. The shortage of trained workers directly impacts family caregivers, who struggle to fill the gaps in their family members’ care.

The future increase in the Massachusetts elderly population will only worsen the worker shortage. The population of elders is projected to grow at a much greater rate than the population of caregiving age. This is particularly true of the 85+ segment of the elderly

population, who are most likely to need assistance with ADLs and other supports. By the year 2010, it is estimated that the demand for direct care long-term care workers will require 1,048,000 new workers. During the same period, the number of women in the age group most likely to perform this work will slow its rate of growth, leaving a job gap of at least 600,000 workers.⁶¹ Without significant changes, Massachusetts' elders will find it increasingly difficult to locate and receive long-term care.

Recommendations

- **Improve the wages and benefits of long-term care workers**

In recent years, the Massachusetts Legislature has authorized legislation increasing the wages of certified nursing assistants, home health and home care workers.⁶² This funding has been critical in improving the retention of paraprofessional health care workers. Yet wages are still low, with a mean hourly wage of \$12.06 for certified nurse aides, \$11.03 for home health aides and \$10.02 for home care aides.⁶³ In addition, a significant number of these workers have no health insurance or rely on MassHealth to provide coverage for their families.

Massachusetts needs to continue to increase the wages of long-term care workers until they receive a “living wage” that allows them to support their families. In addition, the Administration and the Legislature should continue to explore ways to expand access to health insurance for this segment of the workforce. This could occur by an expansion of the Insurance Reimbursement Program or by an expansion of state health insurance benefits to include long-term care workers. It could also occur as part of a comprehensive health care reform initiative aimed at reducing the current number of uninsured individuals in Massachusetts. There are many possible mechanisms for insuring this population, and the Administration as well as the Legislature should actively engage in seeking appropriate solutions.

- **Improve workforce retention by respecting and empowering workers**

One of the common complaints among paraprofessional long-term care workers is that they are not respected in the workplace. This manifests itself in strict hierarchical

decision-making, failure to include paraprofessionals in patient care decisions, and lack of flexibility to accommodate childcare and family issues. Combined with low wages, risk of injury, long hours, and limited training, this perception contributes to a constant turnover of workers and diminishes the quality of life and quality of care afforded to patients.

In recent years, health care professionals have begun to acknowledge and address these issues. A number of efforts are underway around the country to change the workplace and caregiving culture. Known as “culture change,” these efforts support worker retention through better teamwork and communication, better leadership and management practices, ways to include a greater role for paraprofessional workers in patient-care decisions and a change toward a more person-centered approach to caregiving. They also emphasize the importance of orientation and peer mentoring of new staff and of ongoing educational opportunities for experienced staff.⁶⁴

In Massachusetts, the Extended Care Career Ladders Program (ECCLI) is designed to improve hiring and retention rates of long-term care workers and thereby improve quality of care.⁶⁵ The ECCLI Program has funded various models of skills training and advancement for the incumbent workforce in long-term care and has incorporated some of the tenets of culture change. Unfortunately, funding for the ECCLI Program was vetoed by the Governor in the FY2005 Budget. The program should be refunded in the next budget cycle. In addition, the Administration should actively encourage the development of culture change in long-term care settings. This could be done by reviewing the efforts of other states and convening a task force of providers, workers, legislators, and Administration representatives to guide future efforts.

- **Address diverse culture issues within the long-term care workplace**

It is increasingly common for paraprofessional long-term care workers to come from diverse cultures. Often these workers have a primary language other than English. They may have cultural understandings about caregiving that differ from Anglo-European attitudes. Tensions may develop between white supervisors and workers of color, and

tensions may also surface between white patients and caregivers of color. All of these issues can contribute to poor job quality and diminished quality of patient care.

Adequate training is a key to lessening on-the-job tension and increasing mutual understanding of different cultural attitudes. Paraprofessional workers should be offered educational services including English as a Second Language and adult literacy training. Supervisors should be offered training in supervision skills with an emphasis on diversity issues. Both supervisors and workers should discuss how to interact appropriately with family members and how to handle bias or prejudice displayed by residents.

