Long Term Care Dilemmas: Perceptions and Recommendations

Final Report of the
Governor's Task Force on
Long Term Care for Adults

October 1980

LONG TERM CARE DILEMMAS:
PERCEPTIONS AND RECOMMENDATIONS

FINAL REPORT TO

THE HONORABLE JOSEPH E. BRENNAN
GOVERNOR OF THE STATE OF MAINE

BY THE

GOVERNOR'S TASK FORCE
ON LONG TERM CARE FOR ADULTS

OCTOBER 1, 1980

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ON LONG TERM CARE FOR ADULTS**

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MICHAEL R. PETIT
Commissioner

October 1, 1980

The Honorable Joseph E. Brennan
Governor of Maine
State House
Augusta, Maine 04333

Dear Governor Brennan:

I am pleased to submit to you "Long Term Care Dilemmas: Perceptions and Recommendations," the final report of the Governor's Task Force on Long Term Care for Adults. The report, which includes 50 recommendations for your consideration, is a distillation of facts and perceptions of facts expressed, collected and examined over the past year by the 32 members of the Task Force.

You will see that several of the recommendations would involve considerable funding. Please be assured that the Task Force is fully aware of the stark financial situation, which is unlikely to improve in the near future. The Task Force believes that its recommendations would result in more efficient and effective use of our tax dollars.

It cannot be over-emphasized that the work of Diana Scully as Director has been the guiding force for the report and the year long activities of the Task Force. Not once during sessions, which at times have been hectic, has this talented lady shown the slightest bias. Although the guiding principles have been enunciated by the membership, the composition and organization of the report reflect the craftsmanship of Diana Scully. Diana's work and that of her staff, as well as the dedicated service of those on the Task Force who come from the Departments of Human Services and Mental Health and Corrections, give us a very real source of pride in the personnel of our State Government.

On behalf of the Task Force, I thank you for the opportunity you have given us to undertake the first cross-cutting analysis of long term care in Maine and, perhaps, in the Nation. We hope that our report will be helpful to you and members of your Administration.

Sincerely,

Peter Mills

Peter Mills
Chairman

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The Task Force offers a special thank you to Alex Comfort, M.B., Ph.D., and Mrs. Jane Comfort for their expert advice and words of encouragement.

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PRIORITY RECOMMENDATIONS

Among the 50 recommendations in "Long Term Care Dilemmas: Perceptions and Recommendations," the Task Force established priorities of three different types: funding priorities, legislative priorities, and priorities requiring neither immediate funding nor legislation. The Task Force established no order among its priorities.

FUNDING PRIORITIES

The Task Force voted to establish twelve funding priorities for action by the Governor and the 110th Maine State Legislature.

Optional Services. There should be new money in the amount of three percent of the State's share of the Medicaid budget for fiscal years 1982 and 1983 appropriated for optional services not presently paid for under the State Medicaid Program, including especially but not necessarily solely in-home and community support services. State officials and lawmakers should begin to view Medicaid as a useful element which not only helps finance Maine's long term care services, but also contributes to Maine's economy. (Recommendation #35)

Services in Facilites. Boarding care facilities, including group homes and transitional living facilities, should be eligible sites under the State Medicaid Program for the delivery of physical and occupational therapy services. Activity coordinators in boarding care facilities should have increased responsibilities and greater pay, commensurate with these responsibilities. Intermediate care facilities should be reimbursed under the State Medicaid Program for repetitive physical and occupational therapy services. (Recommendations #22, #23 and #30)

Ombudsman Program. There should be funding for one additional, full-time professional position for the Nursing/Boarding Home Ombudsman Program (which brings the total number of positions to two), in order to carry out fully responsibilities required by state and federal laws. (Recommendation #50)

Respite Care. Homemaker and home health agencies should receive funding to provide in-home respite care services. Some boarding care facilities and intermediate care facilities should be reimbursed for keeping an extra bed or two for respite care services. Some adult foster homes should be reimbursed to provide respite care services. A few individuals sould be licensed to rotate among group homes and transitional living facilities, in order to provide respite care to operators of these facilities. "Respite care" means emergency care to meet immediate and critical needs or periodic care to enable

caretakers and individuals being taken care of to have a rest from the constant pressures and demands of their respective roles. (Recommendation #4)

Employment. For each disabled individual who becomes employed on a full-time basis, Supplemental Security Income benefits should continue for a transitional period, and Medicaid eligibility should continue on a permanent basis. (Recommendation #30)

Training. Training programs for aides in skilled nursing, intermediate care, and boarding care facilities and in-home health and homemaker agencies should be considered a reasonable cost item. Aides should be reimbursed for the costs only after they have worked in a facility or agency for a specified period of time. Operators of boarding care facilities should be required to take an 80-hour course for which they will be reimbursed only after they have worked in a facility for a specified period of time. There should be increased training of staff in various settings regarding the mental health needs of the elderly. Intermediate care facilities should be reimbursed under the State Medicaid Program for consultant services of physical and occupational therapists for staff training about safety procedures and care of residents. (Recommendations #45-#48)

Adult Protective Services. There should be increased staff and funding for the Division of Adult Protective Services, Department of Human Services. (Recommendation #6)

Family Subsidies/Tax Credits. There should be incentives in the form of tax credits or vouchers to families who provide in-home care to elderly or disabled family members. (Recommendation #14)

Aftercare Services. The Department of Mental Health and Corrections should have statutory authority and receive funding to provide for an indefinite length of time, depending on need, aftercare services to all individuals who have been discharged from the state mental health institutes. (Recommendation #7)

Personal Care Assistants. The State Medicaid Plan should be amended to reimburse for personal care assistants, whether or not they are employed by agencies. (Recommendation #1)

Wages; Benefits. Wage levels near the lower end of the wage scale and fringe benefits for employees of long term care facilities and agencies in the private sector should be similar to wage levels and fringe benefits for similar positions in the public sector. Improved wages and benefits for private sector employees should not result in loss of positions or decreased availability of long term care services. (Recommendation #45)

Profit. There should be greater profit for proprietary skilled nursing, intermediate care and boarding care facilities which provide quality long term care services efficiently and effectively. There should be "profit" for nonproprietary facilities and agencies which do the same. The ceiling on payments to boarding care facilities should be removed. (Recommendations #36 and #38)

LEGISLATIVE PRIORITIES

The Task Force voted to establish six legislative priorities for action by the Governor and the 110th Maine State Legislature. (Some of these recommendations also involve funding.)

Residential Services Act of 1981. The Governor should submit to the Legislature a bill to amend existing licensing statutes, in order to establish new categories or residential services and to specify standards for each category. The standards should address the particular needs of the types of individuals who reside in the facilities licensed pursuant to each category. (Recommendation #26)

Residents' Rights Act of 1981. The Governor should submit to the Legislature a residents' bill of rights which includes an enumeration of rights, anti-discrimination provisions, and limits on admissions to long term care facilities in emergency situations. (Recommendation #50)

Licensure of Home Health Agencies. The Governor should submit to the Legislature a bill to require licensing of all home health agencies, including both proprietary and nonproprietary agencies. (Recommendation #33)

Rate Setting Commission. The Governor should submit to the Legislature a bill to establish an independent commission, responsible for establishing rates for all long term care services purchased with public dollars. (Recommendation #40)

Study of Reasonable Costs. The Governor should urge the Legislature to undertake a study of what constitutes "reasonable" costs in the area of long term care services. The Legislature should develop statutory standards for defining "reasonable." (Recommendation #36)

Rating System. The Governor should submit to the Legislature a bill to institute a rating system for intermediate care and boarding care facilities. The rating system should be based on types, severity and duration of deficiencies in facilities. Ratings should be published in a readily available directory of licensed facilities and should be clearly stated on the licenses of facilities, which should be displayed openly in the facilities. (Recommendation #31)

OTHER PRIORITIES

Finally, the Task Force established seven priorities, requiring neither funding nor legislation.

Single Plan. There should be a single State Long Term Care Plan. This Plan should be updated every two years. Staff of both the Department of Human Services and the Department of Mental Health and Corrections should participate in developing and updating the Plan. (Recommendation #27)

Medicaid Plan. The State Medicaid Plan should:

- Define, precisely and concisely, the goals and objectives of the State Medicaid Program;
- Describe changes in the State Medicaid Program which are proposed for the period covered by the current plan and which have occurred since the previous plan;
- Include a summary of financing, regulatory and program options available to the State under the federal Medicaid law and regulations, and a determination of which options are appropriate for meeting the long term care needs of Maine's citizens;
- Identify sources of state and local dollars which can be matched with the federal Medicaid dollars;
- Analyze the costs of the State Medicaid Program, broken down by category, age and geographic location of individuals served, by type of service provided and by type of provider; and
- Be updated every two years, with active ongoing participation by consumers and providers. (Recommendation #28)

Case Management. Case management should be available to, though not required for, all Maine citizens with long term care needs. Case management should be developed incrementally, building on the strengths of processes already in place. The Commissioner of Mental Health and Corrections should appoint representatives from the Bureaus of Mental Health and Mental Retardation and the Commissioner of Human Services should appoint representatives from the Bureaus of Maine's Elderly, Rehabilitation, Resource Development, Medical Services, and Health Planning and Development to participate in the development of compatible case management plans. The Governor should appoint a representative of the Maine Health Systems Agency to participate. "Case Management" is defined as a flexible process which includes assessment of the long term care needs of individuals, arrangement for or direct provision of services to meet the needs, and monitoring and coordination of the services. (Recommendation #29)

Housing. "Section 8" existing housing units should be allocated on the basis of need. (Recommendation #18)

Sliding Fee Scales. Sliding fee scales should be used as widely as possible to enable more individuals to receive long term care services. (Recommendation #30)

Relationship between State and Providers. The Department of Human Services should take the following steps with respect to agencies and facilities from whom it purchases services:

- Make advance payments to agencies and facilities. (Hospitals currently receive advance payments.)

- Reduce delays in payments.

- Drop the 90 percent occupancy requirement for determining payment rates for skilled nursing, intermediate care and boarding care facilities.

- Make changes in its current approach to contracting and auditing services. (Recommendation #36, #39 and #41)

Quality of Life. The Department of Human Services and the Department of Mental Health and Corrections should modify regulations which direct and affect the planning for, financing of and provision of long term care services, so that the regulations focus on the quality of life of consumers of long term care services, rather than solely on the operational aspects of the services. (Recommendations throughout the Report)

PREFACE

The purpose of this Report is to pull together for the Governor and interested Maine citizens, the findings and recommendations of the Governor's Task Force on Long Term Care for Adults.

Part One of the Report describes the nature of the Report; the reasons for and responsibilities, members and procedures of the Task Force; the economic, political and legal contexts from which policymakers and taxpayers must begin to consider long term care; the individuals who need long term care; and the definition and principles of long term care.

Parts Two through Eight of the Report are all organized in the same manner. Each Part consists of several recommendations. After each recommendation the Task Force states its major findings and describes the situation and issues underlying the recommendation. Parts Two through Eight include recommendations in the following general areas: in-home and community support services; residential services; planning for and coordination of long term care services; regulating long term care services; financing long term care services; employees involved in the provision of long term care services; and discrimination against and advocacy on behalf of consumers of long term care services.

PART ONE:
INTRODUCTION

THIS REPORT

Purpose:

The purpose of "Long Term Care Dilemmas: Perceptions and Recommendations" is to pull together and justify for Governor Joseph E. Brennan and citizens of the State of Maine the many findings and recommendations developed in one year by the Governor's Task Force on Long Term Care for Adults.

Perceptions:

Readers may be surprised or disappointed as they realize that the very real consensus achieved by the Task Force and reflected in this Report is based on few definite facts. Consensus has been reached, more often, on the basis of perceptions of facts, rather than on the basis of facts themselves. This has been inevitable, because in the field of long term care, the hard facts bearing on the most crucial issues have not yet been assembled in a manner acceptable to all. Where knowledge is lacking, broad consensus based on perceptions is an honest best try.

The Task Force has discussed its findings and recommendations with scores of Maine citizens at numerous meetings and hearings. The Task Force has learned that its perceptions are widely held throughout the State. Indeed, the Task Force's perceptions are widely held throughout the United States: Its major findings and recommendations are within the mainstream of current thinking, nationally.

Important "First":

Readers should understand that Governor Brennan's appointment of this Task Force has resulted in an important "first" in the State of Maine and, perhaps, in the entire United States. This Report is the first examination of long term care services in a broad, cross-cutting manner. Typically, long term care has been analyzed from the point of view of a particular type of client group, a particular type of provider of care, or a particular governmental program responsible for a particular aspect of long term care. The Task Force has studied long term care from the point of view of most adults who need it; most facilities, agencies and individuals providing it; and most state governmental units responsible for some aspect of it.

In the past, there has been great reluctance to look at the total picture, with respect to long term care needs and dollars and other resources required to meet those needs. Agencies which have argued most strenuously against the broad approach have done so, it appears, for one of two reasons.

First, many agencies have already captured the hearts and dollars of the taxpayers and the lawmakers, and would prefer to maintain the status quo. Second, many agencies experience such overwhelming problems that they have little time and tolerance for considering additional factors which, they fear, will only further complicate their problems.

Both types of agencies have made the following arguments against taking the cross-cutting approach to long term care: "It is too complicated." "It is too time-consuming." "It is a useless exercise, because in the end no one can agree anyway." "It is impossible to look at the big picture, until things are perfected in each separate part of the picture."

The Task Force believes that all of these arguments are invalid. The complexities can be unraveled and understood-and, indeed, must be-if there is to be a rational system of services that addresses the long term care needs of the citizens of the State of Maine. The time can be found and is worth it, and individuals can agree and compromise on how best to meet these needs. The Task Force believes that it is foolish to avoid looking any longer at the big picture. Each part of this picture cannot function effectively if the big picture, in its entirety, is not clearly perceived.

The Task Force cannot stress enough the importance of taking a broad, cross-cutting approach to planning, regulating, financing and providing long term care services. Client groups with similar needs and programs with similar functions must be examined side by side. Only in this way can policymakers begin to distribute dollars equitably on the basis (at least in part) of need, rather than solely on the basis of who has achieved the greatest political clout. Only in this way can policymakers begin to distribute dollars in a more cost-effective manner, through requiring coordination of programs, wherever possible.

Dilemmas:

As the title and content of this Report indicate, the Task Force, as William Shakespeare put it, has had to make many of its recommendations "in perplexity and doubtful dilemma." Three of these dilemmas have been particularly perplexing.

First, the Task Force has had a difficult time weighing Maine's responsibility for its citizens who have very real long term care needs and who cannot, by themselves, meet these needs, versus Maine's ability to pay for services to

meet these needs. The Task Force has concluded that Maine must find a way to assist these citizens.

Second, the Task Force has realized that some individuals, in the short-run, may be adversely affected if more individuals, in the long-run, are to receive types and levels of care that they actually need, rather than care that happens to be available, though not necessarily appropriate. For example, it is very likely that there will continue to be waiting lists for nursing home beds, until other levels and types of care have been developed more fully.

Third, the Task Force has experienced considerable frustration, as it has examined the need to concentrate scarce public dollars on critically needed long term care services, versus the need to use some of these dollars for improved management and coordination of services. The Task Force believes that competent management and coordination of services are essential.

THE TASK FORCE

Reasons:

Governor Brennan convened the Task Force on Long Term Care for Adults on October 10, 1979. In an Executive Order, the Governor cited five facts as reasons for creating the Task Force:

- Over 10,000 elderly individuals and hundreds of younger disabled adults reside in Maine's nursing and boarding homes.
- Elderly individuals represent the most rapidly growing segment of Maine's population.
- Payments made to nursing homes under the State's Medicaid Program almost tripled between 1974 and 1978.
- Many individuals who reside in nursing and boarding homes could reside elsewhere, if alternative services were available.
- There are diverse and diverging planning efforts in Maine, relating to long term care for adults.

Responsibilities: The Governor charged the Task Force with several responsibilities:

- To examine various plans designed to meet the long term care needs of disabled adults, regardless of age;
- To determine which aspects of the plans do the most to enable these adults to make as many decisions as possible about their own lives and to reside in the least restrictive, yet safe, settings available;
- To review statutes, regulations, policies and financing which direct and affect long term care services;
- To emphasize ways to improve the coordination of the administration of these services by state agencies;
- To develop recommendations for more fully meeting the long term care needs of Maine's disabled adults, regardless of age; and
- To hold public hearings during the development of these recommendations.

Members: The Governor appointed 32 Maine citizens to serve on the Task Force. One-third of the members, including the Chairman, were "public" members (that is, they did not provide long term care services or work in a related field); one-third of the members were private sector providers of long term care services or professionals in related fields; and one-third of the members were state employees responsible for various aspects of long term care services.

Organization: The Task Force organized itself into three subcommittees: Services and Alternatives, Policy, and Finance. In addition to appointed members, many other Maine citizens served as non-voting members of the subcommittees. The subcommittees met from November 1979 through May 1980.

During the summer, two *ad hoc* committees, appointed by the Chairman and comprised primarily of individuals not appointed to the full Task Force, met to develop recommendations relating to residents' rights and long term care services for physically disabled individuals. In early August, the Task Force adopted the recommendations proposed by both *ad hoc* committees.

Meetings and Hearings:

The full Task Force held full day monthly meetings from October through May, and full day weekly meetings from June through September. The three subcommittees all held meetings at least every few weeks from late November through May.

In April, before recommendations had been developed, the Task Force conducted six hearings throughout Maine in Auburn, Bangor, Caribou, Farmington, Rockland, and South Portland. The purpose of these hearings was to determine whether the general public's perceptions of the issues and facts were the same as the Task Force's perceptions of the issues and facts. By and large, the perceptions coincided. Through this round of hearings, the Task Force learned that it had not given adequate attention to the needs of Maine citizens who are physically disabled. The *ad hoc* committee described above was set up in response to this oversight.

In the middle of August, the Task Force held two more hearings: one in Bangor and one in Portland. The purpose of these hearings was to consider the public's reactions to the preliminary recommendations of the Task Force, which had been distributed to approximately 1,500 Maine citizens around the first of August. Once again, the Task Force found that, for the most part, the public shared its perceptions of the facts and generally supported its recommendations. During these hearings the Task Force learned that it had omitted any references to hospice services and to services for individuals with long term alcohol and drug problems. The Task Force added a recommendation about hospice services, and decided that, even though it did not have enough time to undertake a special consideration of the problems of excessive users of alcohol and drugs, future cross-cutting examinations of long term care should include such a consideration.

During all of these meetings and hearings, the Task Force heard from a host of consumers, relatives of and advocates for consumers, providers, regulators, planners, and educators in the area of long term care services. The Subcommittee on Finance also called upon several individuals, not involved in the long term care field, whose unbiased expertise in such areas as economics, finance, law and regulatory practices was of inestimable value to the Task Force.

Finally, throughout the year, the Chairman of the Task Force and several other members visited many long term care facilities and programs throughout the State.

ECONOMIC AND POLITICAL CONTEXT FROM WHICH TO CONSIDER LONG TERM CARE

Conclusion:

The Task Force believes that, somehow, the Governor and the Maine State Legislature will find the dollars and other resources required to assist its citizens who have long term care needs. They will do this, because they must, in order to fulfill the minimum requirements of a humane society.

It is the conclusion of the Task Force that the effect of economic factors (some already here and others on the horizon), coupled with resulting political factors, will make money harder and harder to come by in the foreseeable future. Nevertheless, the Task Force is confident the Governor and the Legislature will meet their obligations and will determine that funding for long term care services must be a priority.

Economic Context:

The Task Force believes that there are economic circumstances which cannot be ignored. Doubt and tumult have swiftly and darkly clouded the nation's economy during the brief existence of the Task Force. The financial outlook for long term care services is one of somber uncertainties. As murky as the economic picture may appear, one fact stands out in stark clarity: the easy money days for social programs are over.

One of the few points on which most economists appear to agree is that we have reached a genuine watershed, dividing the post-World War II era of unusually sustained growth and prosperity from an era of relative uncertainty in the 1980's and beyond. We are not going through cyclical inflation, cyclical recession or cyclical anything else. Our future will be different from our recent past. The only certainty for the short and middle term future appears to be uncertainty, accompanied by various kinds of economic difficulties.

The nation's economic condition is the dominant political issue this election year. No one expresses real optimism about the economy. Even the Carter Administration's relative optimism is expressed in terms of achieving a 8-9 percent inflation rate and continued correspondingly high interest rates in the years immediately ahead, a six percent unemployment rate, a "mild" recession and like estimates for other key factors. Such conditions would have been simply unthinkable in the 1950's and the 1960's, the "good, normal years," before the oil embargo, the energy

crisis, and double digit inflation. So the near future, even as viewed by optimists, is grim.

Political Context:

The last year has shown that our political system cannot withstand the pressures created by the present economic situation without yielding in significant areas, as indicated by the cuts in the Title XX and other social programs and by the clamor for a balanced budget and increased defense expenditures.

The tenor of the public and political reactions accompanying the uncertain and unhappy nature of the unfolding economic events is generally pessimistic and fearful of a continuing erosion of the national standard of living. Politically, this trend of dejection in our national psyche is bringing to the surface a deep distrust of government, in particular of its taxing and spending methods.

This attitude among the general electorate comes from those who, as John Dewey put it, "...know where the shoe pinches..." Because they do not know why it pinches, their sentiments tend to be amorphous, poorly focused and against "Big Government," "welfare" and other "issues." There is considerable truth to many of their complaints and it is a pity that government seems incapable of acting constructively on them. However, much of their distrust is directed at the less fortunate groups in our society, including groups in need of long term care services.

Thus, popular pressures militate against social programs, generally. Quite possibly, only those that are perceived by the public as working well will escape serious mauling in the public funding marketplace.

Effects:

What have been some of the specific effects of these economic and political circumstances on the financing of long term care services?

The largest problem is that, although federal funds under Medicaid are still generally available, at least for the time being, the State finds its matching share burdensome. Nursing homes, which consume 48 percent of the state and federal Medicaid dollars in Maine, are concerned about their financial future. They perceive that the State's fear of increasing its share of funding of the Medicaid Program has colored many of its reimbursement decisions regarding the reasonableness of costs.

At the same time, as funds have become more and more scarce, providers of a variety of less restrictive and less intensive long term care services have sought reimbursement under the Medicaid Program, which for so long has been considered a limitless source of funds. At present, these providers consume only a tiny portion (less than 1%) of the dollars under the Medicaid Program. Once again, the State's decisions about whether or not to include such services appear to be based, in large part, on the fear of increasing its share of funding of the Program and less on the needs for the services.

Existing boarding homes, which are financed both by individuals who turn over most of their monthly federal Supplemental Security Income checks to the homes, and by a state supplementation to these checks, are also experiencing financial difficulties. The State has placed a moratorium on the development of new boarding home beds.

Title XX cuts at the federal level and decisions about how to spend Title XX dollars at the state level, are straining an already overburdened and under-funded structure of in-home and community support services.

Recommendations: What are the Task Force's recommendations for arranging the financing necessary to meet the long term care needs of our citizens, under such politically and economically difficult circumstances?

The recommendations emphasize a variety of types of long term care services and call for the most prudent selection and competent management of and widest disbursement of funds among these services. The Task Force believes that all branches and agencies of state and federal government must demonstrate, beyond any doubt, that money asked for is both urgently needed and well spent. There must be a dollar's worth of services for every dollar government receives and pays out.

The Task Force believes that these recommendations are appropriate under any circumstances, and comprise the moral, proper and businesslike way of proceeding. But now these recommendations are more than appropriate - they are vital in times of political and economic travail.

The Task Force urges state financial officials and lawmakers to begin to consider the Medicaid Program as a useful element which not only helps to finance Maine's long term care services, but also contributes to Maine's economy. The Task Force believes that the Medicaid Program should be viewed as a source of funds and not only as an expense.

LEGAL CONTEXT FROM WHICH TO CONSIDER LONG TERM CARE

Conclusion:

The Task Force believes that Maine will find a way to assist its citizens with long term care needs in the least restrictive, most "home-like" settings possible. Maine will do this because it makes sense, from both a humane and a cost effectiveness point of view, for individuals to live in a location that enables them to have as much control as possible over their own lives. In addition, there have been, are now and assuredly will be legal actions prompting Maine to move in this direction.

Past Legal Action:

There have already been numerous federal and state court decisions establishing important precedents in such areas as the right to treatment, the responsibility to use the least restrictive form of care, and the right of non-dangerous individuals to freedom.

Pineland Consent Decree:

The most significant legal action currently pending in Maine is Martii Wuori et. al. v. George A. Zitnay et. al. "This action concerns the civil and constitutional rights of mentally retarded citizens in the State of Maine. It was initiated by and on behalf of those persons who were involuntarily confined to Pineland Center, a state institution for the mentally retarded, and persons conditionally released from Pineland Center to state approved community placements. In July 1978 the parties to this litigation concluded a three-year period of intensive negotiation and agreed upon the terms of a decree to be entered into by consent."[1]

"The Court's decree describes the rights of retarded citizens of the State and imposes on the State the duty to provide whatever may be necessary to fulfill those rights ... The State's consent [to the decree] came with the personal approval of Maine's highest executive officials.."[2]

"There are two central objectives of the Court's decree: The first is to secure the right of mentally retarded citizens to be given training and education [and supportive services], designated in the decree as programming. The second is to secure the right to live in the least restrictive environment possible."[3]

Future Actions:

The precedents established in the past and present legal actions are very likely to result in future legal actions by and on behalf of Maine citizens with long term care needs.

The principle of least restrictive environment has implications for all types of consumers of long term care services. The principle of programming has particular implications for consumers of long term care services who are physically disabled and chronically mentally ill (and to some extent, for consumers who are elderly).

Recommendations: What are the Task Force's recommendations relating to the Pineland Consent Decree and past legal actions?

The principles of least restrictive environment and programming run throughout the recommendations. Generally speaking, the Task Force is recommending that just as the State has agreed in the Pineland Consent Decree to carry out these principles for mentally retarded individuals, so should it carry out these principles for other consumers of long term care services. The State should not discriminate against any group of consumers of long term care services by providing or paying for less services than it does for another group.

ADULTS WITH LONG TERM CARE NEEDS

Who: A widely held perception is that long term care means only nursing home care for "the aged, the infirm and the helpless." The Task Force hopes that this Report will help broaden this view.

The Task Force has been concerned with the long term care needs of five categories of adults: the elderly, the physically disabled, adult protective services clients, the chronically mentally ill, and the mentally retarded. The Task Force has examined the planning, regulating and financing of both in-home and community support services and residential services required to address effectively the long term care needs of all five categories of adults.

In reviewing the following descriptions of individuals with different types of disabilities, it is of crucial importance for readers of this Report never to lose sight of the fact that individuals with long term care needs have "as diverse and varied panopoly of human emotions, interests, idiosyncracies, capabilities and talents as anyone else."[4] It is also important for readers to bear in mind that references to "the elderly" in this Report are not to all elderly individuals. These references are to individuals who happen to be elderly and who happen to have actual or potential long term care needs.

The Elderly:[5]

Around one out of every six Maine citizens is age 60 or over. Maine has one of the highest concentrations of elderly individuals (in terms of a percentage of the total population) of all the 50 states.

Studies of elderly individuals conducted by Duke University show that, nationally, 17 percent of the population age 65 and over are "greatly" or "extremely" impaired, that 44.8 percent of this 17 percent are in institutions, and that the 44.8 percent account for 87 percent of the "institutionalized" population.

In 1978, there were 8,500 Maine citizens in nursing home beds in the State. Of these individuals 7,820, or 92 percent, were age 65 or over. In addition, there were 2,665 elderly individuals in boarding homes. Nationally, five percent of the elderly reside in "nursing homes," "homes for the aged," and "rest homes." Thus Maine exceeds the national figure by 2.7 percent.

Individuals who are age 75 or older represent the most rapidly growing segment of Maine's population. Seventy-five percent of the residents of nursing homes are age 75 or older.

Many studies have shown that at least 20 percent of all nursing home residents have been institutionalized inappropriately.

About 70 percent of Maine's elderly live in their own single family dwellings, five percent live in subsidized elderly apartments and five percent live in private apartments. About 29 percent of the elderly live alone, 27 percent live with friends and 37 percent live with family.

Physically Disabled:[6]

About one in every ten Maine citizens is seriously hampered by physical disability. The elderly represent the largest age group of disabled individuals, having roughly a one in three chance of being limited in major activities.

Estimates for the number of individuals in Maine with severe visual impairment range from 6,400 to 10,000.

These estimates are based on national prevalence rates applied to Maine. These individuals are unable to read regular newspaper print, even with the aid of eyeglasses.

Estimates for the number of individuals in Maine who are deaf range from 1,018 to 9,200. The smaller estimate was made by the Pine Tree Society for Crippled Children and Adults. The larger is based on national prevalence rates for 1971 applied to Maine. According to the national rates, 2,120 Maine citizens are "prevocationally deaf" (they have never had or they lost the ability to hear prior to 19 years of age).

There are approximately 400 individuals in Maine who have had spinal cord injuries. There are an estimated 30-35 new injuries each year. Injury to the spinal cord leads to two broad classes of disability: quadriplegia and paraplegia. Paraplegics are paralyzed in the lower body, while quadriplegics have suffered loss of the use of their arms and hands, as well.

National prevalence rates for cerebral palsy applied to Maine show an estimated 3,170 individuals with this condition. Cerebral palsy is a motor dysfunction caused by brain lesions, which is characterized by a variety of symptoms, such as weakness, lack of coordination or paralysis. Since the mortality rate for individuals with cerebral palsy is higher than for the general population, many of these individuals are under age 25.

The Maine Arthritis Foundation estimates that 25,000 Maine citizens suffer from rheumatoid arthritis. Arthritis is a generalized term for a variety of conditions, and rheumatoid arthritis is the most painful, severe and debilitating.

There are an estimated 6,770 individuals in Maine with chronic obstructive lung disease, including pulmonary emphysema, chronic bronchitis and asthma. This figure is based on the results of a 1970 national survey (applied to Maine) by the American Lung Association.

Readers should not construe this as an exhaustive list of physical disabilities. There are many others, including but not limited to muscular dystrophy, multiple sclerosis, spina bifida, results of stroke and severe brain damage caused by accidents.

Adult Protective Services Clients:[7]

The Department of Human Services is required by law to provide protective services to incapacitated adults who are in some degree of danger or jeopardy and who are impaired to the extent that they are not able to make, communicate or carry out responsible decisions concerning their person or their property. The Department has an average statewide total caseload of 750 adult protective services cases.

Adult individuals who become incapacitated and endangered come from any age group, any community, any family or any culture group. Many are elderly individuals living alone and fearful of losing control over their lives. Many are young adults who need help because of a mental incapacity or problems related to excessive use of drugs or alcohol.

The problems of these individuals include:

- Endangered health caused by lack of nourishing meals, unattended medical conditions, and inability to clothe self and maintain the home;
- Legal problems arising from checks, bills and property disputes;
- Other agencies have given up on them and do not provide services to them;
- Severe mental health problems with no awareness of the need for treatment or for whom no treatment is available;
- A combination of physical and emotional problems, hardening of the arteries, failing faculties, intermittent confusion, forgetfulness, irrational fears and phobias; and
- Social isolation (following the death of a spouse, departure of children, or alienation from friends and neighbors, or as a result of decreased mobility).

The Chronically Mentally Ill:[8]

There are an estimated 5,000+ Maine citizens who are chronically mentally ill.

The combined population of Augusta and Bangor Mental Health Institutes is a relatively constant 675-700. The eight community mental health centers throughout the State have a combined total caseload of around 2,900 "aftercare" clients who have been discharged from the institutes. "Deinstitutionalization" policies, coupled with the lack of well coordinated programs and services in the community have created a crisis concerning the needs of the chronically mentally ill both in Maine and nationally.

