The Study Group on Long Term Care Options in Maine

A Final Report and Recommendations

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NATIONAL ACADEMY
for STATE HEALTH POLICY

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The Study Group on Long Term Care Options in Maine

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A Final Report and Recommendations

I. Who We Are

The Study Group on Long Term Care Options in Maine is a group of interested citizens brought together by the National Academy for State Health Policy at the request of the UNUM Foundation to discuss how Maine provides long term care services to people in need. Because all of us could need long term care if we experience an accident, chronic illness, unexpected birth outcome, or the frailties that come with age, it is important that citizens learn about, discuss and guide how the current system of care will serve them. We are not experts on long term care but individuals without a specific agenda or organizational viewpoint to advance. We were invited to participate in the Study Group because of our knowledge of Maine and our ability to think creatively about complex issues. We are from all over the state from Portland to Presque Isle. We see ourselves as potential consumers of long term care, and so bring the voice of the community to some of the issues that policy officials struggle with in financing and delivering a complex array of services to a diverse population.

II. The Charge of the Study Group

The 14 member Study Group was brought together for two purposes:

- To learn about Maine’s long term care system and bring a “common sense” citizen perspective to the discussion.
- To make recommendations for future philanthropic project support that reflect that citizen perspective and improve the long term care system.

III. How We Learned about the Long Term Care System

The Study Group met several times throughout 1994 to learn about who needs long term care in Maine, how they are currently served, and how experts on the cutting edge of service delivery are creating long term care innovations across the nation.

- In three meetings with experts on Maine’s long term care system, the Study Group learned about some of the services available to the elderly, people with
physical disabilities, people with developmental disabilities, and people with mental illness. Administrators, consumers and their advocates, and providers from both public and private programs shared their experiences with us and shed light on how difficult it can be to deliver services to such a diverse population in need of long term care services.

- The Study Group also met with consumers of long term care services to get a personal view of what works and what doesn’t in Maine’s service system. We were able to ask direct questions of consumers who use chronic care services as a part of their daily lives. Out of these discussions, we gained an understanding of the day-to-day needs of people with disabilities and how the current system either helps or hinders how they obtain services.

- To inform our work, the National Academy published *Helping Vulnerable Citizens in Maine: A Sourcebook on Long Term Care Programs and the People they Serve*. This book describes the numbers of people in Maine who need long term care services, the different programs available to them, and the costs of these programs.

- Three symposia, attended by over 250 people, were also organized for us and the general public by the National Academy that showcased successful innovations in long term care from around the nation. We were able to see how some states have been able to provide the services that consumers want within tight fiscal constraints. Open discussion during these meetings always focused on lessons for Maine’s system.
IV. What We Learned

Throughout 1994, the Study Group reviewed the available data on Maine’s long term care users, services, and expenditures and found:

- By long term care, we mean a combination of social and medical services that allow the individual to obtain or maintain the highest level of independence possible. It encompasses all aspects of the individual’s life including housing, nutrition, transportation, education, vocation, and health.

- Long term care is needed by a wide array of citizens, young and old, rich and poor.

- Over one-fifth (250,300) of Maine’s population currently is in need of some type of long term care service.
  - 67,900 people over 65 have some need for support ranging from help with household chores to skilled nursing care.
  - 105,400 people under 65 have some type of physical disability preventing them from working or from caring for their personal needs.
  - About 12,000 people in Maine have mental retardation or developmental disabilities.
  - 65,000 adults in Maine have some type of mental illness ranging from non-recurrent depression to persistent and severe mental illness. 14,000 children in Maine have severe emotional disturbances.

- The vast majority of people who need long term care live in the community. At any given time, there are about 10,000 people in institutions in Maine (nursing facilities, boarding care homes, state mental institutions, and institutions for the developmentally disabled). This is only about 4% of the population who need some type of long term care service.

- The relationship between disability and poverty is strong. Poverty can lead to ill-health, and disability can lead to job loss and spending many resources on health care. The prevalence and severity of disabilities increase as income decreases. This means that many people with chronic care needs must rely on government funded programs for income, housing, and medical care.