Affordability of training is key to addressing diversity issues. There are currently no programs funded by the state to support initial certification training or ongoing in-service training. Until this budget year, Massachusetts funded a Long-Term Care Scholarship Program for initial certification training of entry-level workers.⁶⁶ Unfortunately, the program was not refunded. The Administration and the Legislature should refund the Scholarship Program and identify and appropriate funding for expanded training for incumbent workers.

Personal Responsibility

The role of individual elders in meeting their own long-term care needs is a divisive topic. While most elders want to provide for themselves and their family members who need care, the escalating cost of long-term care often makes that impossible. In addition, the general public is often ignorant about the sources of coverage for long-term care and the attendant cost of private care. Many elders deny the unpleasant and threatening likelihood that they may need long-term care as their health deteriorates. All of these factors result in a significant number of elders and family members who do not plan for their long-term care needs and are rapidly impoverished when those needs arise.

Middle-income, working class elders are most affected by this problem. Medicaid covers lower-income elders with limited assets, while wealthy elders can pay privately for long-

term care. Those in between face unpleasant choices. If they do not seek planning advice, an unplanned nursing home stay can quickly exhaust their assets. What is worse, they may find themselves ineligible for Medicaid nursing home care because they unwittingly violate transfer of asset rules. If they do plan to conserve financial resources, they may be accused of “hiding assets” in order to qualify for Medicaid nursing home care.

For many elders, the only available alternative to Medicaid or private payment for long-term care is long-term care insurance. Yet this product is not suitable, affordable, or available to many individuals. Individuals who want to take responsibility for their own long-term care often have no way to do so.

Recommendations

- **Establish a public education program to encourage informed planning for the cost of long-term care**

Most education about long-term care planning is conducted by private entities. Financial planners, long-term care insurance brokers and estate-planning attorneys provide the bulk of information in Massachusetts, with some assistance from SHINE counselors, providers, and advocacy groups. The information available privately may be colored by the commercial interests of the supplier. There currently is no coordinated, ongoing public program that educates elders and families about the spectra of long-term care alternatives.

If Massachusetts is to meet the long-term care needs of its citizens, this must change. The Legislature should appropriate funding to support such a training program. The program should be coordinated by EOEA and should be part of the services provided by ASAPs and Councils on Aging. Ideally, the SHINE counselors and representatives of advocacy groups would have a role in developing and presenting the curriculum. Hopefully, an appropriate education program will help elders avoid making hasty and ill-informed decisions about how best to finance long-term care.

- **Help minimize long-term care costs by maintaining good health practices**

Another important component of planning for long-term care is education about health habits designed to maintain good health. Elders need information about such matters as healthy diets, exercise, preventive health care, and maintenance of health in the face of chronic illness. Unfortunately, today's medical environment does not always allow physicians the time to discuss such topics, and elders may be unaware of steps they could take to maximize good health.

There are programs currently available to help educate elders about good health habits. These programs should be strengthened and supported by state government (both the Department of Public Health and EOEA) in coordination with medical providers and advocacy groups. Councils on Aging and Senior Centers already provide health education programs and should be supported in their efforts. Senior housing and assisted living residences also present opportunities for elder health education.

Conclusion

The problems in our current long-term care system are numerous and complex. Because of the multi-part and incomplete nature of long-term care coverage, elders who seek services are often bewildered and unable to obtain the best care options. The system's inadequacies often result in excessive costs to government and consumers alike, while furnishing a quality of life and care that is less than optimal. We must do better.

The recommendations for improvement included in this report are modest and do not address the larger issue of the need for universal, affordable health care coverage for all Americans. Only a major overhaul of our health care system will cure the current problems of long-term care. However, we hope that consideration will be given to implementing some of these recommendations in anticipation of the aging of Massachusetts's citizens over the next few decades. If we do not begin now to plan for the future, we and our children will pay the price in years to come.