The chronically mentally ill have recurring emotional or mental problems which are so severe and persistent that they are unable to cope with the ordinary demands of daily living. As a result, they probably have had or will have sustained contact with the mental health system and, in general, their illnesses or disabilities cannot be cured by short-term treatment.

The chronically mentally ill often have difficulties with basic living skills, such as shopping, cooking and budgeting, finding and keeping a job, and seeking out and enjoying leisure time activities. They are extraordinarily vulnerable to stress. They may have temporary episodes of disruptive or antisocial behavior which are harmful to themselves or others. They sometimes make strong demands on others for tolerance of extreme dependency, bizarre behaviors or peculiar interests. As a result of their disabilities, the chronically mentally ill frequently lack enough money to buy food, clothing and shelter for themselves. Often they lack the motivation or ability to seek help from human service agencies.

The Mentally Retarded:[9]

According to national prevalence rates applied to Maine, three percent of the population or 30,000 citizens are mentally retarded. The Bureau of Mental Retardation, Department of Mental Health and Corrections, has an active caseload of roughly 2,000 individuals at any one time, and provides services to roughly 4,000 individuals each year. There are still 342 individuals residing in Pineland Center, the state institution for the mentally retarded, located in New Gloucester.

Approximately 1,100 individuals are members of the plaintiff class affected by the Pineland Consent Decree. Most of the individuals at Pineland are in the class, as are over 700 mentally retarded individuals residing in the community.

DEFINITION AND PRINCIPLES OF LONG TERM CARE

Definition:

The Task Force adopted a four-part definition of the system of long term care services which, it believes, must be in place for the citizens of Maine:

1. *Long term care services must include an array of coordinated preventive, diagnostic, therapeutic, rehabilitative, supportive and maintenance services.*

2. *Long term care services must be available in the home and in a variety of protected environments.*

3. *Long term care services must be available to adults, regardless of age, whose capabilities have been impaired by physical, mental or emotional disability.*

4. *The goal of long term care services for each individual must be the highest level of independent functioning possible in the least restrictive environment.*

The Task Force believes that, at the present time, some services in some settings are available for only some of the adults who need the services. The Task Force also believes that for many adults who are receiving long term care services, the goal of independent functioning in the least restrictive environment is not being met.

The Task Force has consciously omitted the term "continuum of services" from its definition. In addition to the fact that this has become a hackneyed expression, the word "continuum" implies something about long term care services which simply is not true. "Continuum" suggests that individuals move along from one level of care to another (for example, from own home, to foster home, to boarding home, to nursing home). In fact, such movement is not at all typical. Roughly 75 percent of the individuals entering nursing homes are admitted from hospitals, roughly 16 percent are admitted from their own homes and less than three percent are admitted from boarding homes. With respect to individuals leaving nursing homes, somewhere between a quarter and a third return to their own homes, a similar number have died, and, once again, only around three percent are discharged to boarding homes.[10]

Principles:

The Task Force has based the recommendations stated in this Report on the following principles of long term care:

1. *There must be a system of services which fit the needs of consumers of long term care services, so that the needs of consumers will not be misconstrued in order to fit them into the system, and which recognizes the strengths and potentials, as well as the limitations and problems of consumers.*

2. *Consumers must have multiple access to long term care services which permits easy movement among levels and types of care, according to their needs.*

3. There must be increased emphasis in the system of long term care services on the social aspects of care; quality of life should be the paramount concern.

4. There must be a mechanism for identifying, locating and tracking consumers of long term care services. There must be standardized, periodic assessments of consumers' unique needs and capabilities.

5. Consumers of long term care services or their guardians must be involved in all aspects of planning for their care and must have the right to refuse any aspect of care.

6. There must be action to strengthen and promote the role of the family and other natural networks in the system of long term care services. There must be education for the community and participation by the community in order to build informal networks of mutual help and self help.

7. There must be incentives to promote manpower availability, flexibility and training, in order to more effectively meet the needs of consumers of long term care services.

8. There must be adequate funding to ensure the availability of long term care services and to make choices available to consumers of long term care services.

9. There must be a system of reimbursements which offers incentives to both consumers and providers to meet the long term care needs of consumers.

10. There must be a system of long term care policy development which is responsive to the needs of both consumers and providers.

FOOTNOTES

1) "Pineland Consent Decree: Report of the Special Master to the U. S. District Court for the District of Maine"; March 19, 1979; page 1.

2) "Pineland Consent Decree: Report of the Special Master to the U. S. District Court of the District of Maine"; November 14, 1979; page 1.

3) "Pineland Consent Decree: Report of the Special Master to the U. S. District Court of the District of Maine"; March 19, 1979; page 5.

4) Ibid; page 4.

5) "Long Term Care Issues: Paper No. 2: The People Needing Long Term Care Services"; prepared by the Bureau of Maine's Elderly, Department of Human Services. (undated)

6) Maine's Disabled: Needs and Resources-1978 Status Report; Human Services Development Institute, University of Southern Maine; October 1978.

7) Information provided by staff of the Division of Audlt Services, Bureau of Resource Development, Department of Human Services.

8) "Interim Report"; Community Support Systems Project, Department of Mental Health and Corrections; December 1978.

9) Information provided by staff of the Bureau of Mental Retardation, Department of Mental Health and Corrections.

10) "Long Term Care Issues: Paper No. 2: The People Needing Long Term Care Services," Bureau of Maine's Elderly, Department of Human Services. (undated)

PART TWO:
IN-HOME AND COMMUNITY SUPPORT SERVICES

BACKGROUND

Recommendations #1 through #17 are proposals for improving and adding to existing "in-home" and "community support" services. The Task Force defines "in-home" services as long term care services provided in an individual's place of residence (such as personal care, homemaker services, and various types of home health services). The Task Force defines "community support" services as programs which help an individual with long term care needs to reside in the least restrictive setting possible (such as respite care, transportation, protective services, aftercare services for individuals discharged from a mental health institute, meals programs, day programs, employment services, devices and services to minimize disabilities, and hospice services).

The Task Force finds that there are major "gaps" in both in-home and community support services. The Task Force defines "gaps" as the absence or inadequacy of services required to address effectively the long term care needs of individuals.

The Task Force believes that more consumers of long term care services can and should receive services in their own homes or in settings that are less restrictive than where they are currently residing. The Task Force also believes that if a larger portion of funds for long term care services were spent on in-home and community support services, then a smaller percentage of consumers of long term care services would have to live in more restrictive and more expensive settings, such as nursing and boarding homes.

Over the past year, the Task Force has detected considerable apprehensiveness among the citizens of Maine about the availability of in-home and community support services. The remarks of one concerned consumer illustrate this widespread anxiety:

> "I have read that the Government is cutting back on some of its programs. I am all for it for some programs. I hope the homemaker program will stay with us. I have needed their help lately. I've had a stroke and with some help of the homemaker I can live alone and in dignity. I had to go to a good nursing home for a while and it was awful. I had good care and good meals, but that is no way for me to ...live. I hope the homemaker program will go on and on. I expect we will always need it."

RECOMMENDATION #1: CONSUMER-DIRECTED PERSONAL CARE ASSISTANT SERVICES

#1A. Department Support. The Department of Human Services should support the idea of consumer-directed personal care assistant services. Physically disabled and other consumers of long term care services should have the option of hiring and firing their own personal care assistants and should not have to rely solely on services provided by home health and homemaker agencies.

#1B. Medicaid. The Department should amend the State Medicaid Program to allow for reimbursement for personal care assistants, whether or not they are employed by agencies. Members of a consumer's family should be included in the definition of personal care assistant under the State Medicaid Program, so long as they have had training required to provide such services.

#1C. Title XX. The Department should reallocate Title XX funds to allow for consumer-directed personal care assistant services on a sliding fee-scale basis.

#1D. Training. Training for consumers to prepare them to employ and manage their own personal care assistants should be reimbursable under Medicaid and Title XX.

MAJOR FINDING

The Task Force finds that no Medicaid dollars nor Title XX dollars are currently being used to fund consumer-directed personal care assistant services.

SUMMARY OF EXISTING CONSUMER-DIRECTED PERSONAL CARE ASSISTANT SERVICES

Definition: "Personal care assistant services" include tasks which help individuals with routine bodily functions, such as bowel and bladder care; dressing; preparation and consumption of food; routine bathing; ambulation; and any other similar functions of daily living. Such services are rendered by an assistant at any time of day. "Consumer-directed" means that the individual receiving the services hires, fires and directs the assistant providing the services.

Philosophy:

Consumer-directed personal care assistant services are part of a new concept in the field of rehabilitation of the severely disabled. The concept "independent living" embodies the principle that disabled individuals are capable of developing and directing their own programs and services. All services provided under this aegis are aimed at educating disabled individuals to take control of and responsibility for their own lives.

When independent living is approached from this perspective, it becomes clear that there does not need to be a "center," housing a segregated group of disabled individuals. Rather, independent living is a network of services that includes peer counseling, personal health and community skills training, personal care assistant management training, affordable and accessible housing, and transportation. All of these options lead to the ability of disabled individuals to direct and manage their own lives.

Maine is one of ten states chosen to receive independent living funds under Title VII of the federal Rehabilitation Act of 1973, as amended. The State was awarded $100,000 for fiscal year 1980, with $200,000 pledged for fiscal year 1981. The Maine Independent Living Cooperative, a group of individuals with various independent living programs, monitors these programs, and is responsible for resubmitting proposals for additional federal funds. This is a working example of a consumer-directed independent living program that adheres to a true independent living philosophy.

Programs:

There are presently two programs in Maine which help and train physically disabled individuals to find and manage personal care assistants: Adaptive Living for Physically Handicapped Americans in South Portland and Bangor House. There are no comparable programs for other types of consumers of long term care services.

The 109th Maine State Legislature enacted a program of subsidized, consumer-directed personal care assistant services for individuals who are severely disabled, who are employed 20 or more hours per week or are ready for employment, who need 14 to 35 hours a week of personal care assistant services, who are not otherwise eligible for these services and who qualify financially for a subsidy under 22 MRSA § 3904.

Homemaker and home health agencies also provide personal care services, but these are not consumer-directed.

Funding: The program enacted by the 109th Maine State Legislature is funded entirely by state dollars. Title XX is the greatest funding source for personal care assistant services provided by homemaker and home health agencies.

RECOMMENDATION #2: HOMEMAKER SERVICES

#2A. Legislation. The Governor should submit legislation to the 110th Maine State Legislature to fund homemaker services for individuals with long term care needs.

#2B. Availability. Homemaker services should be available during evenings and weekends to meet specialized needs and to provide care whenever it is needed.

MAJOR FINDINGS

The Task Force finds that in Maine the demand far exceeds the supply of homemaker services. The Task Force finds, further, that state and federal funds used for long term care services are allocated in a way which hinders the development of homemaker services, which are so desperately needed.

SUMMARY OF EXISTING HOMEMAKER SERVICES

Definition: "Homemaker services" are defined as an array of support and social services provided to individuals and their families in their place of residence. Homemaker services include assisting individuals with long term care needs in the performance of household tasks and training them in the areas of food and nutrition, home management, personal hygiene, and family economics. The purpose of home management training is to connect individuals with various resources, such as educational programs, employment, transportation, housing, health related services and social services.

Agencies: There are eight agencies in Maine which provide homemaker services, all of which operate on a nonprofit basis:

Androscoggin Home Health
Aroostook County Homemakers
Community Health and Counseling Services (Bangor)
Department of Human Services (Rockland)

Holy Innocents Home Care Service (Portland)
Kennebec-Somerset Home Aide Service
York County Homemaker Service
Washington County Homemaker Service

Need and Availability: Homemaker agencies report waiting lists of 25 to 150 clients on any given day. This situation seems to be worsening as a result of the effects of inflation and reduced or fixed revenues. This situation continues unabated, despite the fact that agencies make every effort to locate other resources for individuals who need services. Homemaker services are very much in demand for clients of the Department of Human Services; clients of the Department of Mental Health and Corrections; and elderly and disabled individuals referred by town officials, community agencies, friends and family members.

Funding: The State pays for homemaker services under Title XX. Many agencies providing homemaker services also receive United Way and municipal funds. In addition, clients who are able pay for services on a sliding fee scale basis.

RECOMMENDATION #3: HOME HEALTH SERVICES

#3A. Legislation. The Governor should submit legislation to the 110th Maine State Legislature to fund long term home health services, including continuous care services.

#3B. Availability. Home health services should be available during evenings and weekends to meet specialized needs and to provide care whenever it is needed.

#3C. Licensing. (See Recommendation #33)

MAJOR FINDINGS

The Task Force finds that state and federal funds for long term care services are currently allocated in a way that hinders the development of long term home health services. Forty-eight percent of the expenditures under Maine's Medicaid Program are for institutional long term care services, while less than one percent of the expenditures are for home health services.

SUMMARY OF EXISTING HOME HEALTH SERVICES

Definition: "Home health services" are defined as a variety of health care services provided to individuals and their families in their place of residence or in ambulatory care settings, for the purpose of preventing disease; promoting, maintaining or restoring health; or minimizing the effects of illness and disability. "Continuous care services" are private duty nursing and aide services, available 24 hours a day.

Agencies: There are thirteen certified home health agencies in Maine which are voluntary, nonprofit agencies and which are eligible to receive third-party reimbursement from Medicare, Medicaid and private insurance:

Androscoggin Home Health Agency
Aroostook Home Care Agency
Bangor District Nursing
Bar Harbor Public Health Nursing Association
Community Health & Nursing Services (Bath)
Community Health Services (Portland)

Community Health and Counseling Services (Bangor)
Four Town Nursing Service (Blue Hill)
Kennebec Valley Regional Health Agency
Kennebunk Public Health Association
Kno-Wal-Lin Community Health of Knox, Lincoln and Waldo Counties
South Portland Health Services
York County Health Services

In addition, several non-certified agencies provide home health services in Maine. These range from small businesses to agencies operated for profit as part of a chain by large companies of national stature. These non-certified agencies are not eligible to receive third-party reimbursement for the services they provide.

Finally, owners of some intermediate care facilities in Maine are becoming increasingly interested in expanding their services to include home health services.

Services:

Home health services provided by certified agencies which are reimbursable by third-party payors include: home health aide services, medical supplies and equipment, nursing services, nutrition services, occupational therapy, speech pathology services, and social work services.

Medical services are primarily provided by an individual's private or clinic physician, although in some instances agencies employ a physician or contract for a physician's services.

Certified agencies are involved in planning and coordinating services to ensure that individuals and their families receive services that are appropriate to their needs.

Need and Availability:

There is a statewide need for home health services. Various national studies conducted by the Federal Government and private standard-setting organizations indicate that as many as 50,000 Maine citizens need home health services each year.

The thirteen certified agencies report approximately 208,000 home visits involving approximately 500 office, professional and contracted support staff. There has been no detailed analysis statewide of the scope and depth of the services needed or currently provided. It is assumed, however, that such an analysis would

demonstrate disparities in the availability of services, both on a per capita basis and by service discipline (nursing, physical therapy, occupational therapy, et cetera).

Medicare Funding:

Governmental funding for certified home health agencies is "categorical" (the government will pay for some people, but not others) and is based on a "medical model." The regulations are too rigid with respect to who can deliver home health services, what types of individuals are eligible to receive the services, and the level of care which is covered under the program.

Under Medicare, medical necessity is the major criterion used to determine reimbursement. Medicare regulations which restrict home health services to individuals include the following:

- Clients must be 65+.
- Clients must be homebound.
- Home health agencies must provide part-time, intermittent services.
- Physicians must approve plans of care.
- Skilled care is a requirement.
- Occupational therapy cannot be the primary service.
- Under Part A of Medicare, patients must have been hospitalized for three days prior to agency start-up.
- Level of care must be acute and episodic, with documented evidence of rehabilitation potential.
- Up to 100 hours per month per client of certified home health aide service is available only if documentation is sufficient.
- Medicare does not cover any maintenance or long term home care.

Medicaid Funding:

Under Medicaid, the regulations are less stringent. Individuals must meet income and other eligibility requirements. Care must be provided in an individual's place of residence. Medicaid does not reimburse agencies for home health services provided under the State Catastrophic Illness Program, even though individuals eligible for catastrophic illness benefits are, generally moderately

to severely disabled persons who need a full range of home health services upon discharge from a facility.

Other Funding: Many home health agencies receive United Way and municipal funding to provide care to clients who are unable to pay for services. In addition, clients who are financially able pay on a sliding fee-scale basis.

Continuous Services: According to testimony received by the Task Force, a large gap in home health services is in "continuous" care which makes private duty nursing and aide care available for 24 hours per day. Very few individuals get reimbursement for continuous care through their health insurance policies. As a result, this type of care is limited to those who can afford it.

RECOMMENDATION #4: RESPITE CARE

#4A. Department's Responsibility. The Department of Human Services should:

- Take steps, immediately, to establish "respite care services" (that is, relief) for caretakers of individuals with long term needs (including family members and operators of group homes, transitional living facilities) and for the individuals, themselves.
- Have a statewide system of respite care services in place by January 1, 1982.
- Work closely with the Department of Mental Health and Corrections and other interested agencies and individuals to establish these services.

#4B. Types of Respite Care. There should be two types of respite care services:

- "Crisis intervention" or intensive care provided on an emergency basis to meet immediate and critical needs; and
- "Relief services" or periodic care provided to enable caretakers and individuals being taken care of to have a rest from the constant pressures and demands of their respective roles.

#4C. Providers. There should be a variety of providers of respite care services:

- Homemaker and home health agencies should be funded to provide in-home respite care services.
- Some intermediate care facilities, boarding care facilities, group homes and transitional living facilities should be reimbursed for keeping an extra bed or two available for respite care.
- Some foster care facilities should be licensed specifically to provide respite care.
- Some operators of group homes and transitional living facilities should be licensed specifically for the purpose of rotating from facility to facility in order to provide respite care services, so that other operators can have a break.

MAJOR FINDINGS

The Task Force finds that any family caring for an individual with long term

care needs is carrying out a continuous and arduous task, that without relief the family is likely to suffer disruption, and that the cost of care of the individual is much less if the public involvement is supportive rather than primary.

The Task Force finds that respite care is presently available for mentally retarded individuals and their caretakers throughout the State, but it is hardly available at all for the other groups within the long term care population.

The Task Force finds that in-home respite care is preferable, in many instances, because it is less disruptive to the individual with long term care needs and to the family.

The Task Force finds that operators of small residential facilities such as foster care facilities, small group homes, and transitional living facilities could also benefit from respite care services.

SUMMARY OF EXISTING RESPITE CARE SERVICES

Purpose: At the present time, respite care is provided in two ways in Maine. Either a trained paraprofessional is sent into an individual's home or the individual is placed in a foster care or institutional setting. The purpose of respite care is to give relief to family members, group home staff or foster families who are the primary caretakers or the individual. The individual who may be mentally retarded, physically disabled or emotionally disturbed, requires continuous and special care which imposes a great strain on the primary caretakers and, surely, on the individual as well.

Agencies: The major providers of in-home respite care are two homemaker agencies: Holy Innocents in Portland and Kennebec-Somerset Aide Service in Waterville. Respite care outside the home is provided by the Levinson Center, Pineland, Houlton Residential Center, and boarding and foster care facilities.

Need and Availability: Even though caretakers of all types of individuals and the individuals themselves could benefit from respite care, the availability of this service is spotty throughout the State. Only for mentally retarded individuals and their caretakers is respite care somewhat available throughout most of the State.

RECOMMENDATION #5: TRANSPORTATION

#5A. Regulation. The Governor should submit to the 110th Maine State Legislature, legislation to eliminate regulation by the Public Utilities Commission of publicly funded regional transportation providers and others receiving public transportation funds.

#5B. Bureau of Public Transportation. The Commissioner of Transportation should assign sufficient staff and administrative resources to the Bureau of Public Transportation in order to more effectively carry out the requirements under 23 MRSA § 4209. The Governor should submit to the 110th Maine State Legislature, legislation to increase funding for the Bureau of Public Transportation to cover, at the barest minimum, increased costs caused by inflation, fuel costs, and declining federal participation.

#5C. Volunteer Drivers. The Department of Human Services and the Department of Mental Health and Corrections both should encourage more volunteer drivers by:

- *Working with insurance companies to develop flexible liability insurance coverage policies; and*
- *Reimbursing drivers for actual expenses incurred, including mileage and liability insurance.*

#5D. Study. There should be a study of the possibility and effects of having all transportation related to social services administered by the Department of Transportation, so that social services agencies will no longer have to provide transportation services.

MAJOR FINDINGS

The Task Force finds that the gaps in transportation services are different for the different groups within the long term care population.

For physically agile elderly individuals, there is little transportation in rural areas, except to social and medical services. For moderately to severely disabled elderly individuals, there is very little transportation anywhere.

For individuals who are mentally retarded, there is very little transportation in rural areas, except for social services.

For individuals who are chronically mentally ill, there is very little transportation in rural areas. These individuals do not use social services in large groups, so transportation related to social services is not even available.

For individuals who are physically disabled, there is very little transportation at all because of accessibility problems.

SUMMARY OF EXISTING TRANSPORTATION SERVICES

Types and Purpose: There are three types of transportation services: free or reduced fare rides; an established mass transit line; and multi-passenger vans, either on a route or door to door. Transportation is a key element in maintaining an individual in the least restrictive environment. It is required to obtain the basic necessities of life, such as food and clothing, as well as to obtain health and social services.

Agencies: There are eight regional transportation agencies in Maine. 23 MRSA § 4209, enacted in 1979, requires the Department of Transportation to divide the State into regions for the distribution of state transportation funds. The Department created a new Bureau of Public Transportation to handle the tasks of selecting a public transportation agency in each region and to coordinate the plans of these agencies to meet the transportation needs of low income, elderly and disabled individuals. The Department has not allocated sufficient staff to the Bureau to handle these tasks. Bureau officials are also assigned to a number of other functions. One result is that technical assistance and funds disbursement to the regional agencies is often inadequate or late.

Regulation: The eight regional transportation agencies and other agencies receiving federal funds through the Department of Transportation are required to have a common carrier certificate and to be regulated by the Public Utilities Commission. This raises insurance rates, adds a layer of bureaucracy and paperwork and thus reduces funds available for direct services. Regulations of the Commission were not designed or intended for social service transportation providers which are primarily funded and regulated through other agencies of government, including Title XX and the Department of Transportation.

Need and Availability:

All of the groups within the long term care population need transportation services. However, one estimate indicates that 90 percent of the State's transportation dollars are spent on two groups: The elderly (65%) and the mentally retarded (25%). The present system does not respond to the need for transportation services.

In general, services are available to individuals in urban areas, and largely unavailable in rural areas. Reduced prices and free fares are available on the State's mass transit systems. However, the small number of door to door vans and cars that operate in rural areas cannot begin to meet the need that exists.

Services are inaccessible for many individuals. Physically disabled individuals, for example, often require specialized equipment, such as wheelchair lifts and door to door service. Sometimes transportation is available, but not accessible for these individuals.

Much Title XX funded transportation is geared largely to support existing social services, such as congregate meals, workshops, and training sites. Since these are high intensity services (used several times per week), a relatively small number of individuals end up making heavy use of the service, leaving fewer resources for needs (shopping, banking, filling of prescriptions) of the larger long term care population.

Under the Older Americans Act, Title III-C funds for the elderly go almost exclusively to pay for medically-related transportation. This means that transportation for other needs is difficult to obtain.

The planning by the eight regional agencies lumps together public transportation with no eligibility requirements, with limited social services transportation. As this process becomes more established, the availability of services to low income individuals may be decreased, as a result of less visibility and siphoning off of dollars to meet the needs of the larger group.

Funds and Costs:

State appropriations to the Department of Transportation for the new Bureau of Public Transportation totaled $400,000 for fiscal year 1981. The funds are a critical element in providing transportation to and from long term care programs and services. The funds are particularly vulnerable to inflation and energy costs.

Medicaid funds are now available to pay for medically-related transportation for some individuals. However,

no other larger funds have recently become or are expected to become available.

A recent unpublished study of transportation services funded by Title XX indicates that inflation drove the cost of a unit of transportation service up almost 50 percent between the 1978-79 and 1979-80 contract years. With no new funds, this resulted in a one-third decrease in service.

Costs are also narrowing the options available to service providers. One major transportation agency has been experiencing a large drop in the number of volunteer drivers it has available. The agency, which had an estimated 270 volunteers in 1976, had lost approximately 170 of them by mid-1978. The problem appears to be twofold. First, it costs much more now to drive, and most of the volunteers were not being paid. Second, as more spouses are being forced to return to work to support the family, the potential pool of volunteers is shrinking.

RECOMMENDATION #6: ADULT PROTECTIVE SERVICES

#6A. Licensing. The Division of Adult Protective Services, Department of Human Services, should not be responsible for the licensing of adult foster homes.

#6B. Staff. The Governor should submit legislation to the 110th Maine State Legislature to increase the staff in the Division of Adult Protective Services, so that resources will finally be available for the Division to meet its statutory responsibilities.

MAJOR FINDING

The Task Force finds that the Maine State Legislature has failed to appropriate state funds to pay for the statutory requirement that the Department of Human Services must respond to complaints involving incapacitated adults. The Task Force finds, further, that the amount of money the Department expends for adult protective services is inadequate to carry out the provisions of 22 MRSA §3460-3464.

SUMMARY OF EXISTING ADULT PROTECTIVE SERVICES

Law:

The State Department of Human Services is mandated by MRSA Titles 18 and 22 to provide protective services to adults. Protective services are defined as those activities undertaken by Department staff on behalf of incapacitated adults who are in some degree of danger or jeopardy, and who are impaired by reason of advanced age, mental or physical illness or incapacity, or other cause, to the extent that they lack sufficient understanding or capacity to make, communicate or implement responsible decisions concerning their person or property. The activities include securing public or private guardianship.

Individuals Served:

The Department of Human Services provides protective services statewide to and on behalf of incapacitated adults. Page 13 of this Report describes the types of individuals who need protection.

Eighteen Department social workers maintain an average statewide total caseload of 750 active adult protective cases in which the Department seeks to:

- Remove the danger from the individual or the individual from the danger.
- Maintain the individual in his own home or, if this is not possible, within the least restrictive alternative possible.
- Maintain the individual's freedom of choice and civil rights or, if decision-making power is to be assigned to a guardian or conservator, to ensure that legal protection is provided the individual through due process.
- Help the individual from becoming endangered again.

Program Areas:

The Adult Protective Services Program includes the following areas:

- Guardianship (public and private) - To protect incapacitated adults and their estates.
- Protective Services - Activities necessary to remove danger from incapacitated adults or to remove incapacitated adults from danger.
- Supportive Services - Activities necessary to maintain incapacitated adults in their own homes or in alternative living arrangements.
- Adult Foster Home Approvals - Recruiting and approving homes for incapacitated adults.

The recent changes in the Probate Code, will require the Department to offer conservator services for adults who are unable to manage their finances.

Funding:

When the state protective services laws became effective in October 1973, a tremendous responsibility, without funding, was assigned to the Department of Human Services. The legislation carried no appropriation, yet it required the Department to respond to requests on behalf of incapacitated adults for services and to provide public guardianship services for those in need. Although the number of requests for services has increased each year, no appropriation has ever been granted to operate the program.

The Task Force received testimony that the Adult Protective Services Program is funded in the amount of around $300,000 per year, compared to more than $8 million per year spent on children's services.

Staff:

The largest gap resulting from the absence of state funding is in staff. Staff currently assigned to provide adult protective services have been borrowed or transferred from other programs. Statewide there are 18 adult protective social workers.

Other than staff in the Attorney General's office, there are no legal services available to the social workers. The often unique situations of some incapacitated adults makes addressing their needs difficult without some legal consultation. The absence of legal consultation sometimes results in no action on behalf of or no resolution of the problems of these adults.

RECOMMENDATION #7: AFTERCARE SERVICES FOR THE CHRONICALLY MENTALLY ILL

The Governor should submit legislation to the 110th Maine State Legislature to provide funding and legal authority to the Bureau of Mental Health, Department of Mental Health and Corrections or its designee(s) to make available to all individuals who have been discharged from a state mental health institute or psychiatric inpatient unit "aftercare services " for an indefinite period of time, depending on need. Aftercare services should include plans of care for each individual.

MAJOR FINDINGS

It appears to the Task Force that of all groups of individuals with long term care needs, the needs of the chronically mentally ill have been addressed the least effectively. The Task Force finds that the State must play a stronger role in ensuring that individuals who have been discharged from Augusta or Bangor Mental Health Institute receive the services they need in the least restrictive settings possible.

SUMMARY OF EXISTING AFTERCARE SERVICES

Services:

Aftercare services help individuals who have been chronically mentally ill move from more restrictive settings (such as Augusta and Bangor Mental Health Institutes) into less restrictive settings (such as halfway houses or their own apartments). Aftercare staff are responsible for assessing the abilities and limitations of these individuals and for acquainting them with the opportunities and difficulties they will face in the community.

Aftercare services include preparation and planning for discharge, placement in the community, maintenance in the community, homemaker services, individual and group counseling, chemotherapy and health care guidelines. Aftercare services also include support, encouragement, advice, training, advocacy, coordination and liaison so that individuals who have been chronically mentally ill will be able to assume community commitments and responsibilities without feeling isolated.

Aftercare services are "outreach" oriented, rather than office-based. They can be provided in many places, including the two state mental health institutes, hospitals, various types of residential facilities in the community, clinics, jails, courts, schools, work places and homes.

Clients: Individuals who need aftercare or community support services include: residents discharged from a mental health center's inpatient unit, either of the two state mental health institutes, or a "residential treatment facility"; individuals who are clearly at risk of being hospitalized because of mental or emotional disability; and individuals with significant mental health problems who have been discharged from general hospitals, halfway houses, or boarding homes.

Funding: Aftercare services are funded by three federal sources: Medicaid, Title XX and community mental health centers grants. In addition, the Bureau of Mental Health, Department of Mental Health and Corrections provides state funds for aftercare services. There is not enough funding to provide a sufficient level of aftercare services to individuals discharged from the state mental health institutes and from local inpatient psychiatric units. Many residents of foster, boarding and nursing homes who need aftercare services are not receiving them.

Deinstitutionalization: The Task Force has found that deinstitutionalization policies, coupled with the lack of well coordinated programs and services in the community, have created a crisis concerning the care of the chronically mentally disabled, both in Maine and nationally. The Task Force is greatly concerned that public policies affecting these individuals have not been articulated clearly and believes that the Department of Mental Health and Corrections must review and clarify policies in the following areas: the role of psychiatry, community education, continuity of services, financial issues, administrative issues and civil rights.

Mental Health Centers: In 1958, Augusta Mental Health Institute helped set up the first community mental health clinic, now Tri-County Mental Health Center, in Lewiston. Other clinics operated by the mental health institutes sprang up throughout the State.

After the passage of the federal Community Mental Health Centers Act of 1963 (John F. Kennedy's "bold, new" approach

to mental health services), the clinics were either phased into or phased out in favor of community mental health centers, serving eight "catchment areas." The eight centers are:

Aroostook Mental Health Center
The Counseling Center (Bangor)
Kennebec Valley Mental Health Center
Tri-County Mental Health Center (Lewiston)
Area V Mental Health Board (Portland)
York County Counseling Services
Bath-Brunswick Mental Health Association
Mid-Coast Mental Health Center (Rockland)

Some years ago officials of the Department of Mental Health and Corrections and representatives of the community mental health centers agreed that the centers would take primary responsibility for the care of individuals discharged from the two mental health institutes.

Because of the multiplicity of funding sources and the different organizational structures of each community mental health center, aftercare is different in different parts of the State. Policies and procedures are varied and have influenced the provision of aftercare services. Quality of care has not been assessed on a regular basis.

Discharge: Various criteria are used to assess readiness for discharge from aftercare services. No uniform standards are in place. With respect to inpatient psychiatric units, the level of discharge planning varies throughout the State. Generally, discharge planning needs improvements statewide.