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1. These data are found in Helping Vulnerable Citizens in Maine: A Sourcebook on Long Term Care Programs and the People They Serve, prepared by Kimberly Irvin Snow and Trish Riley, National Academy for State Health Policy. September 1994.
National data indicate that Medicaid and out-of-pocket expenditures account for most of the spending on long term care. Many people believe that Medicare pays for long term care. The chart below indicates that Medicare accounts for only 18% of total long term care expenditures. Most of Medicare long term care expenditures are for home health care services, not nursing home care.

National Spending on Nursing Home and Home Care Services Combined, by Payment Source, 1993.
Total Spending = $75.4 Billion

Other Payers 3%

Medicaid 34%

Patient Out-of-Pocket 45%

Medicare 18%

Note: Other payers include state and local expenditures, social services block grants, Older Americans Act and Department of Veterans’ Affairs home care funds, charity, and out-of-pocket expenditures by people other than the service recipient.


• When individuals need help in paying for long term care, Medicaid is the largest single payer. In Maine, Medicaid pays for 80% of all nursing facility residents. Nursing facility care is the single largest expense of the Maine Medicaid budget.
While most people with chronic care needs live in the community and many of them rely on public programs for care, most Medicaid funds are spent on institutional care. In Maine's Medicaid program, 87% of spending on long term care services is for institutional care.

**ME Medicaid Spending on Institutional and Non-institutional LTC Services by Category FY93**

- Nursing homes: 69%
- ICF/MR: 13%
- Inpatient mental health: 5%
- Personal care services: 1%
- Home and community based waivers: 9%
- Home health services: 3%

Source: Data are from the Bureau of Medical Services, Medicaid Annual Report 1992-1993, Maine Department of Human Services.
While 33% of enrollees in Maine's Medicaid program are elderly or disabled, they account for 86% of expenditures.

Maine Medicaid Beneficiaries by Eligibility Status, FY93

Source: Bureau of Medical Services, Maine Department of Human Services, 1995. Data are from HCFA Form 2082.

Maine Medicaid Spending by Eligibility Status, FY93

Source: Bureau of Medical Services, Maine Department of Human Services, 1995. Data are from HCFA Form 2082.

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• Spending on long term care services is a large part of the total Medicaid budget. Maine spends more of its Medicaid budget on long term care than most other states.

Medicaid Expenditures by Service Category, National and Maine Data, 1992

Other Acute Care

Inpatient Hospital

Long Term Care

Source: National Academy for State Health Policy, January 1994
State general funds for long term care also favor the institutional setting. Two-thirds of the $75 million budget for mental health--most of which is general funds--is dedicated to the Augusta Mental Health Institute and the Bangor Mental Health Institute. These facilities serve about 1000 people per year. The remaining one-third of the budget is spent on community service contracts for serving about 35,000 people around the state.

**Diagram:**

**ME Mental Health Community and Institutional Expenditures, FY93 Total = $75M**

- BMHI: 33%
- AMHI: 34%
- Community Services: 33%

*Source: Data obtained by facsimile and telephone correspondence from the Maine Department of Mental Health and Mental Retardation, 1994*
The data show that long term care is a large part of the state budget and that much of the money is spent on institutional services while most people with chronic care needs live in the community. While the residents in institutions are arguably the most severely disabled and thus are more expensive to care for, evidence from home and community based service waiver programs indicate that people who meet the functional impairment levels for nursing home care can be served for the same or less money in the community. There is also a lack of information about what services are available in the community.

- **Like many states, Maine has a fragmented long term care system with no centralized location for information and services.** In Maine, a person in need of long term care services may have contact with over 10 different public agencies depending on his or her age and specific disability. But, people with long term care needs may also see a variety of private professionals in physicians’ offices, emergency rooms, home health agencies, and other sources of services. Coordinating the services from all these agencies and providers so that all needs are met takes patience, persistence and resources.

- **Informal caregivers provide thousands of hours of “free” care to loved ones with chronic care needs, making up for some of the deficiencies in the formal care system.** The costs of this care appear in lost workdays, forced part-time employment, and lost jobs of the caregivers, most of whom are women and are already poor themselves. Studies have shown that four out of five caregivers average 4 hours a day, 7 days a week of providing care.