NOTES

- ¹ Kaiser Family Foundation, State Health Facts Online, 2002, at <http://www.statehealthfacts.kff.org>.
- ² AARP Public Policy Institute, “Across the States 2002: Profiles of Long-Term Care, Massachusetts.”
- ³ AARP, 2.
- ⁴ AARP, 2.
- ⁵ Bruce, Ellen and Shulman-Green, Dina, *Background Paper on Long-Term Care in Massachusetts* (2000), Gerontology Institute, University of Massachusetts Boston.
- ⁶ AARP, 2.
- ⁷ Kaiser Family Foundation, State Health Facts Online. Poverty estimates can vary depending on the year and data source utilized.
- ⁸ Gerontology Institute, University of Massachusetts Boston, *Housing in Massachusetts 2000: Characteristics of Householders and Homeowners Aged 65 and Over* (2004).
- ⁹ Kaiser Family Foundation, State Health Facts Online
- ¹⁰ Laschober, Mary, *Trends in Medicare Supplemental Insurance and Prescription Drug benefits, 1996-2001*, Kaiser Family Foundation, June 2004.
- ¹¹ Massachusetts Executive Office of Elder Affairs, enrollment information as of August 2004.
- ¹² Center for Medicare and Medicaid Services Data Compendium, 2003.
- ¹³ Massachusetts Senate Post Audit and Oversight Committee, *Crisis at Home: The Impact of Massachusetts’ Nursing Home Closures*, June 2003.
- ¹⁴ Kaiser Family Foundation, State Health Facts Online.
- ¹⁵ Mass-ALFA website at www.massalfa.org.
- ¹⁶ Mass-ALFA website as www.massalfa.org.
- ¹⁷ Conversation with Julie Deschenes, Home Health Association of Massachusetts, August 2004.
- ¹⁸ AARP, 2.
- ¹⁹ Fact Sheet prepared by Mass Adult Day Services Association, 2003.
- ²⁰ Conversation with Ellie Shea-Delaney, Department of Elder Affairs, October 2004.
- ²¹ For more information on ASAPs see www.800ageinfo.com.
- ²² Department of Elder Affairs website at www.mass.gov.
- ²³ Kaiser Family Foundation, State Health Facts Online.
- ²⁴ Massachusetts FY05 State Budget, Chapter 149 of the Acts of 2004.
- ²⁵ For general information on Medicare eligibility and services, see www.medicare.gov.
- ²⁶ Kaiser Family Foundation, Medicare at a Glance Fact Sheet at www.kff.org/medicare
- ²⁷ Kaiser Family Foundation, Medicaid at a Glance Fact Sheet at www.kff.org/medicaid
- ²⁸ For information on Massachusetts Medicaid eligibility for elders and institutionalized individuals, see generally 130 C.M.R. 515.00 et seq., 130 C.M.R. 520.00 et seq.
- ²⁹ 42 U.S.C. 1396p(c).
- ³⁰ Reester, Missmar and Tumlinson, *Recent Growth in Medicaid Home and Community-Based Waivers*, Kaiser Commission on Medicaid and the Uninsured, April 2004, online at www.kff.org.