Employees: Salaries of aftercare workers have been low and turnover has been a problem in some parts of the State. These are dedicated individuals working with very difficult clients. Often support and encouragement are lacking. In one area of the State there is an aftercare worker with a caseload of 300 clients.

RECOMMENDATION #8: MEALS

#8A. Expansion. The congregate meals program and the home-delivered meals program for the elderly and other eligible individuals should be expanded to provide a second meal on Mondays through Fridays and at least one meal each day during weekends.

#8B. Use of Meal Sites. There should be support for efforts by the Bureau of Maine's Elderly, Department of Human Services, and other agencies to expand the use of congregate meal sites.

#8C. Insurance. The Department of Human Services should help develop and pay for liability insurance for volunteers who transport home-delivered meals and for the individuals who prepare the meals.

MAJOR FINDING

The Task Force finds that congregate meal sites could be used for more than meals. The Task Force questions whether some elderly individuals can survive on meals provided only one time per day, five days per week.

SUMMARY OF EXISTING MEALS PROGRAMS

Purpose: Congregate meals and home-delivered meals play an important role in the lives of individuals who are homebound or who cannot shop for and prepare their own meals. Meals programs assure that these individuals receive one nutritional meal a day, representing one-third of their daily nutritional requirements, five days a week in their own homes or at selected congregate sites. They help prevent malnutrition and premature institutionalization and provide opportunities for social interaction with all the attendant benefits to emotional and physical well-being.

Agencies: The State's five area agencies on aging are primarily responsible for meals programs.

Need and Availability:

In its latest service area plan, the Bureau of Resource Development projected that it would serve an estimated 3,000 individuals in 1980. This was up from approximately 2,700 during the previous year.

The group served is almost exclusively elderly individuals. This leaves physically and mentally disabled, as well as mentally retarded individuals unserved.

Further, although federal guidelines call for provision of congregate meals five days per week, and home-delivered meals seven days a week, this amount of service is not always available.

Funding:

Funding for meals programs comes from Title III-C of the Older Americans Act, Title XX, and the State's Priority Social Services Program.

RECOMMENDATION #9: DAY PROGRAMS

#9A. Medicaid. The State Medicaid Plan should be amended to include day treatment (that is, partial hospitalization), as a reimbursable service under the Medicaid Program.

#9B. Priority. Funding for day programs which are not medically oriented and, therefore, are not eligible for Medicaid reimbursement should be a priority for both the Department of Human Services and the Department of Mental Health and Corrections.

#9C. Staff. The staff of day programs should include paraprofessionals and should be individuals, not only qualified by educational achievement and credentials, but also highly interested in working with individuals with long term care needs.

MAJOR FINDING

The Task Force finds that there is untapped potential in using the Medicaid Program to pay for day programs for both residents of long term care facilities and for individuals with long term care needs who reside at home.

SUMMARY OF EXISTING DAY PROGRAMS

Definition:

Day programs are non-residential restorative, rehabilitative, training, activity or treatment programs. These programs include day activity programs for elderly individuals as an alternative to placement in a facility; training programs for mentally retarded and disabled individuals, ranging from "life activities" programs to vocational training programs; and social, recreational and treatment programs for chronically mentally ill individuals.

Need and Availability:

The Task Force received testimony during its hearings which suggests that some individuals in all of the groups within the long term care population can benefit from some sort of day program.

Day programs are available for mentally retarded individuals, particularly in urban areas. In addition, some treatment programs are available for the chronically mentally ill,

though the number of slots (around 250) compared to the need is grossly inadequate. There are very few day programs for the physically disabled or elderly in need of rehabilitation. One adult day program operates as an integral part of the nutrition program at the Muskie Center in Waterville. Approximately 75 elderly individuals attend the program two or three days per week.

Costs:

The costs of day programs can be high. Day programs for the elderly are particularly expensive. Studies have shown that costs can run from $13 to $39 per day, in addition to other Medicare and Medicaid benefits. The cost per day of the Muskie Center program is approximately $14. In only California and Massachusetts are the costs of day programs covered under Medicaid.

One of the difficulties facing all day programs is the prerequisite that transportation must be available. If it is not available, participants may not be able to obtain service. As costs of transportation go up, overall costs of the program go up, threatening the existence of some established programs. The Task Force learned that a day program at the Camden Community Hospital recently shut its doors. One of the reasons for the closing was a lack of transportation for the users of the program.

A possibility to reduce the costs of these programs would be to expand existing meal site programs to include day services. Transportation would be less of a problem, because individuals are now regularly transported to the meals program. An additional benefit of this would be to integrate individuals with more serious disabilities (the day program users) with individuals who are not seriously disabled (the elderly who have their meals at the site).

RECOMMENDATION #10: EMPLOYMENT SERVICES

The Bureau of Rehabilitation, Department of Human Services; the Comprehensive Employment and Training Administration; and other organizations should initiate more vocational projects for individuals with long term care needs, whether they live at home or in a long term care facility. (See also Recommendation #30C)

MAJOR FINDINGS

The Task Force finds that while there are some vocational training programs for individuals with long term care needs, the potential for these individuals to be productive too often remains unfulfilled.

SUMMARY OF EXISTING EMPLOYMENT SERVICES

Types: There are three types of employment opportunities: programs geared to training for rehabilitation purposes; programs for the disabled who need income support to remain independent; and programs which offer opportunities to remain active and productive, while providing service to others and for which a stipend is received.

Need and Availability: There is a critical need for employment opportunities for many individuals with long term care needs, including, in particular, the physically disabled and the chronically mentally ill. Training programs sponsored by the Comprehensive Employment and Training Administration, the Department of Human Services and the Department of Mental Health and Corrections are available throughout the State. Some are rehabilitative in nature. However, opportunities for employment after training are largely unavailable.

Problems: Disabled individuals can be highly productive and reliable workers. Problems center around convincing employers of this and locating or developing positions that fit the skills of these individuals.

Some Ideas:

The Task Force received written testimony with the following suggestions for employment projects for elderly individuals residing in boarding homes. The Task Force believes ideas such as these should be tried out in a variety of settings:

- Develop a cultural history course at a high school which focuses on the many changes in Maine which have occurred during the lifetime of elderly individuals who are living in the boarding homes. Have these elderly individuals, many of whom are immigrants from Canada, Italy, Poland, Russia, et cetera, available for answering questions by the class.

- Establish workshops in which retired craftsmen who now reside in boarding homes can continue making and selling their crafts and can pass on their skills to younger individuals who apprentice with them.

- Produce, publish and market a cookbook including favorite family recipes of individuals residing in boarding homes.

RECOMMENDATION #11: DEVICES TO MINIMIZE DISABILITIES

There should be greater efforts to develop low-cost group purchasing arrangements for devices which minimize disability including eyeglasses, dentures, hearing aids, television decoders, doorbell lighting systems, low vision devices, braille books, teletype devices, wheelchairs, environmental control units, specially equipped motor vehicles, and drugs. Sliding fee scales for the purchasing of these devices should be used, to the extent possible.

MAJOR FINDING

The Task Force finds that devices to minimize disabilities are costly and widely unavailable for the individuals who need them.

DESCRIPTION OF DEVICES TO MINIMIZE DISABILITIES

Types of Devices:

Technology has developed many devices to help individuals cope with a wide range of physical disabilities. Among these are personal, health-related devices (such as eyeglasses, dentures, hearing aids, drugs and environmental control units); external devices (such as low vision devices, braille books, teletype devices, television decoders, and doorbell and fire alarm lighting systems); and mobility aids (such as wheelchairs and specially equipped motor vehicles). The effect of devices varies from helping an individual to work or to maintain self-sufficiency.

Need for Devices:

Elderly and physically disabled individuals are among those who have the greatest need for devices to minimize disabilities.

Of the 92 percent of the nation's elderly who use eyeglasses, an estimated one-fourth of them are in need of new corrective lenses. Over 50 percent of the nation's elderly suffer at least some impaired hearing (though it is unclear how many might make use of hearing aids). Approximately one-third of the nation's elderly require new or refitting of dentures.

In Maine over 500 individuals who are "sign language deaf"

would be able to make use of teletype and other devices.

There are an estimated 2,600 legally blind, and 4,000 visually impaired individuals in Maine who might make use of braille books and magnification aids.

An estimated 3,170 individuals in Maine suffer from cerebral palsy. Approximately 400 have total spinal cord injury. An estimated 25,000 suffer from rheumatoid arthritis. An undetermined number of these individuals require the use of various mobility aids from wheelchairs to specially equipped automobiles.

Availability:

The Bureau of Rehabilitation, Department of Human Services, provides a full range of devices required to make its clients employable. However, unless the individual falls into this rather select group, obtaining devices becomes a difficult to complex task: difficult because of the limited availability of resources and complex because of the large number of small sources of assistance.

Key medical appliances, including eyeglasses, hearing aids and dentures are virtually unavailable under Medicaid, Medicare or other health benefit programs. Individuals who cannot afford them can obtain some of them through limited, quasi-public efforts. Eyeglasses, for example, are provided in many areas of the State through the Lions Clubs.

Dentures can be obtained at moderate or no cost from such programs as People's Regional Opportunity Program in Portland, the Bangor Adult Dental Clinic, and the Maine effort under the National Health Care Dental program. Other dental programs include one that serves Indian groups, and the dental clinic at Pineland.

No similar programs cover hearing aids on even a modest scale.

External devices are available, also under special circumstances. Services to the deaf and hearing impaired under the Bureau of Rehabilitation provide teletype devices to 80 out of approximately 540 eligible deaf individuals. This allows them limited telephone communication they would otherwise not have.

Costs and Funding:

Hearing aids cost an average of $350 retail. Dentures are similarly priced, including lab fees. Clearly such expenses are beyond the means of many individuals.

At the same time, the present federal and state system of paying for devices reflects a system of values: it is appropriate to spend money on individuals who are going back to work; it is less appropriate to spend money to make individuals' lives a little more comfortable.

The present strategy of developing no cost/low cost purchase arrangements for particular groups has proved useful. Future effort could be geared toward expanding these efforts - in terms of types of devices covered, types of people served, and geographical areas covered.

RECOMMENDATION #12: INTERPRETER SERVICES

There should be interpreter services available to individuals who are hearing impaired and who are in need of long term care services.

MAJOR FINDING

The Task Force finds that interpreter services for the hearing impaired are essential for these individuals to make informed decisions about the type of care they choose and to understand the services they are receiving to address their long term care needs.

NEED FOR INTERPRETER SERVICES

Communication:

Because of the nature of deafness, communication is the crucial problem whenever a severely hearing impaired individual is involved in a long term care setting or service. Professionals in the State of Maine who confer with the severely hearing impaired individual may not have knowledge regarding deafness or the particular needs of and communication used by the individual.

Each hearing impaired individual's communication needs vary, depending on the individual's background, degree of hearing impairment, prior communication training, and the communication setting. Some hearing impaired individuals may prefer to rely on lip-reading or written notes in an informal one-to-one situation, but may need a qualified interpreter in a group or more formal situation. Most often, deaf individuals need sign language interpreters, in order to ensure accurate communications. The hearing impaired individual's judgment should govern, to the greatest extent possible, the determination of need for interpreter service.

Interpreter services are useful in decision-making about home health services; placement in boarding and nursing homes; and medical, legal, educational, rehabilitation, and professional services for the hearing impaired individual with long term care needs.

Laws: In accordance with Section 504 of the Rehabilitation Act of 1973; Section 122(a) of the Federal, State and Local Fiscal Assistance Act of 1972; and Public Law 88 of the State of Maine, all state and local government agencies are required to ensure effective communication with hearing impaired individuals. Recipients of the federal financial assistance through the U.S. Department of Health and Human Services must comply with Section 504 by providing equal benefits and services to the hearing impaired. The intent of these laws is to equalize the hearing impaired individual's opportunity to benefit from the same services and programs offered to the general public.

RECOMMENDATION #13: SUBSIDIES FOR CONSUMERS AND FAMILIES

#13A. Tax Credits. The Governor should submit to the 110th Maine State Legislature a bill to provide tax credits or other subsidies to families who provide substantial in-home care to elderly or disabled family members, who would otherwise be eligible for and require admission to a skilled nursing, intermediate care, boarding care or foster care facility.

#13. Voucher System. The Department of Human Services and the Department of Mental Health and Corrections should seek federal and private foundation funds in order to try out, on a demonstration basis, a voucher system for consumers of long term care services. The system should allow consumers to purchase whatever services they choose, regardless of their financial eligibility.

MAJOR FINDINGS

The Task Force finds that the present system of long term care services does not encourage families to care for elderly or disabled members. The Task Force also finds that the present system of long term care services does not permit consumers of long term care services to make many choices.

DISCUSSION

Law and Regulations:

Law and regulations governing eligibility often make it easier, financially, for families to place elderly or disabled members in nursing homes. (See Recommendation #30) The Task Force received testimony that laws and regulations in areas not even related to long term care services have prevented families from caring for elderly or disabled members.

For example, a recent decision by the Employment Security Commission denied unemployment benefits to a man who for 28 years has worked the second or third shift in the textile industry. The man is unable to work the first shift because during the day he cares for his elderly mother who is ill. Section 1192(3) of the Maine Employment Security Law (Title 26) states that, to be eligible for benefits in any week, an individual must be available for full-time work, with no unreasonable restrictions on his availability.

The Commission denied benefits because the man placed a restriction on his availability for full-time employment.

Choices:

Thus, the present system of long term care services does not permit consumers and their families to make many choices. The Task Force believes that tax incentives and a voucher system would enable consumers to buy the services they choose, rather than settle for less appropriate services for which they happen to be eligible.

RECOMMENDATION #14: HOSPICE SERVICES

#14A. Voluntary Organizations. Voluntary organizations in the private sector should be encouraged to develop, further, the "hospice" services they have initiated for individuals who are dying and for the families of these individuals. (See also Recommendations #5C and #15)

#14B. Other Agencies. Other agencies and facilities which provide long term care services should develop services and attitudes which are responsive to the needs of terminally ill individuals and their families.

MAJOR FINDINGS

The Task Force finds that hospice services have an important place among the many diverse long term care services in Maine. The Task Force believes that these services help individuals die with dignity, in the place and in the manner they choose. The Task Force finds that, too often, individuals with terminal illnesses lose control over where and how they are to die and who among their families and friends are to be there while they are dying.

DESCRIPTION OF EXISTING HOSPICE SERVICES

Definition:

"Hospice" means a resting place. As used in this recommendation, "hospice" refers to a way of caring for the dying. The purpose of hospice services is to provide support to individuals who are dying and their families.

Agencies:

Hospice of Maine, a nonprofit incorporated volunteer agency located in Portland, was the first group in the State to provide hospice services. Established four years ago, Hospice of Maine trains volunteers to give emotional, practical and spiritual support to individuals who have terminal cancer and to their families. Hospice of Maine is supported by contributions and by a special projects grant from United Way.

Seventeen other hospice groups are in various stages of organization around the State. Over half of these are affiliated with or located in nursing and boarding homes and hospitals. Several religious groups are involved in the developing hospice movement in Maine.

RECOMMENDATION #15: VOLUNTEERS

#15A. Local Level. Volunteer efforts should be organized at the local level, with the involvement of agencies providing health care and supportive services, such as hospitals, home health agencies, social service agencies, et cetera.

#15B. Organized Program. Volunteers should be sought as part of an organized program which includes recruitment, orientation, supervision, in-service training, community recognition and reimbursement for expenses.

#15C. Stipends. There should be volunteers from all income levels. Stipends should be considered to make it possible for low income volunteers to become involved.

#15D. Tax-Exempt Organizations. Tax-exempt organizations should be required to substantiate their "good works" if their tax-exempt status is to continue. If these organizations are unable to provide convincing evidence that they have carried out projects of benefit to the common weal, then they should be required to pay taxes.

#15E. Religious Organizations. Churches, synagogues and other religious organizations should be informed about and urged to undertake more projects which address the long term care needs of Maine's citizens.

#15F. State's Responsibility. Through speeches, publications and other means, the Governor, the Commissioner of Human Services and the Commissioner of Mental Health and Corrections should emphasize the need for volunteers in the area of long term care.

#15G. Transportation. (See Recommendation #5C)

MAJOR FINDING

The Task Force believes that there are great reserves of volunteerism in Maine, which should be explored and tapped.

DISCUSSION

The Task Force notes that as the state and federal governments have taken on more and more responsibility for human service programs, voluntary and charitable organizations, including religious organizations, have cut back on their involvement in many areas. The Task Force is most impressed by the recent initiative taken by voluntary groups in the area of hospice services (See Recommendation #14). The Task Force believes that individuals and voluntary organizations will respond positively if they are informed about the very great need for their assistance in the area of long term care.

RECOMMENDATION #16: ACTION AT MUNICIPAL LEVEL

The Governor should submit to the 110th Maine State Legislature a bill to amend the general assistance statutes to require every general assistance administrator to maintain an updated and comprehensive directory of public and private long term care facilities and services available for residents of the municipality.

MAJOR FINDING

The Task Force finds that throughout the State there is a lack of knowledge about what long term care services and facilities are available.

DISCUSSION

The Task Force believes that the Department of Human Services and the Department of Mental Health and Corrections will have to work closely with the general assistance administrators to prepare and periodically update the directories. Governing units, especially those in the more rural parts of the State, should be allowed to use up to $150 per year from the amount raised for general assistance to pay for training for administrators about the types and availability of long term care services and facilities and about the needs and characteristics of individuals who may need such services and facilities.

RECOMMENDATION #17: ACTION AT FEDERAL LEVEL

The Governor should inform members of the Maine Congressional Delegation about the widespread support among Maine citizens for changes in federal law which would encourage the development of more in-home and community support services.

MAJOR FINDING

The Task Force finds that extensive changes are required in federal law and regulations to provide financing for more appropriate levels and types of care.

DISCUSSION

The Task Force believes that the two Senators from Maine should support S. 2809, the Senate bill which adds a Title XXI to the Social Security Act. The new Title would create a program of comprehensive, community-based long term care services, including home health, homemaker, adult day care and respite services; establish tax credits for families caring for dependent elderly relatives; and set up case management teams of health and social service professionals.

The Task Force believes that the two Representatives should support H.R. 6194, the House bill which provides for an increase in the federal Medicaid match to encourage the use of non-institutional alternatives for Medicaid eligibles who are at risk of institutionalization.

PART THREE:
RESIDENTIAL SERVICES

BACKGROUND

Recommendations #18 through #26 focus on changes required in the various types of residential services, in order to meet the two major principles of the Pineland Consent Decree: least restrictive environment and programming. These principles are important ones to keep in mind while examining residential services for all types of consumers of long term care services.

One aspect of the least restrictive environment principle is that the residence of an individual should be as much like home as possible. Readers should not lose sight of the fact that this notion underlies the pages and pages of details and ideas which follow.

Over the past year, the Task Force has heard, repeatedly, that a "home-like" environment cannot be defined. The Task Force disagrees and, to prove that it can be defined, quotes from an eloquent statement by the state official responsible for the licensing of nursing and boarding homes:

> "The word 'home' carries many significant connotations. Among them are coming and going as one wishes, and as one is able; receiving and entertaining visitors; having meals at one's own accustomed rate; having food which follows old familiar tastes and patterns; choosing one's time for solitude or activities with others; familiar possessions; selection of one's clothing for the day; following one's interests; using skills and developing new ones. All of these are important to a person's self-identity and self-fulfillment. All of these can be attained through programs and policies that express this philosophy. This concept of 'home' can be the most distinguishing feature of long term care of excellence for ...tomorrow."[1]

RECOMMENDATION #18: HOUSING

#18A. Section 8 Housing. The Department of Human Services, the Department of Mental Health and Corrections, the Maine State Housing Authority and interested consumers should meet to determine the need and allocation of "Section 8 existing units," and to develop and adopt more appropriate design standards for accessible units.

#18B. Statistics. The State Planning Office through its Housing Monitoring System should issue, annually, new housing construction statistics relating to the needs of elderly and disabled individuals.

#18C. Rehabilitating Homes. The Governor should submit legislation to the 110th Maine State Legislature to increase funding for rehabilitating homes owned or rented by low income elderly and disabled individuals, through a low income home repair grant program.

#18D. Reverse Mortgages. The Department of Human Services should continue its study of the use of "reverse annuity mortgages" by private lending institutions. The Department of Mental Health and Corrections should also examine this mechanism.

#18E. Accessible Buildings. The Governor should submit legislation to the 110th Maine State Legislature to require all newly constructed, publicly owned buildings (not just State owned buildings) to include design features which allow access for the physically disabled.

#18F. Low Rental Housing. There should be more accessible, low rental housing for both elderly and disabled individuals.

#18G. Tax and Rent Refunds. The Governor should submit legislation, recommending a tax and rent refund program for disabled heads of households.

#18H. Revenue Sharing. The Governor should encourage communities to use revenue sharing and community block grant funds to meet the housing needs of elderly and disabled individuals.

#18I. Retrofit Housing. The Governor and the Legislature should support efforts by the Bureaus of Maine's Elderly and Rehabilitation of the Department of Human Services and by the Bureaus of Mental Retardation and Mental Health of the Department of Mental Health and Corrections to build and retrofit housing for elderly and disabled individuals.

MAJOR FINDING

The Task Force finds that there are inadequate housing opportunities for many consumers of long term care services who are able to live in their own homes.

OVERVIEW OF HOUSING NEEDS AND ASSISTANCE

Need:

Many individuals who are elderly or disabled find that single family homes are too expensive, too difficult to maintain, or too isolated. Many of these individuals who reside on fixed incomes in urban areas and who rent apartments find that such accommodations are too expensive. Various housing opportunities have an important place among the long term care services available in Maine.

Subsidized housing can serve a preventive purpose, as well as a treatment purpose. It can delay or prevent institutionalization of an individual and it can encourage the independence of and enhance the quality of life for the individual.

The Maine State Planning Office finds that the "estimated need for housing assistance to the elderly population of the State, whether it be new units, supportive services or financial assistance is 27,453. In other words, approximately 22 percent of the elderly population (65 or over) are in need of housing assistance... The estimated need for housing assistance of the physically and mentally handicapped within the State is 10,657 or 12 percent of this population group."[2]

Federal Programs:

The Federal Government recognizes the importance of affordable housing. Section 8 of the Housing Act of 1937 permits participating owners, developers and public housing agencies to provide decent, safe and sanitary housing

for low income families at rents they can afford. Section 202 provides housing and related facilities for households of one or more individuals, the head of which is at least 62 years old or is disabled. There are also other federal and state programs directed to the housing needs of elderly and disabled individuals.

The Section 8 program is one of the most important housing alternatives that will be available in the future. Section 8 is part of an overall rental assistance program that is offered by the U. S. Department of Housing and Urban Development. In this program there are Section 8 units for substantial rehabilitation, new construction and moderate rehabilitation, and there are Section 8 existing units. It is the existing program that requires no construction expense, and allows individuals to live in their own apartments. HUD is currently expanding this program and this is an ideal time to make certain Maine utilizes these units.

Other Types of Housing Assistance:

Financial assistance (in the form of rent subsidies, tax and rent refunds, reverse mortgages or low interest loans) can help some individuals remain in their present dwellings.

For other individuals, home rehabilitation and modifications can provide assistance required to overcome mobility barriers in their present dwellings.

Shared homes are an approach which can meet the housing needs of many elderly and disabled individuals. Another approach is active solicitation of individuals for donation of homes. For example, parents of an individual with long term care needs can bequeath their home to a service agency, in return for care for the individual in the home. Other individuals with long term care needs could also reside in the home. Another approach involving shared homes is the use of housing companions. The Government could offer tax breaks or an agency could provide increased services to individuals with long term care needs who decide to live together.

RECOMMENDATION #19: CONGREGATE HOUSING

The Maine State Legislature and the Department of Human Services should establish a funding plan for congregate housing, after reviewing the outcome of the two congregate housing pilot projects funded by the 109th Legislature and administered by the Bureau of Maine's Elderly.

MAJOR FINDING

The Task Force finds that congregate housing is a residential option that can be used not only by the elderly, but also by other individuals with long term care needs.

DESCRIPTION OF CONGREGATE HOUSING

Definition:

The Bureau of Maine's Elderly, Department of Human Services, defines "congregate housing" as a "non-institutional, residential living environment," which addresses both the shelter and service needs of individuals who are "functionally impaired," but who do "not require the constant supervision or intensive health care of an intermediate care or skilled nursing facility."[3]

Similar types of housing arrangements include cooperative apartments for the mentally ill, mentally retarded, and the physically disabled. The goals for housing for these individuals are similar to those of congregate housing for the elderly.

The Elderly:

Increasing numbers of elderly individuals are having difficulty remaining in their own homes, including apartments. Many of these individuals are likely to have one or more chronic conditions (for example, heart conditions, hypertension, vision impairments, hearing problems and arthritis) which can lessen their ability to carry out daily living activities (such as shopping, cleaning, preparing meals and meeting personal care needs). Many of these individuals must also try to cope with rising utility expenses, property upkeep and social isolation. Congregate

housing can offer these individuals an important residential option which enables them to maintain their independence and freedom of choice and which, at the same time, provides a supportive environment.

Shelter and Services:

There are two components to the congregate housing concept. The shelter component offers individuals subsidized rental apartments in a residential complex, containing common areas where they may, if they so choose, share meals and other activities. The services component offers individuals, on an as needed basis, access to health and social support services.

The expected outcomes of congregate housing are improved nutrition, reduction of fear and anxiety, increased social interactions, increased physical activity, improved physical health, and feelings of purpose and usefulness.

Present Projects:

The 109th Maine State Legislature appropriated $87,000 (PL 1979, c. 717) to develop two congregate housing demonstration projects (one in a rural area and one in an urban area) specifically designed for elderly Maine citizens who are "frail." Administered by the Bureau of Maine's Elderly, the funding will be used to provide housekeeping, meals, and personal assistance, under the direction of a services coordinator, after the two projects have been built.

The rural project is being financed by the Farmers Home Administration and the urban project will be financed by the Maine State Housing Authority.

Occupancy in both projects is expected by late 1981.

Under PL 1979, c. 717, the Bureau of Maine's Elderly is required to evaluate the two demonstration projects and to report to the legislative Joint Standing Committee on Health and Institutional Services.

RECOMMENDATION #20: EATING AND LODGING PLACES

#20A. Licensing; Inventory. The Division of Health Engineering, Bureau of Health, Department of Human Services, should continue to be the agency responsible for licensing eating and lodging places with long term residents. On or before June 30, 1981, the Division should complete an inventory of eating and lodging places which have long term residents, but no transient guests. The inventory should include the location of each eating and lodging place and the number and type of resident in each.

#20B. Fire Safety. There should be a study group to examine whether and how fire safety needs to be improved in eating and lodging places which have long term residents, but no transient guests. The Commissioner of Human Services should appoint at least the following individuals to participate in the group: a representative of the Division of Health Engineering, a representative of the Division of Licensing and Certification, and an owner and a resident of an eating and lodging place for long term residents. In addition, the State Fire Marshal or his designee should participate in the group. The study group should complete its work on or before June 30, 1981.

#20C. Payments. The Governor should submit legislation to the 110th Maine State Legislature to amend 22 MRSA § 3273 to allow the Department of Human Services to supplement Supplemental Security Income payments for individuals who live in eating and lodging places with long term residents.

#20D. Residential Facilities Act. Eating and lodging places with long term residents should be subject to the provisions of the Residential Facilities Act, proposed in Recommendation #25.

MAJOR FINDINGS

The Task Force finds that there are some eating and lodging places which provide quality room and board services to long term residents, while there are others which provide inadequate services to them. The Task Force finds, further, that the State knows very little about which eating and lodging places have long term residents.

The Task Force believes that the Department of Human Services has taken what can be considered an unnecessarily skeptical view of eating and lodging places

with long term residents, and that the State should begin to concentrate more on and encourage the development of the positive aspects of these places.

DESCRIPTION OF EATING AND LODGING PLACES

Numbers: There are 400 combination eating and lodging places (including motel chains with restaurants) in Maine, licensed by the Division of Health Engineering. It appears that only a small number of these 400 cater to elderly residents or other individuals with long term care needs. In a recent study of eight eating and lodging places with long term residents, the Maine Committee on Aging found that the size of the places surveyed range from six to 50 residents.[4]

Definition: 22 MRSA § 2491, sub-§ 6, defines an "eating and lodging place" as any "building or structure or any part thereof kept, used as, maintained as, advertised as or held out to the public to be a place where eating and sleeping or sleeping accommodations are furnished to the public as a business, such as hotels, motels, guest homes and cottages." Some of these places present themselves as providing programs for individuals with long term care needs.

Regulation: The rules promulgated by the Department, regulating eating and lodging places, concentrate on sanitation requirements for food preparation, personnel, equipment and utensils; storage of equipment and utensils; sanitary facilities and controls; and construction and maintenance of physical facilities. The rules do not mention the provision of personal care or health care.

The Division of Health Engineering inspects eating and lodging places two times a year. When an inspector believes personal or health care is being provided, this is reported to the Division of Licensing and Certification, Bureau of Medical Services. The latter division does not have access to eating and lodging places under law, and must rely on good-will admittance by the owner or on a court-ordered search warrant to follow up on the referral.

Staffing: Rules for eating and lodging places make no reference to an operator or administrator. In its study, the Maine Committee on Aging found that one facility is administered by a Board of Directors, composed of local community

leaders. Others are owned and administered by one individual. Some places have the individuals in charge living full time in the facility, while others have individuals come in around the clock to supervise the residents. The size of staff varies greatly among the places.

Payments:

Many of the residents of eating and lodging places pay their own expenses. In its study, the Maine Committee on Aging found that the method of payment in eating and lodging places varies: Some places are well endowed; others have residents sign over all their assets in exchange for care for life; and others simply charge a monthly rate.

At present, there is no way that an individual who receives Supplemental Security Income payments can get additional assistance from the State to pay for the difference between the rate of an eating and lodging place and the amount of the SSI payments. The same individual would get supplemental state assistance if he or she were placed in a more expensive boarding care or adult foster care facility. The State could save money by supplementing SSI payments (22 MRSA § 3273) to individuals residing in eating and lodging places and, thereby, preventing unnecessary placement in more intensive, more expensive boarding care facilities.

Department's Concerns:

The Department of Human Services has been concerned that there are eating and lodging places which house elderly or other residents who, in fact, need nursing home or boarding home care. The Department often learns about eating and lodging places after former residents in declining health have been admitted into a boarding or intermediate care facility.

Occasionally, the Department receives a request for assistance to locate a boarding care bed for an individual, and later finds that the individual is residing in an eating and lodging place instead. The Department becomes concerned that the individual is receiving care that the facility is not licensed to provide or that the individual is not receiving the care required.

The Department has also been concerned that some facilities which have failed to receive a license to operate as a boarding care facility because of physical plant, budgetary or other limitations, have been able to receive a license to operate as an eating and lodging place.

Quality of Care:

The Maine Committee on Aging found that all of the eating and lodging places studied provide three meals a day, family-style around a table, plus snacks. Residents are ambulatory and encouraged to be independent. Residents are responsible for their own finances.

Individuals in charge of the places surveyed indicated consistently that they care for residents who become ill only for a short time, and that residents with extended illness are relocated to nursing homes or hospitals, if necessary. Residents are responsible for taking their own medications. Assistance is provided, when needed, in bathing or dressing.

The Maine Committee on Aging's study concluded that the residents of the eating and lodging places seem to be as well cared for or better cared for than residents of boarding care facilities. The study also notes that eating and lodging places seem to encourage independence, while boarding care facility residents - through extensive rules - are encouraged to be dependent.