The information from both hard data sources and consumers has helped the Study Group to understand how Maine’s long term care system works today. With this big-picture view of the system in mind, we have been able to make some conclusions about how long term care reform should be guided in the future.
V. Vision for Long Term Care in Maine

When disability strikes us or a family member or friend, we want and need support that is easy to access and allows us and our families to continue to function as independently as possible. Because what is normal for one is not for another, services need to respond to different expectations and aspirations, supporting not supplanting a variety of informal care arrangements. There are, of course, some financial and practical limits to how individualized services can be provided. But, based upon its work, the Study Group believes there are core values grounded in preserving individual dignity that should guide long term care reform. Through discussing what we have learned about what consumers want and need from a long term care system, and using our own judgment as citizens and potential consumers of long term care, we conclude that an effective long term care system must be rooted in these values:

- Respect for the dignity of the individual
- Independence
- Preservation of self-esteem and the values of the individual
- Participation in the community
- Quality of life that balances the risk and safety of the individual
- Comprehensive care which meets the social, physical and mental health needs of consumers
- Access to appropriate and consistent services and support where people live
- Informed choice

Respect for the dignity of the individual This over-arching value cannot be sacrificed in any long term care reform. Consumers need a reliable and consistent service system they can trust and one which respects their individuality and dignity and trusts their judgments.

Independence Services for people with chronic care needs should foster optimum independence. Maintaining a person’s ability to live independently is just one way that this can be done. Choices in care planning and recreational activities must be maintained even when formal care is required.

Preserving self-esteem and the values of the individual The values of people in need of long term care should not be overlooked by the service system. A person’s self-esteem and values will affect how he or she will accept services and from whom. Providing services to people with chronic care needs in a way that makes them feel deficient due to a disability will ultimately destroy self-esteem and hinder the person’s ability to accept those services. Respect for the individual’s self-esteem and values should be maintained in providing services.
Participation in the community  People with long term care needs are still members of families and communities and ought to remain active in them as they choose. Community involvement does not necessarily mean civic leadership, but rather participation in activities that maintain a person's sense of belonging in the community. Such activities can be as simple as shopping, going to the movies, reading the newspaper, or going to church.

Quality of life that balances the risk and safety of the individual  Services for people with chronic care needs often emphasize the providers' needs for liability control rather than the consumers' needs for freedom. For example, consumers of home care services indicate that privacy and personal dignity are important criteria in judging the quality of services, while providers express concern for consumer safety and security. Providers also indicate that they are responsible for determining consumer need and that they can rely on observation rather than direct communication to do so. Service delivery reform needs to close this gap between what consumers and providers believe about quality.

Comprehensive care which meets the social, physical and mental health needs of consumers  People must be treated as complete individuals, not as cases or conditions. A person's physical and mental health will affect how easy it is to maintain social relationships. And social relationships can often make it possible to maintain one's health, as families and friends provide countless hours of informal care, and as the consumer of care remains a valued and active participant in family and community life. Long term care services need to support the whole person.

Access to appropriate and consistent services and support where people live  Access to services involves much more than just the presence of services. Is the service provided in a way that people with chronic care needs can physically access it? Is the service provided at times and locations that are convenient for the consumer? For example, a home health agency that does not provide services at night or on weekends may not be accommodating the needs of consumers. Are there enough services to go around? In Maine, many of the public services have waiting lists that are based on the severity of need. This leads to an emphasis on crisis care rather than preventive care. Is the service affordable? Is the service what people want? As the data show, the emphasis in spending has been on institutional services, while people with chronic care needs overwhelmingly prefer community based services. Some people need services that are available in some type of institutional setting, but a person should not have to enter the institution in order to receive services when he or she could live in the community. This value centers on providing the right services that people want and need in the location of their own choosing within reasonable fiscal constraints.