-
- ³¹ Community Choices is a subset of the Home and Community-Based Waiver and serves almost 800 elders at “imminent risk” of nursing home placement. These elders are eligible for a richer package of services per individual than other waiver enrollees.
- ³² Kaiser Commission on Medicaid and the Uninsured, “The Role of Medicaid in State Economies: A Look at the Research” (April 2004) at www.kff.org.
- ³³ 42 U.S.C. s.1396r-5(c), (d).
- ³⁴ M.G.L. c.118E s.21A.
- ³⁵ 42 U.S.C. s.1396n(d)(1), 130 C.M.R. 519.007(B).
- ³⁶ Chapter 261 of the Acts of 2004.
- ³⁷ Section 317 of Chapter 26 of the Acts of 2003.
- ³⁸ 42 U.S.C. s.1396p(c)(1)(C).
- ³⁹ Kaiser Family Foundation, State Health Facts Online.
- ⁴⁰ Massachusetts Senate Post Audit and Oversight Committee, 10.
- ⁴¹ MADSA Fact Sheet “Massachusetts Adult Day Center Service Gaps.”
- ⁴² See generally M.G.L. Chapter 118G.
- ⁴³ Section 409 of Chapter 149 of the Acts of 2004.
- ⁴⁴ Information on the Senior Care Options waiver can be found at www.cms.hhs.gov/researchers/demos.
- ⁴⁵ Line item 4000-0600 of Chapter 149 of the Acts of 2004.
- ⁴⁶ Thompson, Lee, *Long Term Care: Support for Family Caregivers*, Georgetown University Long Term Care Financing Project, March 2004.
- ⁴⁷ Title III-E of the Older Americans Act, 2002 Amendments, 42 U.S.C. s.3030s-1.
- ⁴⁸ Center for Medicare and Medicaid Services, “Dollars Follow the Person and Balancing Long Term Care Systems: State Examples.”
- ⁴⁹ 211 C.M.R. 65.00 et seq..
- ⁵⁰ 130 C.M.R. 515.014.
- ⁵¹ 26 U.S.C. s.7702B(b), 26 U.S.C. 213(d)(10).
- ⁵² Georgetown University Long Term Care Financing Project, “Private Long-Term Care Insurance” Fact Sheet, May 2003, online at <http://ltc.georgetown.edu/pdfs/pltci-.pdf>.
- ⁵³ Georgetown University Long Term Care Financing Project, “Who Pays for Long Term Care?” Fact Sheet, July 2004, online at <http://ltc.georgetown.edu/pdfs/whopays2004.pdf>.
- ⁵⁴ Online at http://mass.gov/doi/Consumer/css_health_LTCCGuide.html.
- ⁵⁵ S.2415, An Act to Establish Standards for Long Term Care Insurance (2004).
- ⁵⁶ 130 C.M.R. 515.011.
- ⁵⁷ 130 C.M.R. 520.007(G)(8)(d).
- ⁵⁸ S.2077, H.R. 1406, Long-Term Care Partnership Program Act of 2004.
- ⁵⁹ 130 C.M.R. 515.001.
- ⁶⁰ See endnote 51.
- ⁶¹ Citizens for Long-Term Care, “Long-Term Care Financing and the Long-Term Care Workforce Crisis: Causes and Solutions,” January 2003.
- ⁶² Section 409(3) of Chapter 149 of the Acts of 2004.
- ⁶³ Bureau of Labor Statistics, Massachusetts Occupational Employment and Wage Statistics, Health Support Occupations, May 2003.
- ⁶⁴ For information on culture change models of long term care, see the Commonwealth Fund web site at www.cmwf.org.

⁶⁵ Section 620 of Chapter 26 of the Acts of 2003.

⁶⁶ Line Item 4510-0720 of Chapter 26 of the Acts of 2003.

REFERENCES

AARP Public Policy Institute (2003). *Across the States 2002: Profiles of Long Term Care, Massachusetts*.

Bruce, E. & Shulman-Green, D. (2000). *Background Paper on Long Term Care in Massachusetts*. Gerontology Institute, University of Massachusetts Boston.

Citizens for Long-Term Care (2003). *Long Term Care Financing and the Long Term Care Workforce Crisis: Causes and Solutions*.

Georgetown Long-Term Care Financing Project (2003). Private Long-Term Care Insurance. Fact Sheet (May), online at <http://ltc.georgetown.edu>.

Georgetown Long-Term Care Financing Project (2004). Who Pays for Long-Term Care? Fact Sheet. (July). Online at <http://ltc.georgetown.edu>.

Gerontology Institute, University of Massachusetts Boston (2004). *Housing in Massachusetts 2000: Characteristics of Householders and Homeowners Aged 65 and Over*.

Kaiser Family Foundation (2002). State Health Facts. Online, at <http://www.statehealthfacts.kff.org>.

Kaiser Commission on Medicaid and the Uninsured (2004). The Role of Medicaid in State Economies: A Look at the Research (April). Online at www.kff.org.

Laschober, M. (2004). *Trends in Medicare Supplemental Insurance and Prescription Drug Benefits, 1996-2001*. Kaiser Family Foundation (June).

Massachusetts Division of Insurance. *Financing Long-Term Care: Your Guide to Long Term Care Insurance*. Online at http://mass.gov/doi/Consumer/css_health_LTGuide.html

Massachusetts Senate Post Audit and Oversight Committee (2003). *Crisis at Home: The Impact of Massachusetts' Nursing Home Closures*. (June).

Reester, Missmar, & Tumlinson (2004). *Recent Growth in Medicaid Home and Community-Based Waivers*. Kaiser Commission on Medicaid and the Uninsured (April). Online at www.kff.org.

Thompson, L.. (2004). *Long-Term Care: Support for Family Caregivers*. Georgetown University Long -Term Care Financing Project (March) Online at <http://ltc.georgetown.edu>.