RECOMMENDATION #21: ADULT FOSTER CARE FACILITIES

#21A. Changes Required in Licensing Law. The Governor should submit to the 110th Maine State Legislature legislation to modify PL 1979, c. 725 by:

- *Repealing the sunset provision which states that "rules adopted in 1980" by the Department of Human Services for the approval of foster care facilities "shall expire on December 31, 1980";*
- *Authorizing rates based on level of care and establishing minimum rates which the State must pay; and*
- *Requiring one set of standards for both foster care and boarding care facilities which have six or fewer beds.*

#21B. Responsibility. The Bureau of Resource Development, Department of Human Services, should not be responsible for licensing adult foster care facilities.

#21C. Residential Services Act. Adult foster care facilities should be subject to the provisions of the Residential Services Act proposed in Recommendation #26.

#21D. Case Management. There should be individual program plans for residents of adult foster care facilities, developed through the case management process proposed in Recommendation #29.

#21E. Training. (See Recommendation #47)

MAJOR FINDINGS

The Task Force finds that PL 1979, c. 725, enacted by the 109th Maine State Legislature, is confusing and requires modification. The Task Force also finds that the Division of Adult Protective Services, Bureau of Resource Development, is overburdened and understaffed, and, therefore, should not be expected to handle the approval process for adult foster care facilities.

DESCRIPTION OF ADULT FOSTER CARE FACILITIES

Numbers:

At present, there are over 200 approved adult foster care facilities in Maine serving approximately 300 individuals who receive Supplementary Security Income. The Veterans Administration also approves a number of foster care facilities for use by veterans.

There are not enough adult foster care facilities available for individuals who need extra services, especially those who are mentally retarded or who have physical handicaps. There is also a need for more facilities skilled in providing support for those with chronic mental health problems. Facilities are needed in urban as well as rural areas.

Statutes:

P.L. 1979, c. 725, signed into law by the Governor on April 2, 1980, adds the category of "adult foster care facility" to the Chapter (22 MRSA c. 1664) on boarding care facilities. This law states that "no adult foster care facility may be eligible to receive state reimbursement without first being approved by the Department of Human Services." The law requires the commissioner to adopt "rules concerning admission policies, safety, sanitation and protection of civil rights." The law also states that these rules "shall expire on December 31, 1980."

Adult foster care facilities are not subject to licensure. Instead, the Department of Human Services has established a less rigorous "approval" process. The original intent of P.L. 1979, c. 725 was to establish a licensure process. Prior to the enactment of this legislation, the Department carried out its approval process without any specific statutory authorization. The sunset provision and reference to "being approved" in Chapter 725 reflect the Legislature's ambiguity about precisely what role the Department should play in regulating adult foster care facilities.

The definition of adult foster care facility enacted by Chapter 725 overlaps with the statutory definition of boarding care facility. The law now states that adult foster care facilities serve four or fewer residents and boarding care facilities serve two or more residents.

Rates:

Operators of adult foster care facilities receive $255 per month for each resident who receives benefits under Supplemental Security Income (22 MRSA § 3271). The

rate for a resident who has private sources of income can be determined jointly by the operator and the resident. SSI recipients are allowed to keep $25-$45 per month for personal expenses. The Bureau of Mental Retardation can supplement this rate, in limited instances, when its clients have special needs to be met. The rate paid by the Veterans Administration is somewhat higher and is paid for with federal dollars.

Quality of Care:

Quality of care in adult foster care facilities is an issue. While, ideally, facilities should be rehabilitative, most are not and can foster further dependency. It is questionable who would provide these rehabilitative services and what funding sources could be used. However, vocational rehabilitation services might be used to a greater extent. A special type of facility is needed for individuals who may need help with specific activities of daily living, or for whom rehabilitation is a goal.

RECOMMENDATION #22: BOARDING CARE FACILITIES

#22A. New Categories of Facilities. There should be new and separate categories for the various types of facilities presently licensed as boarding care facilities. These facilities, including group homes, transitional living facilities and regular boarding care facilities, should be licensed pursuant to the Residential Services Act proposed in Recommendation #26.

#22B. New Level of Care. There should be a new level of boarding care for individuals who need a degree of supervision and assistance which is more than boarding care facilities are presently authorized to provide, but less than that provided in intermediate care facilities, which:

Reimbursement. Should be reimbursed under the State Medicaid Program;

Focus. Should focus on the social, emotional psychological and physical needs of residents;

Name. Could be called ICF-BC (intermediate care facility for boarding care);

Size. Should include facilities with over 15 beds; and

Residential Facilities Act. Be subject to the provisions of the Residential Facilities act proposed in Recommendation #26.

#22C. Standards. Standards for boarding care facilities, including group homes and transitional living facilities, should be "psychosocial" in nature rather than medical:

Definition. "Psychosocial" services should build on the strengths and potentials of residents and should include:

- Independent living skills training (development of skills in daily decision-making, personal budget planning, personal hygiene, cooking, et cetera);
- Employment skills training (evaluation of current and potential employability, development of vocational plans for individuals, and participation in transitional employment or a sheltered workshop); and
- Social skills training (development of skills for interpersonal social behavior through group therapy).

Participation. The Department of Human Services should actively seek consumer and provider participation prior to and during development of new licensing standards for group homes and transitional living facilities.

#22D. Case Management. An assessment of needs, problems and abilities of residents of boarding care facilities should be undertaken, as part of the case management process proposed in Recommendation #29. Placement of individuals in boarding care facilities and individual program plans for the residents should be accomplished pursuant to the process described in Recommendation #29.

Operators of boarding care facilities should have information about each resident's significant previous history and current treatment plan, and should be informed about any difficulties or extenuating circumstances involving the resident. Operators should participate in the discharge planning process for residents coming into facilities from mental health institutes or other residential facilities.

#22E. Services. In order to fill in the gaps in activities and services in boarding care facilities, the following actions should be taken:

Activities. The State should require and pay for a higher level of activity (including social, psychological and vocational services) so that facilities will more closely approximate "normal" home situations. In addition, the State should provide for increased responsibilities for activity coordinators and commensurate salary increases for these coordinators.

Mental Health Services. The State Medicaid Plan should be amended to designate facilities as eligible sites for the delivery of mental health services by both community mental health centers and private providers of mental health services. A condition of state funding for community mental health centers should be the development of cooperative agreements, between the centers and facilities. A suitable portion of this funding should be allocated for services listed in the cooperative agreements, which are not allowed under the State Medicaid Plan or other third-party payors. The emergency services of community mental health centers and acute care hospitals should provide, as a priority, crisis intervention at the site where the crisis occurs to residents of boarding care facilities (and to consumers of long term care services who reside in other settings).

Vocational Services. The Bureau of Rehabilitation, Department of Human Services, should strengthen and expand its efforts to serve the most severely disabled, including the emotionally disabled residents of facilities and residents with little or no employment potential. The Bureau of Rehabilitation should ensure that counselors are provided with modified success criteria. (See also Recommendation #10)

Transportation. Small facilities should be reimbursed for transportation services and should be encouraged to become involved in car pooling and group purchasing of insurance for vehicles.

#22F. Encouraging Independence. The following steps should be taken to encourage residents to be independent:

Standards. Licensing standards should be reviewed and modified to encourage residents to function more independently. Regulations for particular client groups should be developed to address the particular needs of each group.

Physical Plant. Physical plant requirements should be modified to enable the creation of more home-like settings. Facilities designed to serve physically disabled individuals should meet American National Standards Institute accessibility criteria, as well as any standards adopted by the Maine State Housing Authority.

Legislation. The Governor should submit legislation to the 110th Maine State Legislature to amend the licensing statutes for boarding care facilities (22 MRSA § 7904) so that all facilities with 15 beds or fewer will be allowed to meet less stringent Life Safety Code standards. (The law presently includes his as a special provision for facilities for the mentally retarded. The suggested legislation would simply make the special provision a general provision, applicable to all facilities with 15 beds or fewer.)

Residential Facilities Act. All of the proposals under this recommendation (#22F) should be incorporated to the Residential Facilities Act proposed under Recommendation #26.

#22G. Physically Disabled. The Department of Human Services should recognize the use of transitional living facilities connected to independent living programs as a viable option for severely physically disabled individuals. The Department should amend the State Medicaid Plan to enable these individuals to receive personal care assistant services in these facilities.

#22H. Coordination. There should be reorganization of functions relating to boarding care facilities within the Department of Human Services in order to achieve greater regional conformity, as well as state-level coordination. There should be a single responsible entity, other than the Commissioner, ultimately responsible for decisions relating to all aspects of boarding care facilities.

There should be a boarding care facility information system to apprise agencies and individuals of vacancies on a facility-by-facility basis.

#22I. Substandard Facilities. (See Recommendation #31)

#22J. Payments; Ceiling. (See Recommendation #36)

#22K. *Development of Nonprofit Facilities.* (See Recommendation #43)

#22L. *Wages.* (See Recommendation #45)

#22M. *Training and Qualifications.* (See Recommendation #47)

MAJOR FINDINGS

The Task Force finds that because boarding care facility licensing statutes and regulations apply to a great variety of facilities, they are not always responsive to the goals of particular types of facilities.

The Task Force also finds that because there is inadequate funding for boarding care facilities, there is a lack of programs and services for residents of these facilities.

The Task Force also finds that residents of most boarding care facilities are not encouraged to live their lives as independently and normally as possible.

CURRENT SYSTEM OF BOARDING CARE FACILITIES

Numbers: There are over 300 licensed boarding care facilities in Maine, ranging in size from three beds to over 100 beds. Approximately 235 facilities have six beds or less and 83 facilities have over six beds. Almost 3,500 individuals live in these facilities, including over 1,300 in the small facilities and over 2,000 in the facilities with over six beds. These facilities are licensed by the Division of Licensing and Certification, Bureau of Medical Services, Department of Human Services.

Definition: Maine law (22 MRSA § 7901) defines a "boarding care facility" as "a house or other place having more than two residents which, for consideration, is maintained wholly or partly for the purposes of boarding and caring for the residents." This section of the law goes on to define "resident" as "any aged, blind, mentally ill, mentally retarded or other person 16 years of age or older who is not related by blood or marriage to the owner or person in charge of the boarding care facility in which the resident lives."

Buildings:

Most boarding care facilities are converted, two-story family structures. Very few (around 12) are single story new buildings that comply with the Life Safety Code. Some are converted apartment buildings.

Small Group Homes:

There are no statutory licensing provisions or standards geared specifically to a category called "small group homes." The special category of boarding care facilities with six or fewer beds for mentally retarded individuals referred to above are commonly known as small group homes. There are around 60 boarding care facilities serving mentally retarded residents. These are distinguished from other boarding facilities of the same size by the higher rates of reimbursement required under 22 MRSA § 7906 and by the fact that most of them are private-nonprofit agencies.

Mentally Retarded:

Around one-third of all boarding care facilities have mentally retarded residents. The licensing statutes for boarding care facilities sets up two special categories of facilities for mentally retarded individuals.

22 MRSA § 7904, sub-§ 3 allows any boarding care facility for mentally retarded individuals "which has a capacity of less than 16 beds" to comply with fire and safety provisions for eating and lodging places. These provisions are less stringent than provisions applied to other boarding care facilities of that size and larger.

22 MRSA § 7906, prohibits the Department of Human Services from denying, "solely by reason of size, to any boarding care facility which has a capacity of six or less residents and which serves only mentally retarded persons..." reimbursements based on reasonable costs.

Transitional Living Facilities:

There are no statutory licensing provisions, standards or reimbursement mechanisms geared specifically to transitional living facilities (including halfway houses). Some of these facilities are licensed by the Department as boarding care facilities and others are licensed as eating and lodging places. Transitional living facilities which provide mental health services must also be licensed by the Department of Mental Health and Corrections, insofar as program content and procedures are concerned. (34 MRSA § 2052-A)

Presently, in Maine there are three licensed halfway houses providing services to a total of 31 adult residents. There

are four more transitional living facilities on the drawing board, of which one will be financed by the Farmers Home Administration and three of which will be newly constructed and financed by the U. S. Department of Housing and Urban Development. In addition, there are six halfway houses serving 35 individuals at Augusta Mental Health Institute and one halfway house serving 15 individuals at Bangor Mental Health Institute.

The average length of stay in existing halfway houses is eight months. The cost of one facility located in Augusta is $100,000 per year. In three years this facility has served 45 individuals.

Rates: Boarding care facilities with six beds or less (other than facilities for mentally retarded individuals) receive $305 per month per resident. Facilities with over six beds are reimbursed for reasonable costs, based on principles of reimbursement very similar to those used for intermediate and skilled nursing facilities. However, the facilities with over six beds have a ceiling of $465 per month per resident. The capital costs (interest, depreciation and taxes) are paid in full, in addition to routine service costs.

MAJOR ISSUES

Catch-All Category: "Boarding care facility" is a catch-all category for many different kinds of facilities. Except for small facilities (fewer than 16 beds) for mentally retarded and other developmentally disabled individuals, the law gives no special consideration to the different kinds of facilities. The following facilities are all licensed under the same laws (22 MRSA c. 1663 and 1664) and rules adopted thereunder:

- large facilities, often characterized by a nursing home-like atmosphere and very few activities;
- large facilities for the well-elderly, which are very much like congregate housing programs;
- small boarding homes with restrictive, dependency-creating supervision and very few activities;
- small group homes for mentally retarded and other developmentally disabled individuals, characterized by a home-like atmosphere and heavy programming, both in homes and out in the community; and

- transitional living facilities (that is, halfway houses) for chronically mentally ill individuals, characterized by a home-like atmosphere and a heavy emphasis on preparing residents for independent living out in the community.

New Level of Intermediate Care:

New construction of boarding care facilities is impossible because of ceilings placed on reimbursement. Construction standards for boarding care facilities differ only slightly from standards for intermediate care facilities. The basic differences are in door and corridor size: Boarding care facilities must have corridors that are six feet wide and doors that are 36 inches wide, while intermediate care facilities must have eight-foot corridors and 42-inch doors. Because these standards are so similar, it appears that boarding care facilities could be constructed to meet intermediate care standards for only a small increase in cost.

The State could adopt a new level of boarding care which is less intensive than intermediate care and which would be appropriate for individuals residing in certain boarding care facilities. The State could license the 12 or so single-story new boarding care facilities at this new level of care. This new level of care would provide incentives to build new boarding care beds, because a 70 percent federal match for these beds would be available under the Medicaid Program.

Who is Living in Facilities:

There are some estimates of the extent of use of boarding care facilities by different types of individuals. The Bureau of Maine's Elderly, Department of Human Services, estimates that 2,665 elderly individuals reside in boarding care facilities.[6] The Community Support Systems Project, Department of Mental Health and Corrections, estimates that around 600 deinstitutionalized mentally ill individuals reside in boarding care facilities. One third of all boarding care facilities have mentally retarded residents.

However, of the 3,500 residents of these facilities, the Department of Human Services is not able to state with precision how many elderly, physically disabled, mentally retarded, or chronically mentally ill: are not severely disabled, receive no governmental support and have chosen to live in a boarding care facility, and are clients of the Department of Human Services, or other agency.

Kevin Concannon, Commissioner of Mental Health and Corrections has noted that as mentally retarded individuals

have been moved to higher quality placements, vacancies they have left in boarding care facilities have been filled by the chronically mentally ill.

The State collects no data to indicate the health, mental health or social needs of residents of boarding care facilities. Because residents are not assessed, problems are discovered in a haphazard, case-by-case manner. There is no tracking of residents as they move into and out from boarding care facilities.

Lack of Programs and Services:

Many residents complain of boredom and isolation in boarding care facilities. The level of activities and community interaction varies widely among facilities.

The Principles of Reimbursement of the Department of Human Services state that one half hour per week per resident is the minimum allowable time for resident activities coordinators. Justification and prior approval are required for more than one half hour per week per resident, but the Principles do not include the criteria that will be applied.

Operators have little financial inducement to operate more than custodial care facilities. There are no standards in effect for the social, vocational, avocational and "life skills" training which many residents need.

At present, there are no individual program plans for most residents of boarding care facilities. Inappropriate placements and transfers will continue to occur, unless a plan addressing specific needs is developed and carried out for each resident.

Many residents are able and willing to become productive members of the community, while still living in the supportive environment of a boarding care facility. There has been no concerted effort to assess the potential of residents for employment.

Transportation for residents of boarding care facilities is a major gap.

Lack of Mental Health Services:

The staff of boarding care facilities are not equipped to deal with either emergency or non-emergency mental health problems of residents. At the same time, lack of support by community mental heatlh centers adds to the inadequacy of mental health services for the residents. Individuals

who have been "deinstitutionalized" from Augusta Mental Health Institute or Bangor Mental Health Institute and elderly individuals who are becoming progressively more disoriented are the residents in greatest need of these services.

Specific problems include:

- lack of participation in admission and discharge planning from the two mental health institutes;
- differences in discharge planning between the two institutes;
- lack of availability of clinical staff of community mental health centers to boarding care facilities for routine follow-up or crisis intervention;
- inability to adequately monitor medications;
- inability to refer residents back to a state institute when this is clearly needed;
- lack of training to help staff of boarding care facilities understand and deal with residents exhibiting psychiatric problems.

Encouraging Independence:

The State pays lip service to "least restrictive" environment, "normalization" and home-like settings. However, the licensing and reimbursement policies of the Department of Human Services do not provide the incentives to translate these principles into reality.

For example, small group homes can provide a very normal and supportive environment for many clients. However, boarding care facilities with six beds or under (except for facilities for mentally retarded residents) are paid less per resident than larger facilities are paid. These facilities are clearly in a less favorable financial position than the larger ones. Available capital for opening small facilities, particularly by nonprofit groups, is practically non-existent.

In addition, licensing regulations seem to assume that residents are unwilling or unable to do anything for themselves and that all daily and routine tasks must be performed by staff.

Another problem with licensing regulations is that they seem to encourage facilities to have an institutional rather than a home-like atmosphere. The regulations make it extremely difficult to renovate existing structures which could be more cost-effective and therapeutic than building new facilities. The emphasis is needed on how to make the physical plant meet the program needs of residents.

There appears to be a tendency for operators to discourage residents from developing self-sufficiency and to avoid residents who are more independent. This tendency may be caused by a fear that such residents will create more work for staff who are already overworked.

Coordination:

There is fragmentation and lack of collaboration on the part of agencies involved with boarding care facilities. For example, there have been discrepancies between decisions made by the Division of Hospital Licensing in the Bureau of Medical Services and the Division of Health Care Audit in the Bureau of Administration, regarding prior approvals for training and other activities.

It is difficult to decipher standards, regulations, and policies for boarding care facilities, because responsibility for these facilities is diffused among several different agencies in the Department of Human Services. Other than the commissioner, there is no single entity ultimately responsible for decisions relating to boarding care facilities.

In addition, there is evidence of wide variation among regional offices and individual employees in the interpretation and application of standards, regulations and policies.

RECOMMENDATION #23: INTERMEDIATE CARE FACILITIES

#23A. Specialized Intermediate Care Facilities. The following steps should be taken to develop specialized intermediate care facilities:

Mentally Retarded Individuals: The Department of Human Services and the Bureau of Mental Retardation should continue to work together to develop ICF-MR (intermediate care facility for the mentally retarded) regulations that will result in the least restrictive facilities.

Chronically Mentally Ill Individuals. The Governor should urge officials in the U. S. Department of Health and Human Services to adopt ICC-MH (intermediate care center for mental health) regulations. The Department of Mental Health and Corrections should take the lead in obtaining from the U. S. Department of Health and Human Services a grant or a waiver which would enable the State to try out the ICC-MH on a demonstration basis, as a first step toward developing these facilities where they are needed.

Physically Disabled Individuals. The Department of Human Services should investigate the desirability and possibility of developing intermediate care facilities for physically disabled individuals.

#23B. Rehabilitation Services. The Department of Human Services should:

Maintenance Therapy. Adopt a more flexible approach to the issue of maintenance therapy and should reimburse for repetitive physical and occupational therapy services provided by qualified therapists in intermediate care facilities;

Policies and Allowances. Review its policies and allowances for physical therapy services and occupational therapy services and increase them so that providers will be willing to make these services available;

Aides. Reimburse intermediate care facilities for the cost of physical and occupational therapy aides, above and beyond normal staffing patterns, in accordance with standards mutually agreed upon by the Department and the facilities;

Training and Consultation. Permit intermediate care facilities to engage the services of consultant physical and occupational therapists for the purposes of team conferences and staff education and training in safety procedures and care of residents;

Restorative Nursing. Review provisions in the Principles of Reimbursement relating to licensed nursing staff, with a view toward assuring the provision of "restorative" (that is, rehabilitative) services to residents of intermediate care facilities; and

Social Services. Recognize the importance of professional social service consultants (including, particularly but not necessarily solely, individuals with a Masters degree in social work) by reimbursing for their services in intermediate care facilities on the same basis that their services are reimbursed for in skilled nursing facilities; and work toward improving the qualifications and training of social service designees.

#23C. Residential Facilities Act. Intermediate care facilities should be included in the Residential Facilities Act proposed in Recommendation #26.

#23D. Reimbursement. (See Recommendation #36)

#23E. Wages and Benefits. (See Recommendation #45)

#23F. Training. (See Recommendations #45, #46 and #48)

#23G. Discrimination. (See Recommendation #49)

MAJOR FINDINGS

The Task Force finds that in the case of intermediate care beds, supply meets demand more closely than is true of most other types of long term care services. As a result, major development of new intermediate care facilities is not required. The Task Force finds that any development that does occur needs to be in rural areas and in the area of specialized services for individuals with particular needs, such as mentally retarded, physically disabled and chronically mentally ill individuals.

The Task also finds that the State needs to take several actions to improve the quality of rehabilitation services provided in intermediate care facilities.

DESCRIPTION OF INTERMEDIATE CARE FACILITIES

Numbers: There are over 140 intermediate care facilities in Maine. According to the Bureau of Health Planning and Development, Department of Human Services, almost 8,000 individuals

reside in nursing homes (that is, intermediate care and skilled nursing facilities). Over 95 percent of these 8,000 individuals reside in intermediate care facilities.

In 1978, 76.5 percent of these residents were age 75 and over. Almost 40 percent were age 85 and over. The Bureau's statistics indicate that Maine's population residing in intermediate care facilities is older than the nursing home population in the nation as a whole.

Other individuals residing in intermediate care facilities include the chronically mentally ill and the physically disabled whose degree of disability is such that they cannot live in the community or for whom alternate living arrangements are not available.

In addition, "medically involved" ICF-MR's (intermediate care facilities for the mentally retarded) serve mentally retarded individuals.

Definition:

The Maine Certificate of Need Act of 1978 defines "intermediate care facility" as "an institution which provides, on a regular basis, health-related care and services to individuals who do not require the degree of care and treatment which a hospital or skilled nursing facility is designed to provide, but who because of their mental or physical conditions require health-related care and services above the level of room and board." (22 MRSA § 303, sub-§ 12)

The statute which authorizes the Department of Human Services to license hospitals, sanatoriums, convalescent homes, rest homes, nursing homes or other institutions "for the hospitalization or nursing care of human beings" is outdated. (22 MRSA § 1811 et. seq.) It does not use the term "intermediate care facility," even though the Department licenses over 140 of these facilities.

Specialized Facilities:

There has been a large gap in intermediate care facility beds for mentally retarded individuals. At one time, the need for ICF-MR beds was estimated to be 200. A legislative appropriation provided seed money to develop this number of beds. Presently, six ICF-MR's are in operation, including two owned and operated by the State. In addition, the Department of Human Services and the Department of Mental Health and Corrections have worked together to promulgate new rules, specifically geared to ICF-MR's.

Twenty-two group homes will be converted into ICF-MR's regulated pursuant to these rules and, thereby, reimbursed under the Medicaid Program.

The Court Master for the Pineland Consent Decree is concerned about the new ICF-MR rules because, he believes, they do not satisfactorily meet the two principle objectives underlying the decree: least restrictive environment and programming. (See page 9)

There are no specialized intermediate care facilities for physically disabled or mentally ill individuals. The Task Force heard compelling testimony about the need to develop facilities, specifically geared to the needs of these individuals. For example, the Task Force learned that sometimes younger, mentally alert, physically disabled individuals end up in intermediate care facilities, along with elderly residents with totally different needs, only because no other service or type of facility is available.

Rehabilitation Services:

Rehabilitation services in intermediate care facilities are intended to restore impaired function and maintain function at the highest possible level. They include physical therapy, occupational therapy, speech therapy, hearing therapy, diet therapy, and social work. In addition to restoring and maintaining functioning, they can improve the quality of life and permit discharge from facilities to homes or less costly alternative living arrangements.

Many of the 8,000 residents of intermediate care facilities are eligible for rehabilitation services, but few receive the services. Strong financial and other constraints restrict the availability of services.

Rehabilitation services are mandated by regulation for skilled nursing facilities under the Medicare and Medicaid programs. They are not required services for residents of intermediate care facilities, though they are available in accordance with strictly defined Medicaid criteria.

A distinction is made between rehabilitation and maintenance. The Medical Assistance Manual for the State of Maine states that "evaluation and restoration therapy are the only covered service" and that "maintenance therapy is not a covered service." Physical therapists and providers of nursing home services dispute the State's contention that "the repetitive services required to maintain function

do not involve the use of complex and sophisticated physical therapy procedures, and consequently the judgment and skill of a qualified physical therapist are not required for the safe and effective rendition of such services." They point to the patient with Parkinson's disease, multiple sclerosis, spastic stroke, lung disorders and arthritis and suggest the need for hands-on physical therapy over an extended period of time without which the resident will vegetate.

Maximum allowances for physical therapy services are inadequate to purchase such services, have not been increased for several years, and mitigate against the provision of such services, particularly in smaller facilities with small caseloads. Nor do they take into consideration transportation needs. In some parts of the State, home health agencies have refused to provide physical therapy and other rehabilitation services to intermediate care facility residents because of the inadequacy of the allowance.

The specialized nature of certain therapy can be a problem. Occupational therapy designed to promote restoration of impaired function in activities of daily living involving the upper extremities is an essential component of the rehabilitation process. The demand for the service is less extensive than that for physical therapy; the caseload is very small and treatment infrequent. The inadequate maximum allowance provided by the Department of Human Services operates against the recruitment of occupational therapists to serve Medicaid residents. Home health agencies find it economically unfeasible to provide the service.

Services Not Covered Under Medicaid:

Some necessary services are not covered at all under the State's Medicaid Program.

First, certain supportive services are not covered. The Department of Human Services does not reimburse intermediate care facilities for the services of physical therapy aides. These services are needed. Also excluded is reimbursement for those who provide for transportation of residents to and from the physical therapy room and those who perform other support services under the supervision of the therapist. In the absence of reimbursement, the facility must either absorb the cost of this service or require the therapist or nursing staff to provide transportation and other assistance. Constraints upon available nurse staffing time tend to place the burden upon the physical therapist.

Second, the Department of Human Services reimburses a physical therapist for the initial evaluation of the resident's needs, the designing of a maintenance plan, the instruction of staff and the integration of the physical therapy plans into the total case plan. However, it does not reimburse the physical therapist for educational activity with staff on an ongoing basis, to assure the safety of the resident and staff and the proper implementation of restorative case procedures. With the high staff turnover rate among nurse aides and the financial risks involved in accidents to residents and staff, it appears financially prudent to require staff training in safety procedures in transfer and ambulation of residents by staff.

Third, the implementation of a case plan for intermediate care facility residents involving restorative nursing requires not only the input of professional nurses and physical therapists, but also an adequate number of trained nurse aides. Limitations on levels and quantity of nurse staffing imposed by the Principles of Reimbursement make it difficult for nursing homes to provide little more than custodial care. Restorative nursing becomes the first victim of short staffing and residents are often left to vegetate.

Finally, the intermediate care facility has been viewed traditionally in terms of a medical model, a less costly alternative to hospitalization. The focus of attention by the regulatory agencies has been on nursing and rehabilitation services designed to promote physical well-being. Social and emotional factors have been and continue to be ignored in Medicaid patient classification, levels of care determinations, and staffing requirements. Yet it is the emotional well-being of the residents, their will to live, and their feeling of control over their lives that colors the quality of their lives and often affects their willingness and ability to leave the facility for alternative living arrangements. The role of the social worker in the area of rehabilitation which has been accepted by Medicaid and Medicare in skilled nursing facilities has not been given the same recognition by the Department of Human Services in intermediate care facilities. Social services may be provided by persons without professional training and no professional consultation is required. The State Legislature enacted legislation calling for such professional consultation in 1979, but implementation was postponed to 1981.

Appropriateness of Placement:

Appropriateness of placement is a national concern, which is assuming increasing importance in an era of cost consciousness. The Bureau of Health Planning and Development states that "while no statewide information exists, national estimates imply that inappropriate placement may be widespread."[7] If this were applied to Maine's current estimated 8,000 intermediate care facility population, the result would be 1,600 inappropriately placed individuals.

The Bureau suggests that one way to ameliorate the problem is to combine the mechanism of "entry level screening" with a full complement of service alternatives. It adds, however, that "at present no pre-admission screening programs exist in Maine." (The Task Force notes that the Division of Medicaid Surveillance, Bureau of Medical Services, Department of Human Services, does provide screening for individuals eligible for Medicaid who enter intermediate care facilities.)

The issue of inappropriateness of placement in intermediate care facilities, to whatever extent it exists, will most certainly not be successfully addressed until these recommendations of the Bureau are implemented.

Reimbursement:

A major issue involving intermediate care facilities is the adequacy of reimbursement for services rendered. (See also Recommendation #36. At stake are the financial viability of these facilities and the quality of life of their residents. The State of Maine is the largest purchaser of intermediate care services. Approximately 85 percent of intermediate care facility residents receive Medicaid assistance and the percentage is increasing.

The Department of Human Services promulgates principles of reimbursement and establishes policies governing reimbursement procedures. Providers question the wisdom of some of these principles and policies.

It is understandable that in a period of growing inflation and taxpayers' concern over growing public expenditures for human services as well as other government services, that real problems involving priorities and choices exist. It is hoped that final decisions regarding reimbursement will allow intermediate care facilities to maintain their vital role in the provision of services to individuals with long term care needs.

Discrimination: Added to the issue of reimbursement is the concern expressed by various agencies of government and consumers over the preferential treatment by intermediate care facilities accorded private pay applicants over Medicaid applicants in the admissions process. (See also Recommendation #49) To the extent that economic pressures related to rapidly rising costs and fees are driving private pay applicants out of the market and forcing them to turn to Medicaid for assistance, the problem may be expected to disappear. At present, only a few states deny providers the right to discriminate on financial grounds in the admissions process.

Staff: A major issue relating to the care of individuals with long term care needs is a shortage of staff, particularly on the nurse aide level. (See also Recommendations #45 and #46) This relates primarily to the fact that starting wages paid to non-professional employees in intermediate care facilities are either at or near the minimum wage. Low wages lead to difficulties in recruitment, brief tenure, high turnover, excessive orientation costs, low morale, and most importantly, disruption of the lives of residents who must experience loss of staff, in addition to all the other losses attendant upon entry into the facility.

RECOMMENDATION #24: SKILLED NURSING FACILITIES

#24A. Role Reaffirmed. The Governor and the Commissioner of Human Services should reaffirm the importance of the role of skilled nursing facilities in the array of long term care services.

#24B. Reimbursement. The Governor should alert members of Maine's Congressional Delegation to the threat to the survival of free-standing skilled nursing facilities, caused by the different reimbursement rates paid to free-standing and hospital-based skilled nursing facilities. ($45 per day for the former and $86 per day for the latter.)

#24C. Retention in Hospitals. The unnecessary retention of individuals in hospitals should be discouraged. The Professional Standards Review Organization and the fiscal intermediaries under Medicare should monitor more closely patient needs, adequacy of hospital services to meet those needs and availability of skilled nursing services to meet those needs. Also, there should be improved coordination between physician services (Part B under Medicare) and hospital services (Part A under Medicare).

#24D. Availability. The Maine Health Systems Agency should monitor the need for and availability of skilled nursing facility services in various parts of the State to ensure that those who need these services will receive them.