Informed choice  People in need of long term care make a variety of decisions every day that affect how they receive services and from whom. However,
sometimes the system denies consumers and their families adequate choice. While some programs allow consumers to choose their own personal care attendant, other programs do not. Likewise, some people may not be aware of existing services in the community, and therefore enter the nursing facility when they would not otherwise do so. New Medicaid regulations require that recipients be informed of all services to help avoid this problem. People should be able to make decisions that affect their daily lives. The long term care system as a whole should provide appropriate opportunities for decision-making by the individual. A system that does not allow individuals to participate in decision-making tells people with chronic care needs that it does not trust or respect them.

With these values in mind, we have developed a vision for future long term care reform. Through promoting these values, we believe that the following vision will be achieved.

Maine citizens will be supported to live with
dignity in the setting of their choice.

VI. Conclusions About Maine’s Long Term Care System

This vision for Maine’s long term care system reflects what the Study Group has learned about how care should be delivered. It shows how we wish to be treated if and when we become disabled. We want to build a system that we would feel comfortable being served by and to which we would entrust the care of our loved ones. It reflects the conclusions of a representative group of citizens looking at what kind of system we would like for ourselves, our families and our neighbors. Each of the values presented above relate to elements of the system that we have found to be either lacking or incomplete. Specifically, these findings are:

A. The system is complex and fragmented. Different services are organized by population served, region, funding source and service type. A simplified, localized and coordinated approach to comprehensive care (“one stop shopping”) is required for all persons with chronic care needs.

B. Current systems of information, referral and outreach do not work well; consumers and their families do not know where to turn for information and advice. A centralized, local resource is needed to connect all people with chronic care needs to information, support and services.

C. The system of care is over-reliant on institutions although consumers and their families consistently seek community based care.

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D. The system minimizes choice and has little tolerance for risk, favoring professionally defined protections of individual safety over consumer choice.

E. Informal caregivers need to be better recognized and supported, but caregiver support groups are not a panacea. They sometimes create more stress and do not and likely will not reach all caregivers.

F. The state needs consistent, long term leadership to advance responsive and effective policies and programs of support for people with chronic care needs.

G. No consensus exists about workforce needs and levels of training and supervision required of home care workers. Just as individuals in need of care have different needs and capacities, so the workforce should be varied to support informal caregivers, families, consumer directed personal care assistants, and professional workers, and all should work in teams with the consumer, together assuring quality of care. Incentives must be developed to create such an adequate and varied workforce.

H. It appears that each time a problem is identified by people with chronic care needs, a new program or agency has been created, thus fueling fragmentation and confusion.

I. Particularly in times of fiscal restraint, services need to be cost effective. But measures of effectiveness and efficiency need to balance human need with cost constraint.

J. Technological advances need to be better monitored, understood and made available.

K. Individuals, families, and the state and Federal governments are spending significant resources on long term care, yet still some consumers are not getting the services they need. The “Medical Model” of health care has dominated the service delivery system, focusing on treating people as discrete cases of illness rather than as complete individuals. Money appears to be largely misdirected and should be reoriented to support individual plans of care, not providers and “units of service”. The measure of expenditure ought to be on the outcome it achieves, not the number of hours spent or the activity conducted.
VII. Recommendations

The Maine Study Group on Long Term Care makes the following recommendations designed to assist the UNUM Foundation and other grant makers determine funding priorities. It was not the charge of this group to make broad policy suggestions, but rather to help private philanthropic and governmental entities identify appropriate niches for funding which might advance the vision of long term care reform identified by the citizen study group. We have made these recommendations based on our values and vision for Maine’s long term care system.

A. Laying the Groundwork for Change

1. Establish an on-going forum of key stakeholders (consumers, elected and executive branch officials, providers, media, criminal justice officials, educators) to implement the vision contained in this report. Topics to be addressed by the forum would include but not be limited to:
   
a. Developing methods to increase the availability of preventive care to forestall or avoid disability wherever possible

   b. Identifying policy and financing barriers impeding the functioning of informal caregivers and propose solutions to strengthen the quality and quantity of informal care through educating caregivers on effective care strategies

   c. Creating a guide to state programs and expenditures for people with chronic care needs

2. Fund an independent Coalition for Long Term Care, on the model of the Maine Coalition for Excellence in Education, and empower it to hire a full-time director to promote the vision of long term care reform and guide change.