#24E. Classification. The Department of Human Services should continue its flexible posture, with respect to the determination of eligibility for admission to and continued stay in skilled nursing facilities.

#24F. Residential Facilities Act. Skilled nursing facilities should be subject to the provisions of the Residential Facilities Act proposed under Recommendation #26.

MAJOR FINDING

The Task Force finds that there is a trend to squeeze skilled nursing facilities, in particular free-standing facilities, out of the array of long term care services. The Task Force finds, further, that skilled nursing facilities play and must continue to play an important role in the provision of long term care

services. Most significantly, the Task Force finds that elderly individuals in Maine are being denied their right to receive Medicare benefits, because they are not being classified to skilled nursing care, when needed, as a result of the fiscal intermediary's interpretation of eligibility under Medicare for this level of care.

DESCRIPTION OF SKILLED NURSING FACILITIES

Numbers:

There are approximately 441 licensed skilled nursing facility beds in Maine; 194 of them are in 10 hospital-based facilities and 247 of them are in seven free-standing facilities. Of Maine's 8,000 citizens living in nursing homes, approximately 3-4 percent are classified as requiring skilled nursing facility care.

The number of skilled nursing beds exceeds the number of skilled nursing patients in the facilities at any given time. This may be a result of excess bed supply; unavailability of skilled nursing patients to fill vacancies, which are then filled by patients requiring a lesser level of care; or unavailability of alternative in-home services, community support services, or institutional care settings for patients awaiting discharge from skilled nursing facilities.

Definition:

The Maine Certificate of Need Act of 1978 defines a skilled nursing facility as "an institution or a distinct part of an institution which is primarily engaged in providing to in-patients skilled nursing care and related services for patients who require medical or nursing care, or rehabilitation services for the rehabilitation of injured, disabled or sick persons." (22 MRSA § 303, sub-§ 19)

As in the case of intermediate care facilities, the licensing statute (22 MRSA § 1811 et. seq.) does not use the term "skilled nursing facility," even though the Department licenses such facilities.

Enactment of Federal Legislation:

The skilled nursing facility came into existence in Maine in 1967, following passage in 1965 of the Title XVIII amendments to the Social Security Act, which provided Medicare coverage to individuals age 65 and over. In 1972, there were additional amendments to the Social Security Act, which extended Medicare coverage to disabled individuals under age 65 and to those with chronic renal disease.

The skilled nursing facility was intended to bridge the gap between the acute hospital and the intermediate care facility and to provide a less costly alternative to hospitalization.

Eligibility:

To qualify for skilled nursing facility coverage under Medicare for up to a maximum of 100 days per spell of illness, an individual must need on a daily basis skilled nursing or other rehabilitation services for any of the conditions for which he received medically necessary inpatient hospital care of at least three days in duration, or for a condition which arose while he was in a skilled nursing facility receiving care for such condition.

Federal Medicaid regulations waived the requirement for prior hospital stay; provided for skilled nursing facility care for an indefinite period of time when medically indicated; adopted a more flexible interpretation of the rigid Medicare medically oriented eligibility criteria for admission and continued stay; and allowed for consideration of "social and emotional factors which may jeopardize the patients' health and welfare."

Classification and Certification:

There is much confusion about interpretations of eligibility criteria for admission to and continued stay in skilled nursing facilities. This extends to the public, attending physicians, discharge planners, members of utilization review committees, state surveyors, and skilled nursing facility personnel. Much time and energy and expenditure of funds are devoted to this subject. One result is that physicians are reluctant to certify patients for skilled nursing care, only to have their judgment questioned or countermanded, and patients remain in hospitals for periods longer than may be necessary.

Physicians, with some justification, also resist demands upon their time to countersign medical orders within 48 hours, to make special visits to sign medical necessity stickers and recertifications, and to engage in a host of additional paperwork.

Location of Services:

Skilled nursing facility services are provided in a variety of settings: the hospital-based facility with access to hospital support services, the free-standing facility with its organized medical staff and laboratory and other support services, and the free-standing facility which relies on attending physicians and hospitals for laboratory and diagnostic services.

Funding:

Skilled nursing facility services under Medicare are funded by the Social Security insurance mechanism and by private coinsurance and third-party insurance payors. Skilled nursing facility services have become available to the medically indigent and categorically needy under the Medicaid Program on a state and federal matching fund basis.

Approximately 50 percent of the income obtained by skilled nursing facilities is generated by Medicaid and Social Security sources. Medicare pays for 40 percent of the cost of care and patients and third-party insurance payors provide the remaining 10 percent.

Costs and Reimbursement:

Skilled nursing facility services are more labor intensive than those provided by intermediate care facilities, and are, therefore, more costly. The costs range from $40-$80 per day. Nevertheless, they are much less expensive than similar services provided in hospitals.

There is a trend toward providing a higher per diem reimbursement rate for the hospital-based skilled nursing facilities. This will inevitably lead to higher costs for the public, through increased Social Security and taxes.

In recent months, both Medicare and Medicaid have imposed ceilings on per diem reimbursement for skilled nursing facility care of $45 for free-standing facilities and $86 for hospital-based facilities. This imposes a financial hardship on the free-standing facilities, threatens their very existence, and has already led to the closing of a 74 bed facility in the Portland area in recent months.

RECOMMENDATION #25: STATE INSTITUTIONS

#25A. Part of System. The state institutions for individuals who are mentally retarded and mentally ill should be part of the system of long term care services for these individuals.

#25B. Role. The role of these institutions should be to:

Long Term Services. Provide habilitation, treatment and residential services to a small number of individuals for whom an institution is, in fact, the least restrictive environment, consistent with the best interests of these individuals, as determined by a program plan for each of these individuals.

Specialized Services. Provide time-limited, specialized services such as respite care, emergency service, medical treatment, and other programs for individuals with unique and complex needs until such time that these programs are available in the community.

Resource Center. Serve as a training, educational and resource center for individuals working with consumers of long term care services, including operators and administrators of facilities and agencies and staff providing direct care and support services.

MAJOR FINDINGS

The Task Force finds that, at the present time, there continues to be a limited role for state institutions to play in the array of long term care services. The Task Force also finds that the cost of services is very high: $30,000 per individual per year.

DESCRIPTION OF STATE INSTITUTIONS

History of Mental Health Institutes:

The history of services for the mentally ill in Maine is largely the history of the state mental institutions. Augusta Mental Health Institute (AMHI) and Bangor Mental Health Institute (BMHI) have had primary responsibility for the treatment of Maine's mentally ill. The primary role of these institutions was to keep patients and society safe and to provide adequate comfort, food, medical care, and, lastly, mental health services for the patients.

The veterans Hospital at Togus and Utterbach's, a small psychiatric hospital which operated in Bangor in the 1950's and 1960's, also provided care for the mentally ill.

The combined population at AMHI and BMHI peaked at over 3,000 in the late 1950's. In 1970, despite the arrival of eight community mental health centers, the combined population at the two institutes was still over 2,500.

In 1972 and 1973 Maine began to "deinstitutionalize." This was done in response to numerous federal and state court decisions, establishing important precedents in such areas as the right of involuntary patients to procedural safeguards, the right to treatment, the responsibility to use the least restrictive form of care, and the right of non-dangerous individuals to freedom.

By 1974, AMHI and BMHI had a combined population of 900. At present the combined population is a relatively constant 675-700.

Pineland:

Pineland Center, located in the town of New Gloucester, was established in 1908 as the Maine School for the Feeble Minded. In 1925 the name of the Institution was changed to Pownal State School and in 1957 the name of the school was changed to the Pineland Hospital and Training Center. It received its current name through legislative action in 1973.

Roughly 350 mentally retarded individuals live at Pineland.

Fiscal year 1979 was the first full year of functioning under the requirements of the Pineland Consent Decree. (See also pages 9-10.) Signed on July 14, 1978 by U. S. District Court Judge Edward T. Gignoux, the decree outlined specific standards of care and treatment for Pineland residents.

Costs:

The cost of providing care to individuals in the mental health institutes and Pineland is around $30,000 per year per individual.

RECOMMENDATION #26: RESIDENTIAL FACILITIES ACT

#26A. Submit Legislation. The Governor should submit to the 110th Maine State Legislature legislation to modify and to pull together into one part of the Maine Revised Statutes licensing provisions relating to residential facilities which provide long term care services. The Legislation should be known as the "Residential Facilities Act of 1981."

#26B. Facilities. The following types of facilities should be licensed pursuant to the Residential Facilities Act:

- eating and lodging places with long term residents and no transient guests
- adult foster care facilities
- group homes
- transitional living facilities, including halfway houses
- boarding care facilities
- boarding care/intermediate care facilities
- intermediate care facilities
- skilled nursing facilities

#26C. New Categories. The facilities listed in #26B should be regulated pursuant to the following categories of licensure:

Unsupervised Group Living Facilities. Existing boarding care facilities with over 15 beds and eating and lodging places with long term residents, but no transient residents should be licensed under this new statutory category of care.

Supportive Group Living Facilities. Adult foster care facilities, group homes, transitional living facilities and boarding care facilities with 15 beds or under should be licensed under this new statutory category of care.

Boarding Care/Intermediate Care Facilities. Facilities which provide a level of care somewhere between the level provided by boarding care facilities and the level provided by intermediate care facilities should be licensed under this new statutory category of care.

Intermediate Care Facilities. Intermediate care facilities, which are currently licensed under a general statute referring to hospitals, sanatoriums, convalescent homes, rest homes and nursing homes, should be licensed under a new statutory category specifically geared to intermediate care facilities.

Skilled Nursing Facilities. Skilled nursing facilities, which are currently licensed under the same general statute as intermediate care facilities, should be licensed under a new statutory category specifically geared to skilled nursing facilities.

#26D. Standards. There should be basic core standards and procedures applied to facilities licensed under all of the new categories. For each category and for each type of facility within a category there should be particular standards which reflect and are responsive to the needs of the types of individuals who reside in the facility and the goals of the facility to meet these needs.

#26E. Characteristics. The facilities in each new category and the residents of each type of facility should have the characteristics listed in Chart I (next page). (Intermediate care facilities and skilled nursing facilities are not included in the Chart, because these are not new categories of facilities.)

#26F. Other Recommendations. The pertinent parts of Recommendations #20-#24 should be incorporated into the Residential Facilities Act.

MAJOR FINDING

The Task Force finds that statutory changes are required in order to make licensing standards and regulations, and the long term care facilities directed and affected by them, more responsive to the needs of individuals residing in the facilities.

DISCUSSION

It is the intent of the Task Force that an important focus of the statutory changes should be in the area of supportive group living facilities. It is not the intent of the Task Force to make significant changes in statutes relating to eating and lodging places, intermediate care facilities and skilled nursing facilities.

Chart I describes the new categories of residential facilities.

CHART I. DESCRIPTIONS OF NEW CATEGORIES OF RESIDENTIAL FACILITIES

Category of Facility or Facilities	Size	Characteristics of Residents	Characteristics of Facilities	Agency Responsible for Licensing
Unsupervised Group Living Facility (eating and lodging facilities with long term residents, but no transient guests and some "regular" boarding care facilities.)	Any Size	• Able to function independently. • Require no services from facility other than room and board. • May need home health or personal care assistant services.	• If 15 or fewer beds, must meet provisions in eating and lodging section of Life Safety Code. • If over 15 beds, must meet provisions in institutional section of Life Safety Code. • Must have one person "available" at all times. • Must meet sanitation requirements for eating and lodging places.	Division of Health Engineering Bureau of Health Department of Human Services
Supportive Group Living Facility (includes adult foster care facilities, group homes, transitional living facilities, and some "regular" boarding care facilities.)	15 Beds or fewer	• Psychosocial needs predominate. • Able to function semi-independently. • Require assistance with activities of daily living and with appointments and transportation. • May receive minimum medications routinely. • Participates in day to day operation of facility.	• Must meet Life Safety Code provisions now required for boarding care facilities with 6 beds or fewer and for facilities with 15 beds or fewer which have mentally retarded residents. • Must have sprinklers for certain, but not all types of facilities. • Must emphasize programming to meet psychosocial needs. • May provide special programming to meet psychosocial needs. • May provide special programming to meet special needs.	Division of Licensing and Certification Bureau of Medical Services Department of Human Services
Boarding Care-Intermediate Care Facilities (new level of care)	Over 15 beds	• Not able to function independently. • Need limited physician and nursing services. • Have psychosocial needs. May be confused. • Require assistance with activities of daily living. • Receive medications which require monitoring by licensed staff. • May be incontinent.	• Must meet federal certification standards under Medicaid. • Must meet provisions in institutional section of Life Safety Code. • Must have a licensed nurse 7 days a week. • Emphasis is on psychosocial needs and maintenance of residents. • Staffing ratio is same as for boarding care facilities.	Division of Licensing and Certification Bureau of Medical Services Department of Human Services

FOOTNOTES

1) "The Present and Future Trends in Long Term Care"; speech presented by Elinor F. C. Nackley, Director, Division of Licensing and Certification, Bureau of Medical Services, Department of Human Services; November 28, 1978.

2) "Maine Elderly and Handicapped Housing Needs"; Maine State Planning Office; December 1978.

3) "A Report on Congregate Housing"; Bureau of Maine's Elderly, Department of Human Services; September 1980.

4) A Study of Eight Eating and Lodging Places; Maine Committee on Aging; (undated)

5) "Long Term Care Issues: Paper No. 2: People Needing Long Term Care Services"; Bureau of Maine's Elderly, Department of Human Services; (undated)

6) "Interim Report"; Community Support Systems Project, Department of Mental Health and Corrections; December 1978.

7) "Draft Rehabilitation and Maintenance Program Plan (Long Term Care for the Elderly)"; Bureau of Health Planning and Development, Department of Human Services; page 42.

PART FOUR:
PLANNING FOR AND COORDINATION OF
LONG TERM CARE SERVICES

BACKGROUND

Recommendations #27, #28 and #29 focus on planning for and coordination of the plethora of long term care services in Maine.

It is the contention of the Task Force that there are two ways to help individuals receive long term care services they need and not just services which happen to be conveniently available. One way is to fund and support new and expanded in-home and community support services and certain types of residential services. The second way is to improve the coordination of services.

Coordination of long term care services at the state level can be improved through joint planning. Coordination of long term care services at the local level can be accomplished through the "case management" process, in which individual program plans, tailored to meet the needs of individual consumers, are developed and carried out.

RECOMMENDATION #27: LONG TERM CARE PLAN

#27A. Single Plan Required. A single State Long Term Care Plan for addressing the long term care needs of individuals who are elderly, physically disabled, actual and potential adult protective services clients, developmentally disabled or chronically mentally ill should be completed at least every two years.

#27B. Responsibility for Plan. The Department of Human Services should have primary responsibility for completing those parts of the plan involving the elderly, the physically disabled and actual and potential adult protective services clients. The Department of Mental Health and Corrections should have primary responsibility for completing those parts of the plan involving the developmentally disabled and the chronically mentally ill.

#27C. Content of Plan. The plan should:

Prevention. Include steps for preventing conditions which cause individuals to need long term care services and for preventing placement in settings or receipt of services which are unnecessarily restrictive or intensive;

Purposes. Define, precisely and concisely, the purposes of the various long term care facilities and services, including the state institutions for the mentally ill and developmentally disabled;

Mental Health Needs. Identify and specify ways to address the mental health needs of all types of long term care clients; and

Implementation and Costs. Describe, clearly and specifically:

- Who is responsible for carrying out each aspect of the plan and by when,
- The costs involved in carrying out each aspect, and
- The source(s) of funding which should be used to cover the costs.

#27D. Role of Commissioners. The commissioners of both Departments should:

Planning. Strengthen intra- and interdepartmental planning activities, and

Information. Make sure that information needed for the plans is collected in a form that can be compared among agencies, both within each department and

across the two departments.

#27E. Deadlines; Submitting Plan to Legislature. The single State Long Term Care Plan should be completed by the first of October of every even-numbered year, beginning in 1982. The commissioners of both departments should submit the plan to the Joint Standing Committee on Appropriations and Financial Affairs and the Joint Standing Committee on Health and Institutional Services of the Legislature by the first day of the legislative session in every odd-numbered year, beginning in 1983.

#27F. Clearinghouse. In the collection of information for the purposes of planning, coordinating, regulating and paying for long term care services, the Department of Human Services should refrain from making unnecessary and repetitive demands for the information. The Department should consider the creation of a clearinghouse, the purpose of which would be to protect facilities and agencies from having to answer questions more than once.

MAJOR FINDINGS

The Task Force finds that planning for long term care services is hampered by a lack of adequate and uniform data. The Task Force finds that planning is hampered, almost equally, by severe turf problems among agencies.

SUMMARY OF PLANNING ISSUES AND RESPONSIBILITIES

Data:

Throughout the past year, the Task Force has heard, repeatedly, that planning by state agencies is hampered by a lack of adequate and uniform data. Specifically, the Task Force learned the following:

- State agencies do not collect data in a way that facilitates cross-referencing and comparison with data collected by other agencies.

- Confidentiality requirements sometimes make it difficult to obtain data.

- Existing state computer systems produce little data that is useful for planning. Financial, service, and socio-economic information about consumers of long term care services is scattered among many state agencies. There is no single access point to this computerized information. Nor is staff readily available for writing new programs to extract needed data.

Coordination Among Agencies:

It became quickly apparent to the Task Force that in most instances planning by agencies is done with little coordination with other agencies.

Federal and state laws and regulations require agencies to complete voluminous planning in specific areas. Typically, agencies feel that there are too few staff and too little time to complete the time-consuming planning required by laws and regulations. Thus, coordination of planning efforts has been minimal, because agencies do not feel that they have enough time to do it.

Another reason coordination is weak is because of severe turf problems which exist among agencies, examples of which are illustrated in Chart II.

CHART II. EXAMPLES OF TURF PROBLEMS AMONG AGENCIES

Turf problems exist among agencies which:	Examples:
Have similar functions.	Both created by the Legislature in 1973, the Maine Human Services Council and the Maine Committee on Aging both have broad advisory powers relating to plans, policies and programs affecting Maine citizens. The MCOA focuses exclusively on the elderly, while the MHSC advises on the human services needs of all others. Both created as a result of federal requirements under the National Health Planning and Resource Development Act of 1974, the Bureau of Health Planning and Development and the Maine Health Systems Agency engage in health planning.
Have different functions with respect to the same consumer groups.	Responsible for the Medicaid Program in Maine, the Bureau of Medical Services establishes many policies which affect consumer groups served by other agencies. The same is true of the Bureau of Resource Development, which is responsible for the Title XX (social services) Program. The Bureau of Health Planning and Development engages in planning which affects consumer groups served by other agencies. The long term care section of the 1980 State Health Plan, for example, focuses on the elderly. There has been considerable tension between the BHPD and the Bureau of Maine's Elderly about the Plan.
Compete for the same consumer groups.	Groups representing the interests of mentally retarded individuals resist efforts to address the needs of the retarded along with the needs of a slightly broader group - the developmentally disabled. (Mental retardation is one type of developmental disability.) Home health agencies, homemaker agencies and area agencies on aging all wish to provide services to the same consumer group, that is, individuals living at home. The Community Support Systems Project, Bureau of Mental Health and the Community Mental Health Centers both serve individuals who have been discharged from the state mental health institutes.
Serve different consumer groups.	The Bureau of Maine's Elderly, the Bureau of Rehabilitation, the Bureau of Resource Development, the Bureau of Mental Health and the Bureau of Mental Retardation all engage in separate planning efforts for the particular consumer groups they serve. Pushing for the special needs of each group typically takes precedence over joint pursuit of meeting common needs.
Compete for limited dollars.	As the financial picture darkens, competition for funding among all agencies heightens. The fight for dollars hampers cooperation.

Levels and Branches of Government:

In addition to the lack of coordination among agencies, the Task Force learned that there is a lack of coordination between the State and local levels of government and between the executive and legislative branches of government.

With respect to levels of government, the State might decide on a particular policy (for example, providing services in the least restrictive setting), which municipal ordinance or resistance can easily thwart (for example, zoning ordinances which prohibit a group home from opening).

With respect to branches of government, the executive branch learns of changes in federal laws and regulations (for examples, changes in planning requirements) long before the legislative branch does. In order to act responsibly, the Legislature must receive such information more quickly than is presently the case.

Other Issues:

The Task Force also learned the following:

- Because planning is uncoordinated, providers of long term care services must submit an unreasonable amount of duplicative and unnecessary paperwork.

- Planning is often done, but not implemented. For example, a 3-year "Action Plan" for the chronically mentally ill was developed by the Community Support Systems Project. There has been difficulty in getting this plan carried out.

- Planning for the mental health needs of consumers of long term care services is inadequate and uncoordinated.

- Consumers of long term care services are not sufficiently involved in and informed about planning for these services.

- There is too little emphasis on preventing conditions which cause individuals to need long term care services and on preventing placement in settings or receipt of services which are unnecessarily restrictive or intensive.

- State agencies have not always adhered to the Administrative Procedures Act during planning processes. This appears to be the case, in particular, in giving sufficient notice about public hearings.

Chart III is a summary of agency planning responsibilities required by Federal and State law. (See next page)

CHART III, SUMMARY OF AGENCY PLANNING RESPONSIBILITIES REQUIRED BY FEDERAL AND STATE LAW

Name of Agency	Federal Law Requiring Planning	State Law Requiring Planning,	Description of Planning
Department of Human Services			
Bureau of Medical Services	Title XIX (Medicaid) of the Social Security Act of 1935, as Amended.	No state law	BMS is agency which develops State Medicaid Plan required by federal law.
• Medical Advisory Committee	Same	No state law	MAC advises BMR on State Medicaid Plan.
Bureau of Health Planning & Development	National Health Planning & Resources Development Act of 1974, as Amended.	22 MRSA §§301 et seq.	BHPD prepares preliminary State Health Plan & State Medical Facilities Plan.
• State Health Coordinating Committee	Same	Same	SHCC approves the Facilities Plan and prepares a final State Health Plan, based on work of BHPD & HSA.
Bureau of Maine's Elderly	Older Americans Act of 1965, as Amended.	22 MRSA §5106§§2,4+5	BME develops information system, comprehensive state plan, and plans for desirable programs relating to the elderly.
Bureau of Rehabilitation	Rehabilitation Act of 1973, as Amended.	22 MRSA § 3064	BR makes continuing study of needs of disabled and disadvantaged and of how to meet needs.
• Consumer Advisory Council	Same	No state law	CAC advises BR.
• Governor's Committee on Employment of the Handicapped	No federal law	No state law	GCEH advises BR.
Bureau of Resource Development	Title XX (Social Services) of the Social Security Act of 1935, as Amended.	22 MRSA § 5310 sub §§ 6,9+14	BRD evaluates & coordinates development of social services programs in public and private sectors. BRD also develops plan for training social services personnel.
Bureau of Social Welfare	Title XVI (Supplemental Security Income) of the Social Security Act of 1935, as Amended	22 MRSA § 3203	BSW submits an annual report on the federal and state supplemental income program to the Governor & the Legislative Council.
Department of Mental Health & Corrections			
Bureau of Mental Retardation	Developmental Disabilities Act of 1978	34 MRSA § 2611	BMR plans, promotes, coordinates & develops statewide system of mental retardation services.
• Maine State Planning & Advisory Council on Developmental Disabilities	Same	34 MRSA § 2614	DD Council advises BMR in its planning activities, including any statewide plan for facilities required by federal law.
• Maine Committee on Problems of the Mentally Retarded	No federal law	34 MRSA § 2613	MCPMR advises BMR & Commissioner on assessment of present programs, planning for future programs & developing ways to meet needs of mentally retarded.
Bureau of Mental Health	Community Mental Health Centers Act of 1963, as Amended*	No state law	BMH is agency which develops comprehensive state mental health plan required by federal law.
• Mental Health Advisory Council	No federal law	34 MRSA § 2003	MHAC advises Commissioner on development of state mental health plan.
• Governor's Commission on Mental Health Manpower	No federal law	No state law. Established by Executive Order.	MGMHP

CHART III, CONTINUED

Name of Agency	Federal Law Requiring Planning	State Law Requiring Planning	Description of Planning
Executive Office			
State Planning Office	Description: An annual report and data about the basic housing needs of Maine citizens is required.	5 MRSA § 3306-A	SPO develops housing statistics and plans.
State Councils with Broad Advisory Powers			
Maine Human Services Council	No federal law	22 MRSA § 5316, sub §§ 3+5	Both MHSC & MCOA advise, consult & assist Executive & Legislative branches of State Government. MCOA reviews & evaluates state and federal plans, policies & programs relating to the elderly. MHSC reviews & evaluates state & federal plans, policies & programs affecting people other than the elderly.
Maine Committee on Aging	No federal law	22 MRSA s 5112, sub § 3+5	
Department of Transportation	No federal law	23 MRSA § 4209	DOT divides State into regions for distribution of state transportation funds. DOT, with consent of DHS & DMHC, selects a public transportation agency from each region. Each year regional agency formulates an operations plan, which is supposed to address needs of low income, elderly & disabled individuals.
Maine Health Systems Agency**	National Health Planning & Resource Development Act of 1974.	22 MRSA § 301 et seq.	HSA develops an annual statement of the goals of the State's health care system & strategies for achieving goals. This is called the Health Systems Plan. HSA also issues an annual statement, describing objectives that will achieve goals in Health Systems Plan & setting priorities for the objectives. This is called the Annual Implementation Plan.
Area Agencies on Aging***	Older Americans Act of 1965, as Amended.	22 MRSA ss 5116-5118	BME divides State into program areas and designates an agency in each area to develop an area plan. In order to be approved by BME, each plan must provide for the establishment of a coordinated community program for delivery of social services to elderly individuals living in the area.

*The Community Mental Health Centers Extension Act of 1978 links health and mental health planning.

**Private, nonprofit agency.

***Private, nonprofit agencies.

RECOMMENDATION #28: MEDICAID PLAN

#28A. Policy Vehicle. The Governor, the Legislature, the Commissioner of Human Services and the Commissioner of Mental Health and Corrections should use the Medicaid Program as a major vehicle for formulating and carrying out public policies in the area of long term care, including policies affecting health care, social and rehabilitative services, deinstitutionalization, right to treatment and other areas.

#28B. Updated Plan. To accomplish this, the Commissioner of Human Services should be required to complete an updated State Medicaid Plan every two years.

#28C. Content of Plan. The State Medicaid Plan should:

Goals. Define, precisely and concisely, the goals and objectives of the State Medicaid Program;

Changes. Describe all changes in the State Medicaid Program which are proposed for the period covered by the current plan and which have occurred since the previous plan;

Options. Include a summary of financing, regulatory and program options available to the State under the federal Medicaid law and regulations, and a determination of which of these options are appropriate for meeting the long term care needs of Maine's citizens;

Other Plans. Cite the goals and priorities relating to all aspects of long term care contained in other plans developed at the state level;

Dollars. Identify all actual or potential sources of state and local dollars ("seed money") which can be matched with the federal Medicaid dollars;

Eligibility. Describe eligibility criteria and the categories of individuals served; and

Costs. Analyze the costs of the Program, broken down by:

- category of individuals served,
- age of individuals served,
- geographic location of individuals served,
- type of service provided, and
- type of provider.

#28D. Public Comment. The Department of Human Services should provide opportunity for public comment and review by consumers, providers and other Maine citizens early in the process of:

Format. Initially developing and subsequently changing format of and procedures related to the State Medicaid Plan;

Amendments. Making any amendments to the State Medicaid Plan; and

Updated Plan. Preparing the updated State Medicaid Plan every two years.

The Department should respond in the Plan to all recommendations which result from public comment and review.

#28E. Deadlines; Submitting Plan to Legislature. The deadlines for completing and submitting the State Medicaid Plan should be the same as the deadlines for the single State Long Term Care Plan. The State Medicaid Plan should be completed by the first of October of each even-numbered year, beginning in 1982. The Commissioner of Human Services should submit the updated State Medicaid Plan to the Joint Standing Committee on Appropriations and Financial Affairs and to the Joint Standing Committee on Health and Institutional Services of the Legislature by the first day of the legislative session of every odd-numbered year, beginning in 1983.

#28F. Medical Advisory Committee. The Commissioner of Human Services should consider strengthening and broadening the role and membership of the Medical Advisory Committee to carry out this Recommendation.

MAJOR FINDINGS

The Task Force finds that there has never been a State Medicaid Plan, that is well organized and readable. The Task Force also finds that the style of decision-making regarding the use of state and federal Medicaid dollars has always been characterized by a few state officials "calling the shots" and by considerable ignorance on the part of other policymakers, lawmakers and the general public about the implications of these decisions. Finally, the Task Force perceives that often proposals to make use of Medicaid dollars for services that are clearly needed and desirable have been rejected not only because of budgetary constraints, but also because of the difficulty in estimating precisely the costs of such proposals.

DESCRIPTION OF MEDICAL ADVISORY COMMITTEE

Federal Regulations: Section 246.10, Title 45 of the Code of Federal Regulations requires that under Title XIX of the Social Security

Act, there must be a state Medicaid plan which must provide that:

- There will be an advisory committee on health and medical services to the director of the single state agency which administers Medicaid.

- The committee will include physicians and other health professionals; members of consumers' groups, including Medicaid recipients, and consumer organizations, such as labor unions; and the director of the public welfare department or the public health department, whichever does not head the single state agency which administers Medicaid.

- The committee "will have adequate opportunity for meaningful participation in policy development and program administration..."

- The committee "will be provided such staff assistance from within the agency and such independent technical assistance as are needed to enable it to make effective recommendations..."

The Federal Government "urges" that in all state Medicaid programs, at least 51 percent of the members of the advisory committees should be consumers and consumer representatives.

State Committee: In Maine, there is a 15-member Medical Advisory Committee, with seven professional representatives and eight consumer representatives. The Committee, which meets around nine times per year, advises the Director of the Bureau of Medical Services, Department of Human Services.

It appears to the Task Force that this committee has not been very active. In fact, few members of the Task Force were even aware that there is such a committee. Those few who had heard of the committee knew very little about its purposes and functions.

RECOMMENDATION #29: CASE MANAGEMENT

#29A. Definition. "Case management" should be defined as a flexible, state-administered, locally based process which serves, for individuals who need long term care services, as a point of entry into the system of these services. Case management should include:

- Initial and periodic assessment of the long term care needs of individuals;
- Arrangement for or, if needed services are not available, direct provision of services;
- Monitoring of appropriateness and quality of services;
- Coordination of services for individuals;
- Identification of gaps in services for individuals;
- Development of ways to fill in the gaps; and
- Visible entry points which are acceptable to individuals seeking long term care services.

#29B. Scope; Intent. Case management should be provided throughout the State and should be available to all individuals with long term care needs, regardless of income. Case management should not be mandatory for individuals who pay for long term care services with private funds. Case management should be developed incrementally, building on strengths of processes already in place. It is the intent of the Task Force that case management should not create a new layer of bureaucracy, should not result in a lot of new regulations, and should not involve large expenditures of money.

#29C. State's Role. The Department of Human Services should administer case management for the elderly, the physically disabled and actual and potential adult protective services clients. The Department of Mental Health and Corrections should administer case management for the developmentally disabled and the chronically mentally ill. For the purposes of this Recommendation, the word "administer" means: determining how case management should be done; assigning responsibility at the local level for carrying out case management; and making sure that case management is being carried out adequately.

The departments should either: assign state workers located in local offices to provide case management, or enter into contracts with private agencies which are qualified to provide case management.

#29D. Local Agencies' Role. Case management should be provided by agencies at the local level, pursuant to the following recommendations:

Criteria. The Department of Human Services and the Department of Mental Health and Corrections should require each agency which wants to provide case management to meet the following criteria:

- The agency should be unbiased with respect to the types of services and agencies which, potentially, could be used by individuals who need long term care services.

- The agency should be willing and able to work cooperatively and effectively with other agencies which provide long term care services.

- The agency should be willing and able to address, first, the long term care needs of individuals, rather than its own needs.

- The agency should agree to offer case management to all individuals who seek entry into the system of long term care services through the agency, regardless of how the long term care services will be paid for.

- The agency should be able to provide advocacy on behalf of individuals who need long term care services.

- If a provider of direct services, the agency should be able:

  - to provide case management for both individuals who are and who are not receiving services provided directly by the agency,

  - to ensure continuity of case management, even after the agency has ceased to provide direct services to individuals,

  - to carry out case management according to the model developed by the State, without regard for the agency's role as a direct service provider, and

  - to specify a procedure for ensuring advocacy which is not related solely to the services it provides.

Carrying out Case Management. All relevant local providers and consumer groups and representatives should be involved in establishing a case management system at the local level. The local case management agency should: keep all providers and consumer groups fully informed about changes in the case management system; and enter into negotiations and develop written cooperative agreements with other agencies and facilities regarding the case management process.

#29E. Team. Case management should be provided by a team, pursuant to the following recommendations:

Members of Team. The team should include at the least the following individuals:

- The individual who needs long term care services, or, if this is not possible or appropriate, a representative of the individual;
- A representative of the local case management agency;
- A physician or nurse, if the client has health needs;
- A social worker or psychologist, if the client has psychosocial needs; and
- The individual providing or likely to provide most of the service (for example, homemaker, nurse, personal care attendant, aide, et cetera).

Team Decisions; Veto. Decisions of the team should be based on a majority vote of the members of the team. The individual who needs long term care services or, if this is not possible or appropriate, a representative of the individual should have the right to veto any decision of the team.

Mix of Services. The team should be responsible for putting together a mix of services, tailored to meet the multiple needs of the individual consumer of long term care services.

Responsibility of Case Manager. It should be the responsibility of the case management agency to: initially organize the team, ensuring that the appropriate members are serving on it; set up meetings of and related to the team; and make sure that the decisions of the team are carried out.

#29F. Utilization Control. (See Recommendation #32)

#29G. Advocacy. (See Recommendation #50)

#29H. Compatible Plans. Plans for carrying out case management should be developed pursuant to the following recommendations:

Responsibility of Commissioners. The Governor should require the Commissioner of Human Services and the Commissioner of Mental Health and Corrections to work together to develop compatible case management plans for the elderly, the physically disabled, actual and potential adult protective services clients, the mentally retarded and the chronically mentally ill. The Governor

should also require the two commissioners to:

- Match funding priorities to the services gaps identified through the case management process;

- Assure that funds are available for case management; and

- Use case management as a means of identifying service gaps for the purposes of planning and funding long term care services.

Participating Agencies. The Commissioner of Mental Health and Corrections should appoint representatives from the Bureaus of Mental Health and Mental Retardation and the Commissioner of Human Services should appoint representatives from the Bureaus of Maine's Elderly, Rehabilitation, Resource Development, Medical Services, and Health Planning and Development to participate in the development of compatible case management plans. The Governor should appoint a representative of the Maine Health Systems Agency to participate.

The Governor should designate a lead agency to help coordinate the development of the plans.

Content of Plans. The case management plans should include: timetables for establishing case management on a statewide basis; uniform definitions; consistent requirements for the assessment method to be used to determine long term care needs of individuals; and formats for data collection which will facilitate the comparison of important characteristics across the various groups of consumers of long term care services.

Deadlines. The following deadlines should be met in the development and implementation of case management plans:

- By June 1, 1981, the Commissioner of Human Services and the Commissioner of Mental Health and Corrections should report to the Governor and the Legislature on the definitions and assessment method(s) to be used in all of the case management plans.

- By January 1, 1982, the two departments should have completed the case management process for all of their present clients, including an assessment of the long term care needs of these clients.

- By March 1, 1982, the two commissioners should report to the Governor and the Legislature on the results of the assessments and the models to be used for case management.

- By January 1, 1983, fully operational case management processes should be in place for the elderly, the physically disabled, actual and potential adult protective services clients, the mentally retarded and the chronically mentally ill.

Relationship to Other Plans. After the case management process has become fully operational, it should be a primary source of information to be used in both the single State Long Term Care Plan and the State Medicaid Plan.

MAJOR FINDINGS

The Task Force finds that Maine has a patchwork system of long term care services which fails to meet fully the multiple needs of individual consumers of these services. There is full consensus among Task Force members that: services and programs are fragmented; some efforts are duplicated; there are gaps in some services; some programs work at cross-purposes; and there is a lack of organization and comprehensiveness in service delivery. The Task Force finds, further, that this patchwork system has an adverse effect on individual consumers of long term care services.

CASE MANAGEMENT IN MAINE

Definition:

Case management means different things to different individuals. To some it means helping individuals who need long term care services by putting together for them a package of services and, thereby, sparing them the frustrations of trying to piece things together alone. To others case management means controlling the utilization of long term care services from the point of view of controlling costs or appropriateness and quality of care. To others it means something they are already doing, that is, bringing providers of long term care services together to plan services for "cases."

The Task Force defines "case management" as a flexible process which serves as an entry point for individuals into the system of long term care services, and which includes: assessment of long term care needs of individuals, arrangement for or provision of long term care services to individuals, monitoring appropriateness and quality of the services, coordination of the services, and identification of and development of ways to fill in gaps in the services. In other words, the Task Force defines case management as a process that does all of the things mentioned in the preceding paragraph and more.

Present Systems in Maine:

The Bureau of Mental Retardation, Department of Mental Health and Corrections, has developed the most comprehensive case management system in Maine. Three agencies

in the Department of Human Services (the Bureau of Rehabilitation; the Division of Adult Protective Services, Bureau of Resource Development; and the Division of Medicaid Surveillance, Bureau of Medical Services) provide variations of case management to their clients.

For two groups, the elderly and the chronically mentally disabled, case management services are available only on a haphazard, incomplete basis for only a small number of individuals.

Certified home health agencies report that they are required by Medicare regulations to provide case management services for their clients.

Chart IV is a summary of existing case management systems in Maine. (See pages 115 and 116)

Approaches in other States:

Appendix A of this Report includes a summary of eight case management approaches used in other states. The Task Force believes that the State of Maine should consider these approaches as it develops its own approaches to case management.

Arguments:

Case management has been one of the most provocative issues discussed by the Task Force. While a solid majority of the Task Force favors the concept of case management, it is important to touch upon the arguments raised by individuals who are opposed to it.

The most persistent argument made against case management has been that when there is such a small pot of public funds, it should be spent to pay for long term care services and not to pay the salaries of professionals who will "manage" cases, but who will not provide direct services. A related argument has been that case management will increase government bureaucracy, because it will be "state administered." In response to these arguments, the Task Force has recommended that "case management should not create a new layer of bureaucracy, should not result in a lot of new regulations, and should not involve large expenditures of money."

Another argument vociferously raised against case management has been that individuals whose cases are being managed will lose their freedom of choice. The Task Force

firmly believes that in no instance should case management result in manipulation or coercion of an individual. The Task Force has recommended that "the individual who needs long term care services, or if this is not possible or appropriate, a representative of the individual should have the right to veto any decision" made pursuant to the case management process. The Task Force has also recommended that individuals who are paying for long term care services with their own funds should not be required to become involved at all in the case management process.

A third argument posed against case management has been that case management already happens and is required under Medicare law for community and home health agencies. The Task Force believes that the weakness in this argument is that while case management occurs for individuals while they are clients of a community or home health agency, it does not continue when they are no longer clients.

Finally, it has been argued that having a case management system does not mean that services which simply do not exist will somehow miraculously become available. Many agencies which provide long term care services have commented about how frustrating it is to receive referrals from advocacy groups (coordinators of services which do not provide direct services themselves) and to be unable to provide services to the individuals referred because of insufficient funding and staff. The Task Force acknowledges that this is a problem and realizes that case management is not a panacea.

Turf:

The Task Force has been disappointed that discussions about case management have been punctuated by the turf problems described under Recommendation #27. The Task Force believes that agencies can and, indeed, must begin to work together to develop effective case management systems which are in the best interests of the consumers of long term care services.

CHART IV. EXISTING CASE MANAGEMENT SYSTEMS IN MAINE

Type of Consumer of Long Term Care Services	State Agency Involved	Legal Requirements	Approach	Source of Funding
Elderly individuals	Bureau of Maine's Elderly, Department of Human Services	None	BME funded one CM demonstration project in Waterville & has submitted a $1.5 million proposal to the Federal Government for another demonstration project in southern Maine. BME's approach calls for BME to be the lead state agency for administering CM & for area agencies on aging to serve as case managers at the local level.	Proposal submitted to Health Care Financing Administration and Administration on Aging in the U.S. Department of Health & Human Services.
Physically disabled individuals	Bureau of Rehabilitation, Department of Human Services		The purpose of CM is to provide services necessary for BR clients to reach a vocational objective or where a handicap is too severe to reach such an objective, to develop services to assure maximum levels of independent living. For BR clients who can attain a vocational objective, BR staff in the 5 regional offices meet with clients to develop an Individual Written Rehabilitation Plan (IWRP). Where health needs exist, BR staff meet with physicians paid for by the State. For BR clients for whom a vocational objective is not realistic because of the severity of disability, BR has initiated an independent living program. This program is subcontracted to private, nonprofit agencies which have a counselor & counselor aide develop for each client a plan of care to assure personal care services required to maintain maximum independence.	Primarily federal funds under the Rehabilitation Act of 1973
Incapacitated individuals	Division of Adult Protective Services, Bureau of Resource Development, Department of Human Services	18 MRSA 22 MRSA §§ 3460-3464	APS is required to "respond to complaints concerning & requests for assistance by or on behalf of all incapacitated adults," other than the developmentally disabled. APS is authorized to provide protective & supportive services "from its own resources, by mobilizing available community resources, or by purchase of services..." For APS, the purposes of CM are to identify problem(s), assess the need for specific services, & coordinate, provide & expedite services for incapacitated clients who are in danger of hurting themselves or others. APS workers in the 5 regional offices of the Department engage clients & appropriate others in a diagnostic process; acts as the case manager, identifies gaps which make it impossible to meet stated objectives; and monitors services to make sure they are in accord with the objectives.	Title XX of the Social Security Act is the only funding source, at present.

CHART IV. CONTINUED

Type of Consumer of Long Term Care Services	State Agency Involved	Legal Requirements	Approach	Source of Funding
Mentally retarded	Bureau of Mental Retardation, Department of Mental Health & Corrections.	34 MRSA §§ 2651-2658. U. S. Federal Court, pursuant to Pineland Consent Decree.	The purposes of CM are to put together services to help BMR clients achieve optimal levels of functioning; to generate information about the needs of clients; & to identify resources required to address needs. CM is carried out by each of BMR's 5 regional offices. An Individual Prescriptive Plan (IPP) if written for each client. The IPP, based on assessments by a variety of professionals, affects all aspects of the client's life. The IPP is developed by an interdisciplinary team (IDT), which is made up of the client, individuals responsible for the client, various professionals, the major service providers, an advocate and a representative of BMR. Following intake, each client is assigned to a case manager who has the ongoing responsibility for delivering, coordinating and monitoring the services planned by the IDT.	State's General Fund
Mentally ill individuals	Bureau of Mental Health, Department of Mental Health & Corrections	None	The Community Support Services Project (CSSP) sponsored by the Department has begun a limited CM program.	No ongoing funding. Only temporarily funded as part of the CSSP by the National Institute for Mental Health in the U.S. Department of Health and Human Services
Individuals receiving Medicaid who enter nursing homes	Division of Medicaid Surveillance Bureau of Medical Services Department of Human Services	Medicaid		Medicaid
Individuals receiving services from home health agencies	None	Medicare		Medicare

PART FIVE:
REGULATING LONG TERM CARE SERVICES

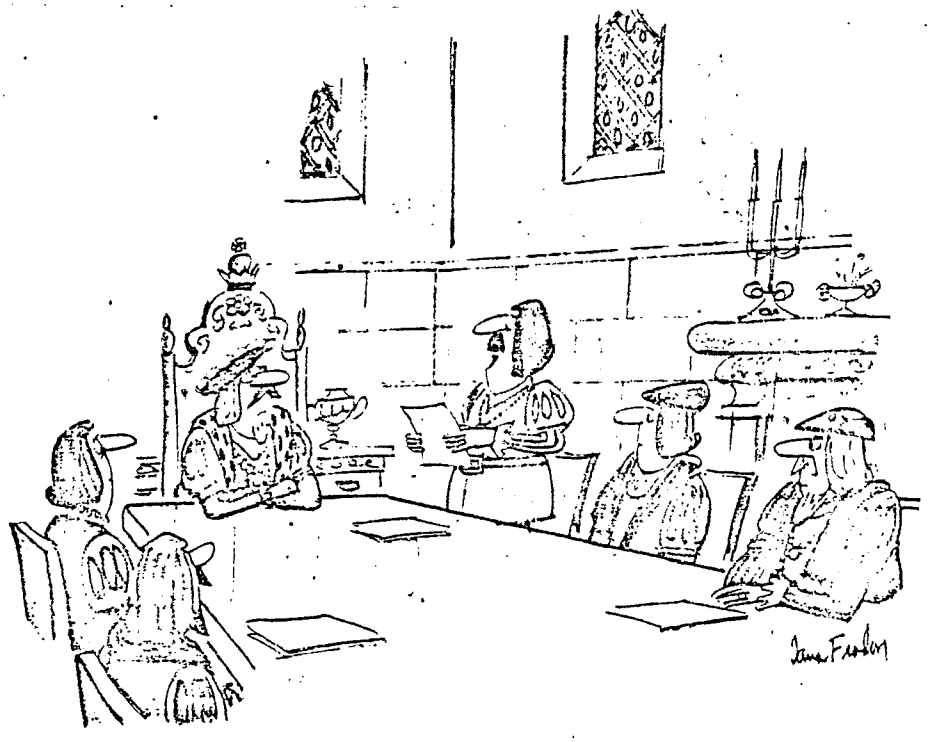
BACKGROUND

Recommendations #30 through #34 address issues relating to the regulation of long term care services.

The Task Force heard, repeatedly, over the past year that regulations often hinder the delivery and receipt of effective long term care services. Both providers and consumers of long term care services noted that regulations have often resulted in levels and types of care that are inappropriate or unnecessarily restrictive, intensive and expensive. As the Maine Community Health Association remarked to the Task Force:

> "...(A) political and economic imbalance has been allowed to develop and grow to the point where alternatives such as home care, if at all feasible, are discouraged from consideration through the use of regulatory and financial reimbursement mechanisms that clearly weigh in favor of more costly forms of health care."

Many providers expressed concern that the surfeit of regulations has forced them to spend too much time on unnecessary paperwork and too little time on direct care to their clients. The following cartoon best expresses the sentiments expressed about over-regulation:



"Your Majesty, according to our study the shoe was lost for want of a nail, the horse was lost for want of a shoe, and the rider was lost for want of a horse, but the kingdom was lost because of overregulation."

RECOMMENDATION #30: ELIGIBILITY

#30A. Instant Eligibility. The Governor should:

Urge Congressional Action. Contact, immediately, members of Maine's Congressional Delegation and urge them to seek enactment of federal legislation (S.934 and HR.4000) to deny Medicaid eligibility for a specified amount of time to individuals who apply for admission to intermediate care and skilled nursing facilities and who have disposed of significant assets in order to establish eligibility.

Submit Legislation at State Level. Submit to the 110th Maine State Legislature legislation to prohibit the transfer of significant assets in Maine which is consistent with the proposals before the U.S. Congress, and which includes a provision to make the state law effective if and when the federal enabling or mandatory legislation goes into effect.

#30B. Deeming. The Governor should urge the Maine Congressional Delegation to support H.R. 6194 and any other federal legislation to prohibit "deeming" (the practice of taking into account the incomes of a spouse and other household members in the determination of an individual's financial eligibility for home health services).

#30C. Eligibility after Employment. The Governor should submit legislation to the 110th Maine State Legislature to:

- Increase from $300 to $800 per month the limit on "substantial gainful activity" under the Supplemental Security Income (SSI) Program;
- Enable disabled individuals to discount additional work expenses under the SSI Program; and
- Continue Medicaid coverage, on a permanent basis, for disabled individuals who are employed and for whom no comprehensive medical insurance is available as a fringe benefit of the employment.

#30D. Uniform Requirements. The Governor should urge members of Maine's Congressional Delegation to support federal legislation to require uniform federal financial eligibility requirements across the various types of federally funded long term care services. The Department of Human Services and

the Department of Mental Health and Corrections should use a uniform assessment form, developed to encompass the various eligibility requirements of all funding sources for long term care services.

#30E. Coverage of Services. The Department of Human Services should consider intermediate care and boarding care facilities as Medicaid eligible sites for the provision of services by mental health professionals, occupational therapists and physical therapists. The Department should work with the Health Care Financing Administration, U.S. Department of Health and Human Services, and with the fiscal intermediary to get occupational and physical therapy covered under the Medicare Program when ordered by a physician. The Department should make sure that it is in compliance with 22 MRSA § 3172-A, (a law that provides for reimbursement for physical and occupational therapy in skilled nursing and intermediate care facilities).

#30F. Functional Need. Eligibility for long term care services should be related to functional need - not just financial status. ("Functional need" means the type and level of long term care service(s) needed by an individual.)

#30G. Sliding Fee Scales. The Department of Human Services should use sliding fee scales to a greater extent for non-residential long term care services.

#30H. Eligibility Determinations. The Department of Human Services should amend its Public Assistance Payments Manual to require financial eligibility determination for each individual who seeks long term care services to be completed within 10 working days from the date of application by the individual.

#30I. Catastrophic Illness Program. The Department of Human Services should examine the Catastrophic Illness Program, which is funded entirely by state dollars, to determine whether these state dollars can be matched with federal dollars and, thereby, used more effectively.

#30J. Dependents' Allowance. The Department of Human Services should study the adequacy of income for dependents of individuals who reside in the various types of long term care facilities, and should determine whether allowances for dependents are needed. In conducting the study, the Department should make sure that it is in compliance with federal regulations relating to dependents under the Supplemental Income Program. (42 CFR § 435.725 (c)(2)(ii)).

MAJOR FINDINGS

The Task Force finds that financial eligibility requirements under the Medicaid Program, which is the largest funding source for long term care services, make it much easier for an individual to obtain restrictive and expensive care in an intermediate care facility than to obtain less restrictive and less expensive care at home or in group living facilities.

The Task Force finds, further, that eligibility requirements under the Supplemental Security Income Program and the Medicaid Program make it very difficult for disabled individuals to afford full-time employment.

The Task Force also finds that the practice of transferring assets in order to establish eligibility for Medicaid is widespread and is, in some instances, encouraged by staff of the Department of Human Services, as well as by other counselors of individuals in need of long term care services.

FINANCIAL ELIGIBILITY UNDER MAJOR PROGRAMS

Medicaid:

Eighty-five percent of all residents of intermediate care facilities receive Medicaid. The Federal Government allows each state to have a lot of flexibility in setting standards for eligibility. The Maine Public Assistance Manual, which has been through many revisions since 1974, lists the criteria used to determine financial eligibility under the Medicaid Program. Assistance for intermediate care is available under the Categorically Needy and the Medically Needy parts of the Medicaid Program.

Home health services are available to a small number of individuals under the Medicaid Program. All conditions of eligibility of the Supplemental Security Income Program are applied.

Individuals who are mentally retarded can be eligible for Medicaid and Supplemental Security Income as a result of their disability - 95 percent of the clients of the Bureau of Mental Retardation of the Department of Mental Health and Corrections are eligible.

Title XX:

Title XX eligibility requirements for the homemaker program, nutrition program, housing, mental health and mental retardation programs are at 80 percent of the State's median income. This is a higher eligibility criterion than for the Categorically Needy Program. The Priority Social Services Program has the same income guidelines for eligibility as Title XX has.

Older Americans Act: Title III-B and Title III-C of the Older Americans Act pertaining to nutrition, transportation, homemaker and home repair services may not apply an income or means test. This legislation contains an interesting inconsistency. On one hand, it prohibits means tests, but on the other hand, it states that individuals with the greatest social and economic need must be served.

Catastrophic Illness Program: Another program, the Catastrophic Illness Program, is 100 percent state-funded and does not pay for intermediate care services. However, it will cover 60 days per year of skilled nursing services.

Instant Eligibility: Individuals who are medically eligible for intermediate care services, can transfer their assets in order to become eligible for public assistance. During hearings held throughout the State, the Task Force heard that staff of the Department of Human Services assist individuals in need of intermediate care to transfer their assets. The Task Force notes that this practice is widespread, that lawyers and social workers who do not work for the Department do this all the time, and that there is nothing illegal about doing this.

Deeming: Individuals can be financially eligible for intermediate care at a higher income than for other types of care. Eligibility for home health services is limited to income levels specified in the Supplemental Security Income Program.

The income of a spouse and other members of the household is taken into account in the determination of financial eligibility of an individual for home health services. This is known as "deeming." Deeming does not occur when the individual seeks entry into an intermediate care or skilled nursing facility. As a result, there are greater financial barriers to obtaining home health services than there are to getting into an institutional setting.

Employment: When long term care clients get a paid job, they often lose their Supplemental Security Income benefits and their Medicaid coverage. This is a serious obstacle to individuals who could otherwise become more productive and independent. The Task Force has heard compelling testimony about this issue throughout the State.

Increasing the allowed amount of "substantial gainful activity" from $300 to $800 per month for all individuals who receive Supplemental Security Income benefits would be relatively inexpensive and would make many more individuals who are disabled or elderly eligible for medical and other services. It would also provide a more realistic test of ability to work prior to suspension of SSI benefits.

It has been estimated that an individual who is paraplegic (that is, unable to control voluntarily foot and leg movements) must earn $12,000 per year just to be able to afford the same kind of medical coverage available under Medicaid. An individual who is quadriplegic (that is, unable to control voluntarily arms or legs) must earn $18,000 per year for the same amount of coverage. Such incomes are rare. Most severely disabled individuals earn less than $3,000 per year. As a result, coverage by Medicaid (or Medicare) becomes crucial.

Data from the 1972 Social Security Survey of Disabled and Nondisabled Adults indicate that while 85 percent of the population aged 20 to 64 nationwide had private health insurance coverage, only 58 percent of severely disabled individuals and 69 percent of all disabled individuals had such coverage.

Varying Requirements: The availability of in-home and community support services is limited by a morass of varying financial eligibility requirements. An agency which can provide a variety of services must break down the time spent on each service and charge it to different funding sources. This creates employment for more administrative staff.

With respect to the Department of Human Services, inconsistencies exist from one regional office to another in applying eligibility criteria.

Coverage: Recommendations #22 and #23 include lengthy narratives supporting the need for increased services in intermediate and boarding care facilities.

Functional Need: Availability of services is geared to financial levels of eligibility. Too little attention is given to eligibility, based on an individual's functional level and needs.

Sliding Fee Scale: 22 MRSA § 9 authorizes the Department of Human Services to have sliding fee scales for all Title XX services. It

requires that there be a sliding fee scale for "child day care services" and for "developmental day care services for pre-school children with developmental disabilities." The Department has also instituted a sliding fee scale for family planning services. Some home health agencies and homemaker agencies have sliding fee scales, as do community mental health centers. However, these scales do not exist for many types of long term care services.

Eligibility Determinations:

The Public Assistance Payments Manual permits 45 days for financial eligibility determinations. This creates a hardship for both consumers and providers.

RECOMMENDATION #31: LICENSING AND CERTIFICATION

#31A. Rating System. The Governor should submit to the 110th Maine State Legislature a bill to establish a rating system for intermediate care and boarding care facilities, based on types, severity and duration of deficiencies in the facilities. Ratings should be:

Published. Published in a directory of licensed facilities, which should be more readable and readily available to the public than are the directories currently kept in Social Security offices and public libraries; and

Displayed. Clearly stated on the license of facilities, which should be displayed openly in a public part of the facilities.

Publicized. Publicized so that the general public can be knowledgeable about facilities and can make informed decisions.

#31B. Limit on Admissions; Emergency Situations. To ensure the health, safety and welfare of residents of skilled nursing, intermediate care and boarding care facilities, the Governor should submit legislation to the 110th Maine State Legislature to:

License Under Appeal. Prohibit any facility from admitting new residents while its license is under appeal;

Conditional License. Authorize the Department of Human Services to limit admissions, as a condition of a conditional license; and

Emergency Situations. Authorize the Department of Human Services to place a licensed administrator in any facility in an emergency situation, that is, when conditions exist which cause danger to the health and safety of the residents.

#31C. Home-like Facilities. The Certificate of Need process and licensure review by the Division of Licensing and Certification, Department of Human Services, should show preference for new designs that are "home-like."

#31D. Quality of Life; Contact with Residents. There should be increased focus in the Department of Human Services' survey process on the quality of life and contact with residents of skilled nursing, intermediate care and

boarding care facilities.

Commissioner. The Commissioner of Human Services should:

- Require the Division of Licensing and Certification and the Division of Medicaid Surveillance to evaluate the job responsibilities of their staff members, examine the survey and utilization control processes, and eliminate unnecessary duties, in order to free up time for contact with residents;

- Require the Division of Licensing and Certification to establish priority areas to be checked during inspection visits, in order to eliminate the need to review areas in which there have been no deficiencies and to free up time for contact with residents;

- Eliminate annual surveys for facilities which have shown no areas of deficiencies in environment and care for a specified number of years and require full surveys only every 2 years;

- Require Department staff to conduct studies in facilities in areas such as accidents, why restraints are used, incidence of epidemics and mortality rates;

- Require the staff of the Division of Licensing and Certification to make periodic, announced visits for the purpose of consultation with and education of staff of the facilities regarding improvements in the quality of life of the residents; and

- Assure that there is sufficient staff to monitor, on a quarterly basis, facilities which have been given deficiencies relating to quality of life.

Governor. The Governor should inform Maine's Congressional Delegation and officials of the U.S. Department of Health and Human Services that changes are needed in the areas of utilization review, physician certification of residents, the survey process and requirements for the licensing and certification of facilities, in order to enable staff of both the Department of Human Services and facilities to concentrate more on care of individuals and less on paperwork.

#31E. Sanctions. The following steps should be taken to curb non-compliance with licensing laws and regulations:

Procedures. The Department of Human Services should establish procedures to promote corrective action in a timely manner and to eliminate ongoing non-compliance with licensing laws and regulations. The Department should strongly enforce its policy of making unannounced annual surveys on a variable cycle, if a facility has had deficiencies. Investigations of complaints should be

unannounced and should be made within 10 working days from the date the Division of Licensing and Certification receives the complaints.

Economic Sanction. The economic sanction of reducing payment to 90 percent of costs, which is presently permitted in the Principles of Reimbursement of the Department of Human Services, should be strengthened by creating and enforcing standards to ensure that the 10 percent reduction in payment does not reduce the quality of care. The Principles should stipulate that insofar as proprietary facilities are concerned, the 10 percent reduction will occur in the areas of depreciation, return on equity and administrative allowance.

Licensure Prohibited. No agency of the State should be permitted to license a facility, if the owner or administrator of that facility has had a license refused or revoked by another agency, because of jeopardy to the health, safety or welfare of residents.

#31F. Physical Plant and Life Safety Code Requirements. The following steps should be taken to ensure the enforcement of physical plant and life safety code requirements:

FSES. The Fire Safety Evaluation System (FSES) concept should be supported for purposes of licensing all types of residential facilities.

Ambulatory. By March 1981, all facilities without elevators should have only individuals who are ambulatory above the first floor, regardless of their Life Safety Code status in relation to waivers or the FSES. State regulations should be based on the following definitions: "Ambulatory" individuals should be defined as individuals who are physically and mentally capable of moving from place to place without assistance from another individual or device. "Semi-ambulatory" individuals should be defined as individuals who are able to walk under their own power, but only with assistance from another individual or supportive device (a cane, crutches or a walker). "Non-ambulatory" individuals should be defined as individuals who are unable to walk, but who are able to be moved from place to place, if in a device propelled by themselves or another individual (a wheelchair or wheeled platform). "Non-mobile" individuals should be defined as individuals who are unable to be moved from place to place, except in emergencies.

#31G. Statewide Panel. There should be a statewide panel of consumers, providers and advocates of consumers to assist the Division of Licensing and Certification, Bureau of Medical Services, Department of Human Services in the conduct of its work and to make recommendations regarding licensing standards for long term care facilities.

MAJOR FINDING

The Task Force finds that there has been insufficient focus on the quality of life of residents in long term care facilities in the State's licensing and certification system. The Task Force believes that new "conditions of participation," issued by the U. S. Department of Health and Human Services but not yet in effect, are an improvement in this regard.

EXISTING LICENSING AND CERTIFICATION SYSTEM

Purposes:

The purposes of licensing facilities in which people with long term care needs reside are to protect the health and safety of these individuals and to ensure that minimum standards for services provided by the facility are met.

Division of Licensing and Certification:

The Division of Licensing and Certification, Bureau of Medical Services, Department of Human Services, is responsible for ensuring the health and safety of individuals residing in several types of health care facilities. This responsibility is carried out through licensing pursuant to requirements of both the Medicare Program and the Medicaid Program.

The Division licenses over 300 boarding care facilities and six ambulatory care centers. The Division certifies (according to Medicare requirements) thirteen rural health centers, four end-stage renal disease units, and thirteen home health agencies.

Many facilities must meet both state licensing requirements and certification requirements under either either or both the Medicare Program and the Medicaid Program:

- The Division licenses 50 hospitals. The Division also certifies any hospital according to Medicare regulations, which has not been accredited by the Joint Commission on Accreditation of Hospitals.

- The Division licenses and certifies - pursuant to the Medicaid and Medicare programs - eighteen skilled nursing facilities. Many of these are untis co-located with other types and levels of care.

- The Division licenses and certifies - pursuant to the Medicaid Program - over 140 intermediate care facilities, including four facilities expecially for the mentally retarded. In addition, the Division certifies one state-operated intermediate care facility

and one state institution (with both acute care and intermediate care beds) for the mentally retarded. Some intermediate care facilities are located in acute care and skilled nursing care settings.

- Finally, the Division certifies (under both the Medicare and Medicaid programs) two state institutions for the mentally ill, both of which have acute care and intermediate care beds.

Licensing by Other State Agencies:

The Division of Health Engineering, Bureau of Health, Department of Human Services, licenses 400 eating and lodging places including Howard Johnsons, Ramada Inns, etc., and also including an unknown number of places which cater to long term care clients.

The Division of Adult Protective Services, Bureau of Resource Development, Department of Human Services approves (not licenses) over 200 adult foster care facilities in the State.

Fire Marshal's Office:

The State Fire Marshal's Office inspects all of these facilities, except for eating and lodging places, rural health centers and home health agencies. Follow up inspections are done, based on the number and seriousness of deficiencies found. The State Fire Marshal is required by state law to make sure facilities meet various requirements included in the Life Safety Code, which is developed by the National Fire Protection Association.

Surveys:

The Division of Licensing and Certification surveys each facility once a year. An exception to this is that the Division surveys hospitals accredited by the Joint Commission on the Accreditation of Hospitals every other year, the year in which the Commission does not survey. Individuals who form the survey team include not only Division staff, but also the Fire Marshal. Division staff involved include registered nurses, social workers and sanitarians. Surveys are unannounced, but facilities know the month in which they occur.

Follow-ups to surveys are done to determine if deficiencies have been corrected and consultation is provided to assist in improving the care provided.

Duration of Licenses:

Licenses and certification can be for a full year or for a shorter period, again depending upon deficiencies.

Temporary licenses for no more than 90 days are issued for a number of reasons, such as the facility is new and has not had time to comply fully; the facility has failed to address deficiencies satisfactorily; there has been a change of ownership of the facility; or there are water supply problems.

Conditional licenses are issued for more serious reasons and are usually set for a year, with the conditions set forth that must be met. If the conditions are not met, the license is in jeopardy.