3. Fund community-based collaborations to conduct long term care assessments, reviewing community resources and policies to determine how people with chronic care needs are served. Based upon the assessments, fund related, innovative community-based demonstrations which foster consumer and family centered non-institutional care, use technology creatively, and develop interagency collaborations to generate new approaches to service delivery.

4. Support municipalities to include issues of people with chronic care needs in comprehensive and/or regional planning efforts.
5. Educate legislators about long term care issues through a series of seminars and meetings which include active consumer participation.

6. **Learning More About People with Chronic Care Needs and the Long Term Care Service System**

   Underwrite a study of the impact of changing demographics on service demand, supply, and costs and create an annual long term care indicators report.

7. Fund a study to identify regulatory and statutory barriers that prevent the development of flexible, coordinated, consumer based services and recommend regulatory and statutory reforms.

8. Finance the examination of models of managed care which serve people with chronic care needs and issue a report with recommendations for Maine.

9. Conduct a study of the use of advanced directives and living wills by people with chronic care needs to determine the prevalence of their use and the consistency with which they are followed by medical providers.

C. **Building “Consumer Friendly” Services for the Telecommunication Age**

10. Develop and maintain an interactive, computerized information and referral system for all persons with chronic care needs; then conduct an evaluation of the system to determine whether people were served and identify policy and programmatic obstacles that restricted service. Model systems that build on the strengths of existing consumer bulletin boards such as the Maine Meeting Place and that use consumers to staff the systems should be given preference for funding.

11. Fund innovative uses of interactive television to link providers, consumers and caregivers for peer support and for consultations with experts in mental health, disability, geriatrics and related specialty expertise not readily available in much of Maine.

12. Fund demonstrations that incorporate a single, computerized, patient record for all service settings.

13. Fund the creation of new approaches to quality assurance which are consumer oriented, measure the satisfaction of consumers and address the outcomes of care provided, including outcomes which focus on the quality of life not just the adequacy of individual services.
FACT SHEET

The National Academy for State Health Policy (NASHP) was formed in 1987 to provide a multi-disciplinary forum for the timely examination of complex health policy issues affecting states. The Academy provides a non-profit forum for leading state health policy officials to exchange insights, information and experience, and to develop practical solutions to problems confronting states.

The Academy recognizes that responsibility for health care does not reside in a single state agency or department and provides a unique forum for productive interchange across both department and agency and executive and legislative lines of authority. Steering committees of volunteers from various executive branch agencies, state universities and legislatures play a key role in identifying the Academy’s agenda and in developing innovative and effective strategies to improve the delivery and financing of health care. The Academy links policymakers with practical and useful policy research through affiliation with three universities, University of Southern Maine’s Muskie Institute, Brandeis University’s Institute for Health Policy and University of Minnesota’s Long Term Care Center.

The Academy convenes forums and workshops; provides technical assistance to states; and develops and distributes publications and analysis. Current programs include:

Annual State Health Policy Conference
Held each August, the conference is a unique collaboration of key policy makers examining cutting edge issues and best practices.

Health Reform Initiatives
The Academy analyzes state and Federal health reform, works with the academic community to help expand primary care capacity and provides support to states in implementing reform. Through a subcontract with the Research Triangle Institute, the Academy assists HCFA and states with 1115 waiver programs.

National Long Term Care Resource Center
Co-sponsored with the University of Minnesota and funded by the Administration on Aging, the Center provides technical assistance and policy analysis to states in all areas of long term care policy and practice.

Center for Vulnerable Populations
Co-directed with Brandeis University, and funded by the Henry J. Kaiser Family Foundation, the Center conducts research and policy analyses, examines best practices for vulnerable populations and aggressively disseminates the results.

Medicaid Managed Care Resource Center
Supported primarily by The Pew Charitable Trusts, the Resource Center places special emphasis on the needs of key groups of Medicaid enrollees: women, children and the elderly. The Center creates a centralized source for technical assistance to states.

For more information about the Academy or to order publications, please contact the Academy at 50 Monument Square, Suite 502, Portland, Maine 04101, 207-874-6524, fax: 207-874-6527.