Facilities with temporary or conditional licenses, or facilities whose licenses are under appeal for revocation or non-renewal may be allowed to continue admitting new residents, depending upon their deficiencies.

Provider Agreements:

The Division of Licensing and Certification certifies that a facility meets the conditions of participation of the Medicaid Program, and issues a Provider Agreement, which states the per diem rate of reimbursement and the provisions of the agreement. The Federal Government, based on the Division's survey and recommendations, certifies providers reimbursed under the Medicare Program. These agreements contain an automatic cancellation clause that may be involved if deficiencies are not corrected within a specified time. To decertify a provider and cancel their Provider Agreement, is time consuming, as appeals are made and due-process observed.

Boarding care facilities that are reimbursed on a reasonable cost basis also have provider agreements. These are issued by the Bureau of Social Welfare, Department of Human Services. These may include automatic cancellation dates, based on the survey and recommendations of the Division of Licensing and Certification.

Enforcement:

Facilities that are certified pursuant to the Medicaid Program and boarding care facilities are subject to the Principles of Reimbursement set forth by the State. The Principles address financial sanctions which may be taken for certain areas of non-compliance. Under the Principles, the Department can drop reimbursements back to 90 percent of the Medicaid payment after 30 days, if there are serious deficiencies. Revocation of licenses and certification is another enforcement mechanism.

Bed shortages may result in lack of enforcement of certain state licensure laws and regulations and in the issuance of waivers. This is an issue, in particular, in old two-story facilities without elevators which have non-ambulatory residents on the second floor.

Often physical plant and Life Safety Code deficiencies are allowed to continue and waivers are granted year after year, with no actions taken to correct deficiencies. Strict enforcement cannot occur without an increase in beds to allow for the flexibility needed for the placement of residents.

Waivers:

States have the authority to grant waivers for both Life Safety Code and physical plant deficiencies.

The State Fire Marshal's Office has the authority to grant Life Safety Code waivers. The Office advises the Division of Licensing and Certification of decisions for waivers. The Division may not issue a license without the approval of the State Fire Marshal's Office. The Division and the Office have addressed the provider associations and those facilities with restrictions on non-ambulatory residents above the first floor regarding compliance.

The Division of Licensing and Certification has the authority to issue waivers with respect to physical plant deficiencies other than Life Safety Code deficiencies. The criteria used to determine whether to allow a waiver are: that the regulation (if it were strictly enforced) would create an unreasonable financial burden for the facility, and that the regulation (if it were not enforced) would not result in a threat to the health and safety of residents in the facility.

When a waiver is granted, the requirement for which the waiver has been issued, even though not met, is no longer considered a deficiency.

Quality of Life:

The licensing regulations and standards do not focus on quality of life, outcomes of care, or on the resident. There is too much emphasis on the medical model. The survey is a review of the facility and its capabilities of providing care. The Division of Licensing and Certification has a policy which encourages quarterly visits to monitor facilities for quality of life and continued compliance with licensing regulations. Other visits are encouraged, as necessary, to provide consultation. How-

ever, the Division's staff do not usually have time to follow this policy.

Licensure often results in a more restrictive environment than is necessary. The regulations do address "least restrictive environment." However, the interpretation and implementation of these regulations often result in more restrictive environments than are necessary.

RECOMMENDATION #32: UTILIZATION CONTROL

#32A. Relationship to Case Management. Utilization control should be part of a larger case management process. If an individual needs services paid for by Medicaid, then the case management process should be recognized as a form of utilization control. The staff of the Division of Medicaid Surveillance, Department of Human Services, should not be required to be part of the case management team, even when an individual is receiving or applying for long term care services paid for by Medicaid and subject to utilization control requirements. (See Recommendation #29.)

#32B. Study. Prior to January 1, 1981, the Department of Human Services should analyze data collected by the Division of Medicaid Surveillance to see what effects utilization control has had in Maine.

#32C. Waiver. If the study indicates that utilization control has not been effective, the State should apply to the Federal Government for a waiver from at least some of the utilization control requirements. If the State successfully obtains a waiver, the money and staff, formerly used for utilization control, should be redirected to support other aspects of the case management process, such as ensuring quality and appropriateness of care.

MAJOR FINDING

The Task Force finds that it is probable that utilization control has not been effective in Maine.

DESCRIPTION OF UTILIZATION CONTROL

Federal Regulations:

The federal regulations for the Medicaid Program (42 CFR, Part 456) include requirements concerning control of utilization of all Medicaid services. The thrust of these requirements is to safeguard against unnecessary use of care and services.

Utilization review is a process required under utilization control. Through this process, each Medicaid recipient's need for care is initially and periodically evaluated by a physician and others, depending on the type of provider the Medicaid Program is expected to reimburse.

State Responsibility:

The Division of Medicaid Surveillance, Bureau of Medical Services, Department of Human Services, is responsible for initial classification of individuals coming into the Medicaid Program. The Division of Licensing and Certification, in the same bureau, is responsible for conducting ongoing utilization review.

ICF & SNF Procedures:

For individuals eligible for Medicaid coverage in intermediate care and skilled nursing facilities, there are several procedures in place designed to make sure that the care is actually required:

- Pre-admission certification of need by the attending physician.
- Pre-admission classification of level of care by the Division of Medicaid Surveillance.
- Recertification by the physician every 30 days in skilled nursing facilities and every 60 days for intermediate care facilities.
- Reclassification by the Division of Licensing and Certification no less often than every 30 days in skilled nursing facilities and every six months in intermediate care facilities.
- Utilization review committees for skilled nursing facilities.

Home Health Agency Procedures:

Utilization of home health agency services is controlled by:

- The Division of Medicaid Surveillance, by prior approval of each plan of care within seven days of admission and every 60 days, thereafter.
- In-house review procedures, whereby the plan of care is reviewed by subcommittees and Medical Advisory Committees.

Procedures for other Services:

There are no utilization control requirements for long term care services not covered by the Medicaid Program (e.g., Title XX services, boarding home care, adult foster care, mental health services).

There have been attempts to evaluate some programs, but evaluation and utilization control are two very different processes. Utilization control is used to control program costs, on a client by client basis. Evaluations have generally been used to determine overall program effectiveness and have focused on aggregate data about clients, rather than how individual clients have been affected by services.

Relationship to Case Management:

Monitoring the appropriateness and quality of services is part of the case management process. Utilization control should be viewed as part of the larger case management process.

The primary purpose of utilization control is to ensure that the State reimburses providers for appropriate types and levels of care for individuals eligible for Medicaid. In Maine, the underlying concern of utilization control has been controlling the amount of money the State is responsible for paying for long term care services. The purpose of case management is to make sure that individuals receive the care and assistance required to meet their long term needs. These two emphases - controlling costs and meeting the needs of individuals - sometimes run at cross-purposes. If utilization control were one part of a much larger case management, perhaps the interests of the cost controllers, the providers of services, and the consumers of service could be better balanced.

Effectiveness:

No statistics have been compiled in Maine to determine whether the considerable investment of time by provider staff and staff of the Department of Human Services to carry out utilization control procedures has had the desired effect on the use of services reimbursed by Medicaid.

A recent study in New York State has found that there is no measurable effect of these procedures. New York is requesting from the Federal Government a waiver from the utilization control requirements.

During hearings held throughout the State in April, the Task Force heard, again and again, that these procedures are unnecessarily duplicative. There are many who believe that the time involved in completing these procedures could be much better spent with the individuals receiving the care.

RECOMMENDATION #33: LICENSING HOME HEALTH AGENCIES

The Department of Human Services should license all home health agencies, whether proprietary or nonproprietary, and whether or not they receive public funds. The Governor should submit legislation to the 110th Maine State Legislature to authorize the Department to license all home health agencies and to establish statutory standards, including, at least, standards relating to the types of services provided and to allowable rates established for services.

MAJOR FINDINGS

The Task Force finds that, at present, proprietary home health agencies that are not certified to be reimbursed under the Medicare Program are subject to no regulation by any level of government. The Task Force also finds that rates charged by both proprietary and Medicare certified nonproprietary agencies appear, in some instances, to be unnecessarily high. The Task Force believes that competition among home health agencies needs to be encouraged.

DISCUSSION

Summary: Recommendation #3 includes a summary of existing home health services.

Need for Regulation: The Task Force received persuasive testimony that regulation of home health agencies is necessary. A frequently mentioned concern related to the high rates which agencies charge their clients. For example, at least some certified home health agencies charge over $30 per visit for nursing services, $20 per visit for home health aides, and $12 per visit for homemaker services. Among proprietary agencies, both large and small, there are no standards for assuring quality and appropriateness of care; nor are there adequate mechanisms for protecting vulnerable consumers from being taken advantage of financially.

RECOMMENDATION #34: COSTS OF REGULATION

All regulations relating to long term care services should be evaluated on the basis of the following questions:

- *What would happen if the regulation were deleted or not adopted?*
- *What is the outcome of enforcement of the regulation?*
- *What are the total compliance costs, in relation to the benefits?*

MAJOR FINDINGS

The Task Force finds that a significant amount of money spent on long term care services is for the costs of regulations relating to the services. The Task Force also finds that individuals throughout the State have serious concerns about whether regulations are effective in accomplishing the purposes for which they were promulgated.

Of course, the Task Force acknowledges that regulation is necessary: the question is how much regulation is necessary?

MAJOR AREAS OF COSTS

Physical Plant:

Multiple codes are applied to long term care facilities (for example, the Life Safety Code for fire protection, the ANSI code to ensure accessibility for handicapped individuals, and Occupational Safety and Health regulations to ensure employee safety). The costs of either replacing outdated buildings or upgrading substandard buildings will continue to push up the costs of residential services.

However, while the many codes have increased the costs of services, they have also resulted in both safer and more therapeutic environments.

Manpower Costs:

Over 60 percent of the costs in nursing and boarding homes, and a much larger percent of the costs of agencies providing in-home services are for personnel. The higher the qualifications of personnel, the higher the cost of employing these individuals. Improved skills are desir-

able goals, and statutes and regulations requiring licensure of professionals and certification of aides can be expected to increase the costs of long term care. Minimum wage laws result in increases in costs of all personnel every time the floor is raised. Basic and ongoing education and staff development also increase the costs of long term care.

However, the Task Force believes that these costs result in better staff, which, in turn, results in better care and services.

Utilization Control: Federal regulations require a variety of admission and ongoing review processes, which are described in Recommendation #32. These requirements involve a substantial investment of time by facilities and agencies in completing forms and contacting physicians. There are sizable bureaucracies in place at the state and federal levels to carry out these reviews.

Licensing and Certification: Costs of long term care services increase as standards are upgraded. Many of the requirements result in paperwork. There is a sizable bureaucracy in place to develop regulations and to implement procedures to evaluate compliance.

Reports: There is a variety of reporting requirements throughout the long term care sector. Each funding source has different requirements. In addition, labor laws require reports.

Certificate of Need: The Certificate of Need Process is a device that promotes price control. Although it prevents duplication, it also limits entry of providers into the system and, thereby, limits competition. It can be argued that costs increase when there is insufficient competition to hold prices down.

Licensing Home Health Agencies: It should be noted that licensing home health agencies pursuant to Recommendation #33 would add to the costs of regulations.

PART SIX:
FINANCING LONG TERM CARE SERVICES

BACKGROUND

In the Introduction to this Report, there is an examination of the effects of economic factors on long term care and on the recommendations of the Task Force (pages 6-8). The Task Force would like to elaborate now on the particular effects of these factors on Recommendations #35 through #43.

First, economic uncertainties have forced concentration on the basics. The Task Force's recommendations in the area of finance are limited to fundamental policy considerations, rather than encompassing "programs."

Second, plans for financing long term care services must be made in light of such economic problems as high (8-10 percent) inflation, accompanying high interest rates and continuing uncertainty for some time to come. Most economists agree that these problems exist, but their opinions about what should be done differ greatly and offer no reliable guidance.

Third, funds will continue to be in relatively short supply.

In view of these factors, Recommendations #35 through #43 emphasize financing for a variety of long term care services, thereby improving cost effectiveness, while also delivering what the Task Force believes are more desirable services. The Task Force believes that many nursing home residents could be better taken care of, and at less expense, outside the institutional setting. Many individuals are in nursing homes or hospitals because Medicaid and Medicare, as now administered, put them there because of the reimbursement provided and not because of the needs of the individuals.

The Task Force believes that new and better ways of evaluating long term care services and handling the pertinent data must be developed so that there are assurances that money requested is both urgently needed and spent in the best possible way. The Task Force has learned that no state in the Union has developed adequate methods of evaluating and collecting and processing data relating to long term care services. This fact has been documented amply by two significant reports.[1,2]

The Task Force believes that case management (Recommendation #29) points the way to improved handling of data, required to provide assurances needed in the fund request mechanism.[3] Only through effective data gathering and processing can there be aggregate measures of "quality of care" and "outcomes," which are essential features in any quality based incentive payment system.

RECOMMENDATION #35: FUNDING SOURCES

#35A. New Optional Services Under Medicaid. The Governor should submit legislation to the 110th Maine State Legislature to require that at least three percent of the State's share of the Medicaid budget for fiscal years 1982 and 9183 should be for optional services not presently paid for under the State Medicaid Program. The Department of Human Services should use thses state dollars to generate federal Medicaid dollars for optional services for consumers of long term care services, including especially but not necessarily solely, in-home and community support services.

#35B. Medicaid as a Source of Income. State financial officials and lawmakers should consider the Medicaid Program as a useful element which not only helps to finance Maine's long term care services, but also contributes to Maine's economy. The program should be viewed as a source of funds and not only as an expense.

#35C. Grant Writer. The Department of Human Services and the Department of Mental Health and Corrections should employ and share the costs of an experienced grant writer. The grant writer should provide leadership and direction to state agencies in locating, applying for and obtaining both federal funds and support from private foundations for various long term care projects.

#35D. Clearinghouse. (See Recommendation #27.)

MAJOR FINDINGS

The Task Force finds that the State of Maine has not made optimal use of Medicaid and other federal dollars in the funding of long term care services. The Task Force finds, further, that multiple sources of funding for long term care services result in unwieldy and sometimes unnecessary requirements for record-keeping, eligibility determinations, and coverage of services

ISSUES RELATING TO FUNDING SOURCES

Chart V is a summary of the major federal funding revenues for long term care services administered by the State.

CHART V. MAJOR FEDERAL FUNDING SOURCES FOR LONG TERM CARE SERVICES IN MAINE
(Rounded Figures in Millions of Dollars for Fiscal year 1980)

FUNDING SOURCE	FEDERAL SHARE	STATE SHARE	TOTAL
Title XIX (Medicaid),* Social Security Act: Payments to intermediate care facilities	42.51	17.43	59.94
Title XX (Social Services)**			
• Mental Health	.58	.20	.78
• Mental Retardation	1.50	.50	2.0
• Homemaker Services	1.65	.55	2.2
• Nutrition	.43	.14	.57
• Transportation	.71	.24	.95
Older Americans Act	3.02	-	3.02
Rehabilitation Act	5.88	1.07	6.95
Developmental Disabilities Act	.20	-	.20

* The total amount of state and federal funding under the Medicaid Program is $133,549,868.

** The total amount of state, local and federal funding under the Title XX Program is $22,653,427. One-half to two-thirds of the transportation funds paid for transportation for adults going to medical appointment and day treatment programs.

Responsibility: Municipalities historically had the responsibility to meet the needs of their poor and disabled citizens, but the burden has shifted to the state and federal governments. However, it is not clear that any level of government is required by statute to fully meet the long term care needs of any individual who cannot afford or who is otherwise unable to address these needs without assistance of some kind.

Multiplier Factor: As indicated in Chart V, the largest source of funding for long term care services is, by far, the Medicaid Program. Payments to nursing homes under the Program almost tripled between 1974 and 1978. In 1980, nursing homes received almost $60,000,000 under the Program.

As the costs have climbed so high, so rapidly, policymakers and lawmakers have become reluctant to do anything that would result in the costs climbing higher, even more rapidly. This is understandable.

The Task Force believes that officials should begin to view the Medicaid Program as a significant source of revenue, rather than merely a burdensome expense. Roughly 30¢ of general revenue funds brings into Maine 70¢ of federal matching funds. The 30 percent state match can be considered "spending money to earn money," in that it brings into Maine a lot of federal money that the State would otherwise not receive.

This money can be considered "better" than some other kinds of incoming money, because it tends to stay in Maine longer. Medicaid supported capital expenditures strengthen the State's economic base. Also, additional Medicaid dollars go largely for personnel related payments (pay increases, benefits, training, et cetera) while other kinds of dollars, in large part, leave the State more directly.

According to a recent report by the National Foundation for Long Term Care, in 1977 Maine received $27.5 million in federal Medicaid dollars for nursing homes.[4] Of this amount, $24.1 million showed up as personal earnings of state residents. These figures are based on economic impact analysis computations by the Bureau of Economic Analysis of the U. S. Department of Commerce. The computations lead to "economic impact multipliers" for various industries in the different states which demonstrate the impact of spending and re-spending.

Maine now collects $.0604 on each dollar of personal income (on the average). Put up as the state match for Medicaid dollars, $.0604 brings in $.1409 in federal match. This would give additional personal earnings of $.1235 from federal dollars. Because there would be state taxes on the $.1235, the $.0604 of state match would bring in $.00746 in state revenues. In the long run, then, the state match would be only $.0604 minus .00746 equals $.05294. This means that the state match for federal Medicaid dollars is really 26 percent - not 30 percent. Furthermore, we are not speaking here of "seed" money which can dry up (leaving the State to support programs), but regular Medicaid funds specified by federal statute.

Even though to the taxpayer taxes are taxes, state financial officials must consider the relative benefits of various expenditures of tax monies. As important as a state service may be, it should be viewed in the light of the financial costs or benefits it brings to the State's economy. Tax-supported programs which merely redistribute income within the State irk the taxpayer, but the mythical "average" taxpayer doesn't suffer. Programs which redistribute state taxes and bring in federal monies benefit the "average" taxpayer - and benefit him or her on the personal earnings basis, to the tune of, for 70 percent federal matching funds, just over double the taxes he or she put up for redistribution. Some will lose a little, some gain something, but, overall, the state economy will gain at least two for one and, probably, a bit more on top.

In sum, entirely apart from the crucially important humanitarian issues, Medicaid is an important element in financing the Maine economy, and should also be seen as a source of funds...not simply as an expense.

Research:

The Task Force believes that the State must work more aggressively to seek out research and demonstration funds to attempt innovations in the delivery of long term care services.

Multiple Sources:

Throughout the State, the Task Force heard testimony that multiple funding sources for long term care services result in a variety of unnecessary and unwieldy requirements for record-keeping, eligibility determinations, and services covered.

Funding by multiple federal sources of the same or similar services is a prevalent phenomenon. Unquestionably, it is a major contributor to needless expense at all levels of government, as well as a cause of considerable frustration and additional wasted dollars at the service provider level.

An unfortunate and virtually unavoidable consequence of multiple funding sources is fragmentation in service provision. For example, the sheer variety and numbers of administrative units charged with responsibility for financing in-home care has produced some interesting challenges for agency administrators, among which are the following:

- Each program has a defined constituency based on age or income, with client groups frequently overlapping.

- Service definitions and the range and duration of services covered vary substantially from program to program.

- Each program has its own standards for performance and reporting requirements. (Two programs actually have no standards, but do have unique reporting requirements.)

- There are three different reimbursement principles and two different methods of defining units of services.

It is not uncommon to find two or three programs covering services to a single client, either simultaneously or successively as the physical condition or eligibility of the patient changes. With long term patients, shifts in coverage are common.

Changes in funding represent a considerable administrative expense to the provider who must verify eligibility, recertify eligibility, change billing procedures, and so on.

RECOMMENDATION #36: REIMBURSEMENT

#36A. Statement of Philosophy. The Department of Human Services should add a statement of philosophy to its Principles of Reimbursement, including the goals and objectives it wishes to accomplish through the Principles.

#36B. Reasonable Costs. Representatives of the Joint Standing Committee on Health and Institutional Services and the Joint Standing Committee on Appropriations and Financial Affairs of the 100th Maine State Legislature should:

- Undertake a study of what constitutes reasonable costs for purposes of state reimbursements to private providers of long term care services; and

- Develop legislation to present to the Second Regular Session of the 110th Maine State Legislature to establish statutory standards for reasonable costs on which the Department of Human Services will be required to base its reimbursement regulations.

#36C. Allowable Costs. The Department of Human Services should allow the costs of legal retainers and other fees incurred in disputes, pension plans for employees, and ward clerks to be included in payments to skilled nursing and intermediate care facilities and boarding care facilities that are reimbursed on a reasonable cost basis. However, the Department should reimburse for the costs of legal retainers and other fees incurred in disputes, only when a facility wins a dispute.

#36D. Case Management. The Department of Human Services should use information gathered during the case management process (Recommendation #29) to determine what services are required for an individual's care, and, therefore, what services should be included as allowable costs in payments to the skilled nursing, intermediate care, or boarding care facility in which the individual resides.

#36E. Cost Centers. The Department of Human Services should establish "cost centers" for all providers of long term care services whom it reimburses. Through a provider agreement, the Department should specify the services to be purchased from the provider and the characteristics of the consumers for whom it will purchase the services.

#36F. Occupancy Requirement. In order to remove one incentive for skilled nursing and intermediate care facilities and boarding care facilities that are reimbursed on a reasonable cost basis to admit or keep residents unnecessarily, the Department of Human Services should drop its 90 percent occupancy requirement for determining payment rates for these facilities. This means that no matter whether the occupancy of a facility is 90 percent or higher or less than 90 percent, the Department should establish the per diem rate by dividing costs by the actual number of "patient days."

#36G. Boarding Care Facilities. The Department of Human Services should remove the ceiling from payments to boarding care facilities and should reimburse all such facilities, regardless of size, on a reasonable cost basis.

#36H. Delayed Payments. In order to reduce delayed payments to skilled nursing, intermediate care, boarding care and foster care facilities and other programs providing long term care services, the Department of Human Services should:

- Determine financial eligibility and expedite related paperwork prior to admission or receipt of services;
- Require residents who have been paying with private funds, but who apply for Medicaid or other public funds, to continue paying with their private funds until the day on which their financial eligibility is approved; and
- Eliminate the practice of "redlining" (that is, holding up payments to facilities and agencies because of apparent errors or inconsistencies)

#36I. Advance Payments. Every twelve months facilities and agencies should receive an advance payment of 1/12 of the previous year's payment, as done in the "PIP" system for hospitals.

#36J. Administrative Allowances. For skilled nursing and intermediate care facilities and boarding care facilities that are reimbursed on a reasonable cost basis, the Department of Human Services should:

- Eliminate the administrative allowance;
- Allow reasonable administrative expenses as reimbursable costs; and
- Determine the salary for each administrator (whether owner or employee) as part of the contracting process and relate the salary to the location of the facility, the types and numbers of residents, and the qualifications of the administrator.

#36K. Payments for Business Costs. The Department of Human Services should reimburse skilled nursing, intermediate care and boarding care facilities for all reasonable costs associated with doing business.

MAJOR FINDINGS

The Task Force finds that some of the decisions by the Department of Human Services regarding what constitutes "reasonable costs" for purposes of state reimbursements to private providers of long term care services are affected by the Department's fear of increasing costs under the Medicaid Program.

The Task Force finds that some of the reimbursement regulations of the Department contribute to the unnecessarily restrictive and intensive nature of Maine's system of long term care services.

The Task Force believes that the 90 percent occupancy requirement for determining payment rates for skilled nursing and intermediate care facilities and boarding care facilities that are reimbursed on a reasonable cost basis encourages inappropriate admissions to fill up beds and may serve as a disincentive to return residents to the community, if the occupancy falls close to 90 percent.

The Task Force is concerned that if the present ceiling on payments to boarding care facilities is not removed, these facilities may well cease to be a viable part of Maine's system of long term care services. Some of the individuals who require the degree of supervision provided by boarding care facilities may be forced into intermediate care facilities.

SUMMARY OF MAJOR REIMBURSEMENT SYSTEMS AND PROBLEMS

Social Security Act:

Under the federal Social Security Act, there are several programs funding long term care services which are operated under different reimbursement systems.

Title XVI, the Supplemental Security Income Program, provides direct money payments directly to individuals whose income and assets fall below federal standards. SSI pays for boarding care facility care and for room and board for persons living at home. Because payments to individuals are at the beginning of the month, at least part of the payments to the boarding care facilities are made in advance of the services delivered. However, payments to boarding care facilities in excess of the SSI payment are state dollars paid retrospectively. In Maine, the Bureau of Social Welfare, Department of Human Services, is

responsible for administering reimbursements to the boarding care facility program.

Since Title XVIII, Medicare, is a federally administered program, the reimbursement is subject to federal regulations, carried out by fiscal intermediaries who agree to act as agents of the Federal Government. Fiscal intermediaries determine rates based on reasonable costs or charges, do audits, and make retrospective adjustments in reimbursements.

Under Title XIX, Medicaid, reimbursement is subject to state regulations developed within federal parameters. In Maine, the Division of Health Care Audit, Department of Human Services, establishes interim rates, does audits, and makes retrospective adjustments in reimbursements. Rates are based on costs, as defined in the Principles of Reimbursement. These are vendor payments, direct to the provider, made after the service has been delivered.

The Bureau of Resource Development, Department of Human Services, administers reimbursement under the Title XX social services program. This, also, is a retrospective system of reimbursement.

Occupancy: For facilities reimbursed on a reasonable cost basis, payment rates are based on actual days of service provided, at a minimum of 90 percent occupancy. This encourages inappropriate admissions to fill up beds and very well may serve as a disincentive to return residents to the community, if the occupancy rates falls close to 90 percent.

Ceiling: The Department of Human Services imposed a ceiling of $465 per resident per month on operational costs of boarding care facilities with over six beds. The Task Force heard comments during work sessions and public hearings that indicate that the costs in many facilities exceed the ceiling. One operator reported a loss of $22,000 last year in a 24 bed facility. The Department is aware that some facilities may have to close as a result of the ceiling and is not licensing any new facilities. The present flat-rate payments to boarding care facilities with six or fewer beds are also too low.

Delayed Payments: Facilities reimbursed on a reasonable cost basis usually receive payments on around the 17th of each month, provided they have submitted their invoices to the Department

of Human Services prior to the 5th of the month. Payments are made through a manual system.

Sometimes "redlining" occurs. This means that the Department crosses out the names of residents who are either admitted or discharged near the end of the month. It is not unusual for a billing form to be redlined by as much as $5,000 to $9,000 per month.

Some delays in payments occur in the regional offices of the Department in the determination of financial eligibility. Inconsistencies in determining eligibility dates arise when a resident runs out of private funds and becomes eligible for Medicaid funds. For example, one regional office communicates with facilities to determine what date the resident has paid up to and makes eligibility from that date. Another regional office makes the eligibility date during the month the application for Medicaid funds is received, even though the resident has prepaid the facility for 30, 60 or 90 days of care.

Processing financial eligibility tends to slow down once an individual eligible for Medicaid is in a facility. Facilities have waited for as long as two to six months to receive payments from the Department for these individuals.

Administrative Allowance:

The administrative allowance for facilities reimbursed on a reasonable cost basis is fixed by regulation. Originally established in 1972, the allowance was not changed until January 1, 1978, when it was increased by 33 percent. It has not changed since that time.

In a 60 bed intermediate care facility, the salary for the administrator would be $400 per week, in order not to exceed the allowance of $20,800 per year. This administrator would be responsible for managing a $650,000 annual budget.

The present system permits an owner to hire a low-priced and, possibly, relatively poorly qualified administrator and pocket the rest of the administrative allowance, promotes the construction of larger facilities (the larger the facility, the greater the allowance), and does not require that administrators' salaries should be commensurate with experience, qualifications, ability or quality of operation.

RECOMMENDATION #37: DEPRECIATION

The Governor should urge the 110th Maine State Legislature to consider devising a suitable decision-making mechanism in the areas of depreciation, property transfers and associated issues. The Legislature should do this as part of its study of "reasonable" costs proposed in Recommendation #36B.

MAJOR FINDING

The Task Force finds that the current depreciation policies relating to nursing homes lend themselves to unsound and undesirable financial practices, and contain potentially undesirable features. Owners are encouraged, under some circumstances, to sell facilities with resulting higher rates of reimbursement following a sale. The Task Force also finds that individuals are able to purchase and own facilities without putting in very much of their own money and, thereby, achieve "leverage" (as in a "margin" purchase) and increase the profit at the time of sale during periods of high inflation.

ISSUES RELATING TO DEPRECIATION

Purpose of Depreciation:

The purpose of depreciation, which is an accounting principle, is to cover the reduced value of real property as it wears out. Depreciation is handled in diverse ways in such different fields as rental housing, public housing, and health care. Within the nursing home field, it is handled in widely differing fashions among the 50 states.

In recent years depreciation has become an accepted accounting mechanism, even in situations where property does not wear out and, in fact, increases in dollar value.

Low Initial Equity:

With respect to nursing homes in Maine, depreciation exceeds payments on the principle in the early years of a mortgage and provides funds which the owner can use for any purpose he chooses. In addition, the interest on the mortgage is allowable under the Principles of Reimbursement of the Department of Human Services. If depreciation is funded to replace fixed equipment, the Principles require the owner to use the funds to purchase the equipment. The equipment is then added to the equity value of the property on which a 10 percent return is paid to the owner.

In sum, because depreciation is a return of capital, the equity decreases as depreciation payments are received. The depreciation payments are determined on the value of the property, regardless of mortgage, and are the same each year over the depreciation for the item.

Incentives to Sell and Buy:

In later years of a mortgage period, depreciation payments do not cover the payments on the principal of the mortgage. This encourages the owner to sell the facility after he has reached the break-even point (the point at which depreciation payments no longer exceed principal payments). The profit to be made on a sale is not sufficiently reduced by depreciation recapture provisions to effectively discourage the sale of property, in the presence of other factors of possibly overbearing weight (for example, low initial equity, inflation, pressures to sell, et cetera).

Ten provider representatives, including seven especially invited guests, attended a special meeting of the Subcommittee on Finance on June 17, 1980. After a statement by a Department of Human Services official that the purpose of recapture was to discourage sale, the chair asked a provider spokesman, point blank, whether recapture did so, in fact. The reply was negative, and there was a tacit consensus on the part of all providers present.

As a banker has commented, owners of the real estate are "...working the system as hard as they can - taxes, inflation, etc., - to get everything they can out of it and they're doing a good job of it," and there is no question that a property can really be milked. Frequently, a purchaser must be ready to make a considerable investment in the physical plant, and he is scrutinized by the bankers before he can get a mortgage. But although the seller has clearly maximized his profit in such a situation, the buyer's interest may still be to acquire a home with a good clientele and reputation in order to be an operator and not necessarily to be a speculator although, of course, he hopes for a high residual value in the long run.

The Principles of Reimbursement allow a buyer of an existing facility to start a new depreciation schedule, based on the allowed purchase price of the property. This practice is not permitted in some states.

Value of Limited Partnership:

Generally, if the operator is the owner of a facility, the rates will increase following the purchase of the facility and its approval under the certificate of need process. However, under a limited partnership arrangement, when the

owners/builders have entered into a long term lease agreement (which is consistent with Internal Revenue Service regulations for tax shelters) there will not be an increase in rates for the life of the lease, even if a change in ownership of the real estate or of the operator occurs. A rate change can occur only if there is a merger of the two interests. Such a combination of interests would, of course, be subject to the 1122 review process.

During the early most effective tax shelter years, the limited partners enjoy very good profits, but it should be remembered that, to do so nowadays, the developer (usually the general partner) must place substantial up front monies at risk during the Certificate of Need process and while project completion is by no means assured. Frequently, the operator is also a limited partner and may well be, in everyone's eyes, the most appropriate eventual purchaser (in which case the appropriateness is subject to the 1122 review process mentioned above). However, if the operator is not a limited partner, but only the lessee, he derives no benefits from the tax shelter, has no equity in the real estate, and any profit he earns must be earned solely from operations.

"Trafficking": Nursing homes can become highly attractive to real estate speculators when the confluence of reimbursement principles (especially depreciation), economic conditions (especially high, continuing inflation) and tax policies favor "trafficking." This term means trading in properties held for relatively short periods of time to earn very high profits, after taxes and inflation, using the leverage of small equity mortgage financing (essentially "margin" buying).

The recent Ohio report[5] cites enormous and still growing real estate manipulation, with 30 percent of for-profit homes changing ownership arrangements in one year (1978) alone. Not only is this costly in terms of constantly increasing reimbursement rates, but - even more serious - a widespread marketplace of this sort tends to bring in those with an interest in large, rather quick profits and, presumably, little interest in providing humane long term care.

Maine has been fortunate, so far, in escaping this problem, probably for a number of factors. These factors, some of which may be unique to Maine, include: a small, poor and scattered population; the isolated geographical location of

the State; and a community of individuals working in nursing homes, banks and the Department of Human Services, with a high coefficient of everybody-knowing-everybody else. These factors make Maine relatively unattractive to the hit-and-run outsider. Well known indigenous real estate speculators must generally move with some relative decorum. Several years ago, the Department did detect an incipient trafficking trend, which failed to develop following the emplacement of depreciation recapture and Consumer Price Index inflator limited sale prices in the Principles of Reimbursement. The potential for trafficking still remains in the present economic environment. With the present Principles, even a six percent Consumer Price Index permits a very high rate of return on a facility held only a few years. Vigilance, therefore, is mandatory.

Heavy trafficking in other states has been shown to damage care while escalating its cost.[6] Maine must prevent trafficking and, hence, must be in a position to impose preventive measures quickly if the need arises. At the same time, Maine must avoid taking premature action in a situation with such a brief, ad hoc regulatory history based nationwide on only the flimsiest legislative and case law.

Costs of New Construction:

In passing, the Task Force notes that some years ago, fixed capital costs were roughly 15 percent of daily bed costs for newly built homes. That figure is now over 20 percent and is rising rapidly, because of the swiftly escalating construction and financing costs. This means, of course, that Medicaid nursing home costs will increase with newly constructed homes because of these higher fixed charges, as well as increasing labor, food and energy costs. However, where long term leases exist, the capital bed costs will remain fixed, while the others rise with inflation, and the fixed operating cost ratio will improve over the years of the life of the lease.

RECOMMENDATION #38: INCENTIVES

#38A. Incentives for Providers. With respect to skilled nursing and intermediate care facilities and boarding care facilities that are reimbursed on a reasonable cost basis, and other agencies providing long term care services, the Department of Human Services should establish a system of reimbursements in which:

- *Rates are negotiated - based on budgets, prior year's experience, valid aggregate data and clearly defined responsibilities - before the Department and a facility or agency enter into an agreement;*
- *Rates are related to the needs of different types of residents or other consumers and are based, in part, on information about needs collected during the case management process (See Recommendation #29);*
- *Rates are higher for a specified length of time for services provided to any resident or other consumer who is temporarily severely impaired and who needs intensive services for a limited length of time; and*
- *There are profits beyond the negotiated rate which are related to outcomes of care, based on aggregate data and achievement of goals established as part of the case management process.*

#38B. Incentives for Consumers. (See Recommendation #14.)

#38C. Incentives for Volunteers. (See Recommendation #15.)

MAJOR FINDING

The Task Force finds that there are very few incentives to encourage proper and efficient use of long term care services.

DISCUSSION

Providers: Presently, the major incentive for intermediate care facilities to contain costs and operate efficiently is the need to keep down rates in order to attract private pay residents. However, because 85 percent of all residents are covered by the Medicaid Program, many facilities

have an extremely high percentage of these residents, and, thus, even this incentive is lost.

The retrospective system of settlements of payments, used for all the major funding sources of long term care services, does nothing to encourage efficient operation. Even worse, it is reasonable to assume that if a facility or agency administrator knew that costs were going to be less than the interim payments, he or she would incur expenses in order to avoid returning to the Department funds already received.

The only profit permitted under the Principles of Reimbursement for proprietary operators is 10 percent on net equity.[7] No profit is allowed for nonproprietary providers.

Reimbursement is not related to the quality of services provided, nor to the outcomes of the services. There are no incentives for a facility to admit an individual who is "difficult" or who requires a great deal of care.

Neither are there incentives for agencies to provide in-home services to such individuals.

Consumers:

When third-party payors pay for all or most costs, consumers are not motivated to exercise discretion in the use of services. The system of billing, third-party payments and the resulting paperwork are confusing for consumers.

When individuals live in an intermediate care, boarding care or other long term care facility, all services are available under one roof, including meals, activities and other services that are not reimbursable by a third-party payor in other settings. Once institutionalized, dependency is fostered among these individuals.

RECOMMENDATION #39: CONTRACTING AND AUDITING

#39A. Reactive Regulations. In order to avoid the formulation and interpretation of "reactive" reimbursement regulations (that is, regulations adopted across the board to address problems that are present in only a few instances), the Department of Human Services should:

- Resolve particular situations, through the agreement mechanism, on an individually negotiated basis;
- Spell out more clearly in agreements, the rights and responsibilities of the Department and the provider; and
- When faced with an exceptional situation, bring together representatives of both the provider and the Department, in order to negotiate a solution, rather than imposing additional regulations, applicable to all providers.

#39B. Negotiations. A Department of Human Services contract officer within the agency with program responsibility for the long term care service the Department wishes to purchase should handle negotiations with the provider.

#39C. Contractual Relationship. There should be a clear contractual relationship between the Department of Human Services and each provider of long term care services.

#39D. Title XX Contracts. Contracts for services under Title XX and other similarly financed programs should be written on 2-3 year cycles, whenever possible, with budgetary amendments to replace the annual contracting process.

#39E. Contracts with Community Mental Health Centers. The Department of Mental Health and Corrections should move toward funding community mental health centers by purchasing "units of services" rather than through the block grant basis which now, generally, is the case.

#39F. Interest Incurred. Interest incurred as a result of the contracting process should be reimbursable at cost.

#39G. Single Audit. Each provider of long term care services should be subject to only a single audit by the State for all of its contracts.

#39H. Scope. The scope of the single audit should be defined in the contract between the Department of Human Services and the provider. The audit should not encompass policy matters.

#39I. Certified Public Accountant. The Department of Human Services should accept the report of a certified public accountant, audit for exceptions based on desk review, and do sampling.

#39J. Policy Decisions. State auditors should not make policy decisions. Final decisions about allowable costs should be made by the contracting officer on the basis of information verified by the state auditor.

MAJOR FINDINGS

The Task Force finds that the present auditing process administered by the Department of Human Services includes some functions which are not customarily part of this process. The Task Force also finds that present auditing and contracting processes, administered by the Department, result in unnecessary inconvenience for providers of services.

PROBLEMS RELATING TO CONTRACTING AND AUDITING

Cost Control:

The Department uses the auditing process as a mechanism for controlling costs. Rather than simply carrying out audits, Department auditors are making policy and program decisions which they are not qualified to make.

Inconveniences:

There are no clear Principles of Reimbursement for Title XX. As a result there are a lot of differences of opinion between providers and auditors.

Decisions of auditors are not consistent throughout the State.

Providers of services, funded from a variety of sources, not only must deal with a variety of eligibility and reporting requirements, but also are subjected to a different audit for each program. There is no uniform "chart of accounts" that providers can maintain that is acceptable to all funding source.

Definition of Auditing:

According to the Encyclopedia Brittanica, "the most familiar type of auditing is the administrative or pre-audit, which consists of investigating individual vouchers, invoices or other documents for accuracy and proper authorization before they are paid or entered in the books." The Task Force believes that auditing done by Department of Human Services staff does not fit into this definition.

RECOMMENDATION #40: RATE SETTING COMMISSION

The Governor should submit to the 110th Maine State Legislature a bill to establish an independent commission, responsible for establishing rates for all long term care services purchased with public dollars.

MAJOR FINDING

The Task Force finds that the Department of Human Services constitutes a "monopsony" with respect to long term care services.

DISCUSSION

During its discussions over the past year, the Task Force has noted that the Department of Human Services purchases the great preponderance of long term care services and, thus, constitutes a "monopsony." This enables the Department, acting as the buyer, to make decisions unilaterally on any basis, including budgetary considerations, and precludes free negotiations.

RECOMMENDATION #41: PRIOR APPROVAL

The Principles of Reimbursement of the Department of Human Services should be revised to eliminate the prior approval process for staffing, consultants and educational expenses.

MAJOR FINDING

The Task Force finds that decision-making regarding a safe level of staffing for the supervision of residents of skilled nursing and intermediate care facilities has been transferred from facility administrators to the Department of Human Services. The Task Force also finds that the Department rather than facility supervisory staff, is making determinations about the educational needs of facility staff.

SUMMARY OF "PRIOR APPROVAL" PROCESS

Staffing:

Effective January 1, 1978, the Principles of Reimbursement were amended to require that the Department of Human Services must approve in advance any nursing staffing (including registered nurses, licensed practical nurses and nurses aides) above minimum standards, in order to be a covered cost under the Medicaid Program. The amendments also required that activities and social service personnel above the number of hours permitted in the Principles must be approved in advance.

Pharmacist consultants are reimbursed on a per capita basis, and the allowable cost for dietary consultants is limited to eight hours per month, unless there is advance approval for additional time. Social worker consultants and advisory dentists are not an allowable cost in intermediate care facilities, but are permitted in skilled nursing facilities.

The staffing hours to be approved are determined by a level of care system used in both skilled nursing and intermediate care facilities, in which all residents in a facility on a given day are classified into one of three levels of care. Level one residents require the least amount of care and level three residents require the most care.

Each level of care is assigned a number of hours. The hours for the level of care for all residents are added to arrive at the total number of hours of nursing care needed per day. The total number of hours is then divided by eight to determine the number of nursing care staff the Department approves for reimbursement.

Licensed nurses, not including the Director of Nursing, are allowed up to one half-hour per resident in intermediate care facilities and up to one hour in skilled nursing facilities. These licensed nurses are subtracted from the number of approved nursing staff, and the remaining staff are nurses aides.

Additional licensed nurses are prior approved for charge duties, depending on the size of the facility.

This procedure has discouraged administrators from hiring licensed practical nurses instead of aides to meet the staffing ratios, a practice that had previously been encouraged to improve the quality of care. It also limits the employment of registered nurses in intermediate care facilities.

The staffing that is approved at the time of an on-site visit to a facility remains in effect until the next on-site visit in six months, even though there may have been empty beds that day, or a level one care resident is discharged and there are all level three patients waiting in a hospital to be admitted to the facility.

The facility may request prior approval for additional staff to meet the increased needs. This is usually not necessary, because the approved staffing, in most instances, is greater than the current staffing.

There has never been a study done to determine the effectiveness of the prior approval process for staffing. One of the objections to the system is that it removes from the professional staff of the facility the responsibility to determine their own staffing needs and places this responsibility in the Department of Human Services.

Liability: The question of who (the Department or the facility) is liable in the event of accidental injury to a resident because of inadequate supervision with limited staff remains unanswered.

Education: Educational activities such as participation in workshops and seminars, also require prior approval. However, orientation, on-the-job training, in-service education and similar work learning are recognized as normal operating costs and are carried out by staff of facilities. If others, such as physical and occupational therapists or restorative nursing specialists are to conduct special training programs, prior approval must be obtained for the cost to be allowable.

RECOMMENDATION #42: PURCHASING PRACTICES

#42A. Group Purchasing by Facilities. The following steps should be taken to organize group purchasing efforts:

Group Purchasing Organization. The Maine Health Care Association and the Maine Personal Care Association should begin to work immediately with their members to establish an organization for group purchasing for both proprietary and nonproprietary skilled nursing, intermediate care and boarding care facilities. The organization should establish relationships with the Hospital Association's Shared Services program (HASS), in order to build on their experiences and contracts, to the extent possible.

Incentive to Participate. As an incentive for providers to participate in group purchasing, the Department of Human Services should allow providers to retain part of the savings for their personal gain or use the savings for additional staffing, activities or other operational costs to improve the quality of life. Cash discounts for prompt payment of bills should be an allowable income item that should not offset cost.

#42B. Purchasing Devices to Minimize Disability. *(See Recommendation #11.)*

MAJOR FINDING

The Task Force finds that various group purchasing arrangements can be used to promote more efficient and effective use of scarce dollars.

PRESENT PURCHASING PRACTICES

Principles of Reimbursement:

Under the present Principles of Reimbursement, all savings realized through group purchasing are reflected in lower per diem rates. As a result, in skilled nursing, intermediate care and boarding care facilities in which 90 to 100 percent of the residents are Medicaid or Supplemental Security Income recipients, there is little incentive to participate in group purchasing arrangements.

The Principles also prohibit intermediate care units in hospitals from filling prescriptions in hospital pharmacies. This prohibition obstructs an opportunity to find lower costs through group purchasing.

Facilities are resentful that under its Principles of Reimbursement, the Department of Human Services "nickels and dimes" them in areas such as disallowing educational seminars, but, at the same time, wastes thousands of dollars because of the present purchasing practices.

Suppliers: Suppliers of goods are not going to be interested in delivering to small purchasers. Warehousing of goods is a way to respond to this reluctance. Standardized menus are also a possibility.

Organization: The existing group purchasing organization in Maine is affiliated with the Maine Hospital Association and is limited to nonproprietary facilities and agencies. Another organization is needed for proprietary facilities.

RECOMMENDATION #43: "SEED" MONEY FOR NONPROFIT FACILITIES

There should be a "seed money" funding source - for use by the Bureaus of Mental Health and Mental Retardation of the Department of Mental Health and Corrections and by the Bureaus of Rehabilitation and Maine's Elderly of the Department of Human Services - to promote the development of nonprofit group homes and transitional living facilities.

MAJOR FINDING

The Task Force finds that nonprofit groups have played a much smaller role than have for-profit operators in the development of residential services for consumers of long term care services.

DISCUSSION

The Bureau of Mental Retardation, Department of Mental Health and Corrections, has been instrumental in developing small group homes for its clients. However, there has been very little development of group homes or transitional living facilities for the chronically mentally ill, the physically disabled and the elderly.

Development of facilities for these other groups can be encouraged through the mechanism used by the Bureau of Mental Retardation. This mechanism includes the use of "seed money" for the development of group homes. The Bureau loans seed money to a nonprofit group to pay for the up-front development costs of the home (legal fees, architect costs, soil tests, et cetera). The seed money is then used again in the Bureau's development process when the outgoing funds are reimbursed during permanent closing. These reimbursed funds are then used again for start-up costs (furniture, staff hiring before the home starts, dishes, et cetera).

Another way of handling this mechanism so that the funds return to the lending authority, would be to broker it to another nonprofit entity that would administer the seed fund for a small handling fee. In this way, funds would be returned to the nonprofit entity after the pernament financing and would not be used for a second round of start-up costs, but could be used again for the development of another nonprofit group home.

RECOMMENDATION #44: FINANCIAL IMPLICATIONS OF UTILIZATION PATTERNS

#44A. Research. The Department of Human Services and the Department of Mental Health and Corrections should conduct research to determine the cost effectiveness of in-home care, as compared with the cost effectiveness of care in various types of facilities. In addition to cost data, the quality of life and satisfaction level should be evaluated as part of the research. The research should be based on costs per case rather than on costs per day. The rising costs of new construction should be reflected in the research, especially since in-home care and certain types of residential care may rapidly become less costly than care provided in newly built nursing and boarding homes.

#44B. Placement in Facilities. Individuals should not be admitted to skilled nursing, intermediate care, boarding care or foster care facilities unless available in-home care that can be financed has been considered, first. This should be one of the steps in the case management process. (See Recommendation #29.)

#44C. Spend Down. The Department of Human Services should develop sliding fee scales for in-home services, as part of the "spend down" provisions of the Medically Needy Program.

MAJOR FINDING

The Task Force finds that thousands and probably millions of dollars are being spent needlessly to pay for care in residential and institutional settings for individuals whose needs could be met in less costly settings. In addition, the goal of a long term care system, as defined by the Task Force, to care for people "in the least restrictive setting," is not being met.

SUMMARY OF ISSUES RELATING TO UTILIZATION PATTERNS

System Overload: The following facts indicate that demand for long term care services exceeds supply of these services, and that this system overload results in individuals receiving inappropriate services.

- There is a much greater demand for housing for the elderly and disabled than can be met at present, as evidenced by waiting lists for most housing projects.

- There are not enough boarding care facility beds in most areas. Therefore, boarding care placements for individuals who have improved in intermediate care facilities rarely occur.

- Hospital discharge planners report that they are unable to place individuals in boarding care facilities because no vacancies exist.

- Intermediate care facilities are 95 percent to 98 percent occupied. Some will not admit Medicaid recipients.

- Skilled nursing facilities are being utilized for individuals needing and waiting for an opening in an intermediate care facility.

- 150-200 individuals who have been determined eligible for intermediate care may be occupying hospital beds throughout the State on any given day. Hospital discharge planners report stays of two to six months of individuals awaiting intermediate care facility placement, with the Medicaid Program paying the bill. One hospital reported a cost to the Medicaid Program of $37,600; another, $220,000 for a six month period.

- Individuals who need skilled nursing care, including rehabilitation services, are staying in hospitals because skilled nursing beds are not available. Some of these same hospitals need these beds for acute care. Individuals are kept waiting for elective admissions, and overcrowding occurs.

- Landlords do not always hold rooms or apartments for an elderly individual who is hospitalized. The result is the admission of the individual to an intermediate care facility because there is no place else to go. After an individual is admitted to an intermediate or skilled nursing facility, assets can be transferred in order to establish eligibility for Medicaid. Then there is no home for the individual to be discharged to.

- Because of lack of available beds, individuals are being classified to lower levels of care or are retained in facilities when their needs have increased or where their needs are not being met.

Use of State Institutions:

The annual costs of care in the state-operated institution for mentally retarded individuals range from $20,000 to $30,000 compared with $10,000 to $20,000 in the community. The annual costs of care in the two state-operated institutions for mentally ill individuals are similar, ranging from $20,000 to $25,000.

As is true throughout the country, residents of the state institutions have been returned to the community in large numbers. For example, the population of the two mental health institutions has declined from 2900 in 1970 to 700 in 1980. This movement out into the community has not resulted in reduced costs in the institutions. Admissions have continued at the same level, while the length of stay for residents has decreased.

Until recent years, residents were used as workers to help staff in many areas of the institutions. This no longer happens, but the number of staff has remained constant.

Costs of Institutional Vs. In-Home Care:

There has been considerable effort to determine whether cost-effective alternatives to institutions are already in place or can be developed to provide necessary services in the most appropriate and least restrictive setting.

There have been several attempts to determine the cost effectiveness of in-home care as an alternative to institutional care. Most studies conducted to date show that in-home care can cost less than nursing home care in certain circumstances.

A General Accounting Office report published around a year ago discussed results from a study conducted in the Cincinnati area which compared health costs between institutionalized and non-institutionalized individuals over 65 years of age.[8] The purpose of the study was to determine at what level of impairment the break-even point would be reached in the cost of care. The results of the study showed that in-home care was "less expensive until the individual is greatly or extremely impaired."

In 1975 (Chelsea-Village Program), a cost analysis of home health programs and nursing home costs in New York was conducted by Boehringer Associates. Costs for the three patient categories used - ambulatory, semi-ambulatory, and bedbound - were higher for the nursing homes than for the home health programs. The study also pointed out that as more services were needed in the home, the difference in

costs between in-home care and nursing homes decreased.

Although the studies mentioned above indicate that, in some cases, in-home care can present a more cost effective method of care than nursing home care, more research needs to be conducted. It is difficult, perhaps impossible, to compare results from one study to another or to compare results from past studies to a home health agency or intermediate care facility here in Maine. The difficulty arises partly because of differences in the methodology and design of the studies in question. Costs can be difficult to compare due to different methods of definition, collection, and analysis. In addition, the populations under study may not be comparable for a number of reasons, including differences in the kind and amount of services required, the impairment levels, and living arrangements of the clients.

Effect of Local Attitudes:

While the Task Force has made no recommendations relating to local attitudes, it would like to point out that as federal and state programs have taken over more and more responsibility for the care of individuals, local communities have relinquished their former obligations for their citizens. Public assistance statutes have been changed to free local communities from financial responsibility for individuals in intermediate, boarding or foster care facilities. It is easier and often less costly for local officials to have an individual admitted to an intermediate care or other facility, than to try to care for him at home. Communities and society, generally, are reluctant to let elderly and disabled individuals take risks in order to maintain independence.

Effect of Physician's Role:

The Task Force would also like to note that the physician plays a significant role in determining where an individual will be cared for, and thus has a great effect on the costs of long term care. In classifying an individual as needing intermediate or skilled nursing care and selecting the facility that will give that care, the chief decision-maker is a physician. Entry into such a facility must be medically necessary, and so certified by the physician.

The physician often responds to the needs and wishes of the family when recommending placement of an elderly parent or disabled family member in a facility.

Most physicians are not knowledgeable about approaches to long term care, other than medical models of care. Many physicians would probably recommend boarding care for a larger number of their patients if they knew more about such care. Some physicians seem to be reluctant to use in-home service providers, and sometimes refer to intermediate care facilities patients who could probably be cared for at home.

FOOTNOTES

1) Entering a Nursing Home - Costly Implications for Medicaid and the Elderly, Report to the Congress by the Comptroller General of the United States; United States General Accounting Office; PAD-80-12 Washington, D.C., November 26, 1979.

2) A Program in Crisis: Blueprint for Action; Final Report of the Ohio Nursing Home Commission; Ohio General Assembly; Columbus, Ohio; October 1979.

3) With the additional necessary "Applications Programming" and storage, the existing Bureau of Central Computer Services, Department of Finance and Administration, could handle this load.

4) The Social and Economic Impact of Nursing Homes; National Foundation for Long Term Health Care; Washington, D.C.; 1979.

5) A Program in Crisis: Blueprint for Action, Final Report of the Ohio Nursing Home Commission; State House Columbus, Ohio; October 1979; page 134.

6) It should be pointed out that the short term turnover of a nursing home is not necessarily evidence of an intention to provide degraded care, since sale (often a time and energy consuming venture in Maine) is clearly facilitated if the facility has provided good care under the present owner.

7) The nursing home industry is a low equity industry. Many providers have negative or no equity during their early years of ownership.

8) Home Health - The Need for a National Policy to Provide Better Care for the Elderly; Report to the Congress by the Comptroller General of the United States; United States General Accounting Office, Washington, D.C., December 1979.

PART SEVEN:
EMPLOYEES INVOLVED IN PROVISION OF LONG TERM CARE SERVICES

BACKGROUND

Recommendations #45 through #48 address issues relating to wages, fringe benefits, training and qualifications of employees involved in providing long term care services.

Testimony by Holy Innocents, a homemaker agency in Portland operated by the Diocesan Human Relations Services, captures many of the Task Force's special concerns about the lowest paid employees in the long term care system.

> "...The quality of services is dependent on the quality of staff. Unpredictable funding is a major concern for all staff, as well as inadequate funding which limits the needs that can be met. For the paraprofessionals who are the major service deliverers, the most important need is for a livable wage and adequate fringe benefits. A dilemma for agency administration is to balance the desire to provide decent salaries and fringe benefits with the need to keep costs down. These direct care workers are of inestimable value, yet they are often held in low regard and see themselves as low in status. A variety of supports are necessary to counteract this."

RECOMMENDATION #45: AIDES

#45A. Wages; Benefits. Wage levels near the lower end of the wage scale and fringe benefits for employees of long term care facilities and agencies in the private sector should be similar to wage levels and fringe benefits for similar positions in the public sector. Improved wages and benefits for private sector employees should not result in loss of positions or decreased availability of services.

#45B. Turnover. The Governor should inform the Legislature and the public about the high rate of turnover among aides and the human and financial costs involved and urge the Legislature to appropriate adequate funding for improved wages and pension benefits for aides, which will result in a more stable and productive work force.

#45C. Organized Efforts. There should be more organized efforts by both employees and employers to improve wages, fringe benefits and working conditions for aides.

#45D. Career Development. Individuals beginning employment in long term care facilities and programs at the basic aide level should have opportunities, through a variety of qualifying processes, to progress to specialized paraprofessional responsibilities (such as activities assistants, rehabilitation aides, and medication technicians) and to advance to professional levels (such as nursing, social work and therapy).

#45E. Training. The following steps should be taken with respect to the training of aides:

Standardized Training and Certification. Training and certification of aides should be standardized throughout the State.

Partners. The Department of Mental Health and Corrections, the Department of Human Services, the Department of Educational and Cultural Services, the State Board of Nursing, and the Maine State Nurses Association should work together as equal partners to:

- Develop a statewide approach for the training and certification of aides, including a plan for statewide adult education and vocational technical institute programs in the area of long term care;

- Approve curricula proposals for training aides;

- Provide technical assistance to instructors and ensure that they use standardized curricula;

- Certify training programs for aides offered by both schools and long term care facilities and programs.

Content of Curricula. Curricula for aides should:

- Be geared to the total needs of consumers of long term care services, including an emphasis not only on medical and physical needs, but also on areas such as mental health, gerontology and psychosocial needs;

- Include classroom and clinical experience with a designated number of hours required in long term care facilities and programs, and, when appropriate, in hospitals;

- Be thorough with respect to the administration of medications, in particular for aides who will be working in boarding care facilities.

Role of Public Education. Both vocational technical institutes (post-secondary level) and adult education programs (secondary level) should:

- Become part of a statewide system of training centers for aides; and

- Offer more training programs for aides, including "traveling road shows" to areas not served by closeby vocational technical institutes or adult education programs.

Allowable Cost. The Department of Human Services should allow training programs for aides as a reasonable cost item for long term care facilities and programs. The individual receiving the training should pay for it, initially, and should be reimbursed for this cost only after working in a long term care facility or program for a specified amount of time (for example, six months or one year).

Job Applications. Applicants for aide positions in long term care facilities and programs should be required to include copies of their certificates with their applications. Applicants should receive written job descriptions.

#45F. Single Classification. Serious consideration should be give to eliminating the present classifications of "certified nurses assistant" and "medications technician" and having the single classification of "nurses aide." If the classification of medications technician is to con-

tinue, then the technicians should be required to take periodic refresher courses, in order to retain their certification.

MAJOR FINDINGS

The Task Force finds that aides have an awesome responsibility in their responsibility in their provision of direct care services to individuals with long term care needs.

The Task Force also finds that aides throughout the long term care system are under-compensated, overworked, and inadequately trained for their job responcibilities. All too frequently, there is little opportunity for promotion.

BACKGROUND ON EMPLOYMENT SITUATION FOR AIDES

Definition:

For the purposes of Recommendation #45, "aides" refer to individuals who have all of the following characteristics: are employed in a skilled nursing facility, intermediate care facility, boarding care facility (including a group home or a transitional living facility), home health agency or homemaker agency; work directly with consumers of long term care services; and earn wages at or close to the minimum wage established by Maine law.

Low Wages; No Benefits:

There is widespread agreement that wages are at unacceptable levels. Testimony presented by several individuals to the Task Force corroborate that the field is characterized by minimum wage payments.

According to the Maine Department of Manpower Affairs, $3.03 per hour was the average minimum wage offered to aides in intermediate care facilities by employers using the job bank in 1979.[1] (The figure for licensed practical nurses was $4.07 per hour.) Because employers report the minimum wages they pay employees, the job bank figures are only around 80 percent of what actual wages are. The minimum wage in 1979 was $2.90 per hour.

There is also widespread agreement that fringe benefits for aides are virtually non-existent. The Department of Human Services stopped reimbursing facilities for pension plans when the 1978 Principles of Reimbursement went into effect. Even prior to the 1978 Principles, less than two percent

of the free-standing intermediate care facilities in Maine had pension plans. The Department of Human Services will reimburse facilities for health insurance benefits.

There has been considerable discussion by and before the Task Force about who bears the responsibility for the low wage, no benefit situation. The Department of Human Services maintains that it does not limit the salaries of or refuse to reimburse for health insurance for aides. Department officials have stated to the Task Force that if providers wish to make reasonable increases in wages, the Department will reimburse for the increases. Providers argue that through audit exceptions, the Department would not allow them to increase wages for their aides. They have expressed concerns that if wages are increased at the lowest level of employees, then wages for all other levels of employees must also be increased.

Unions:

It is interesting to note that where sectors of the long term care system have been unionized (the state mental health institutes and Pineland) wages and working conditions are considerably better than in the unorganized sector. The minimum wage for state employees who work as aides in the state institutions is around $5.00 per hour, or $2.00 per hour more than the minimum wage reported by intermediate care facility employers to the job bank of the Department of Manpower Affairs.

In the opinion of the Task Force, the manpower needs of the long term care system could be better met if workers were organized. The Task Force stresses the importance of sound labor management relations in agencies providing long term care services. It opposes the use of state funds to promote educational programs of a pro or anti-union nature.

Deinstitutionalization:

The process of deinstitutionalization, while philosophically appealing, has presented some real problems with respect to staffing. It has made little sense to transfer individuals out of institutions to locales where staffing resources are inadequate and where the specially trained workers needed to meet the needs of these individuals will not work because the pay is too low. This statement should not be construed to mean that the State should stop the process of deinstitutionalization

Turnover:

Job satisfaction is just as significant as job compensation. Aides in the long term care system should be able not only to take pride in their work, but also to look at it as a career. Such is not the case now.

An AFL-CIO Report[2] indicates that there is a 75 percent annual turnover rate for workers in nursing homes nationwide. The Task Force has heard testimony that turnover in intermediate and boarding care facilities is a disturbing phenomenon in Maine. It has been reported that in some facilities the turnover of aides may be as high as 200 percent.

Continuity of care is essential to the quality of care. If the quality of life for long term care clients is to be improved, the aides must be well paid and must receive fringe benefit packages comparable to those in other professions.

Working in the system must come to be perceived as an honorable and respected pursuit. In all, few individuals have such a burden as caring for those in need. The long term care system has been viewed too long as a market for low-skilled labor.

Training:

At the present time, there is no comprehensive system for training and certifying aides. Aides' certificates do not mean the same thing throughout the State. Many aides have learned that a certificate earned in one facility means absolutely nothing to another facility.

RECOMMENDATION #46: NURSES

#46A. Mandatory Continuing Education. There should be mandatory continuing education for both registered nurses and licensed practical nurses who work in long term care facilities and programs. Continuing education for these individuals should be allowed as a reasonable cost item for the long term care facilities and programs in which they are employed.

#46B. Enrollment. The State Board of Nursing should examine how to increase enrollment opportunities in training programs for both registered and licensed practical nurses.

MAJOR FINDING

The Task Force finds that registered nurses in the long term care field would like to do a lot less paperwork and a lot more "hands-on" care. The Task Force also finds that, with a few exceptions (stated below), training programs and licensing requirements are satisfactory for registered and licensed practical nurses.

DISCUSSION

Paperwork: Testimony presented to the Task Force indicates a widespread concern that registered nurses, including directors of nursing, must spend too much time on paperwork. Many individuals believe that this time is misspent, considering the training registered nurses have received.

Training: Presently, geriatric training for registered and licensed practical nurses is not adequately emphasized. In addition, there are no continuing education requirements for registered or licensed practical nurses. Finally, there are only limited opportunities for registered and licensed practical nurses to enroll in training programs. This limits their access to jobs in the field of long term care.

RECOMMENDATION #47: PERSONNEL OF FOSTER CARE AND BOARDING CARE FACILITIES

#47A. Training Opportunities. Title XX training, community mental health centers training and other educational opportunities, such as programs offered by the University of Maine and the Comprehensive Employment and Training Administration should be available to adult foster care and boarding care facility personnel. The Council of Community Mental Health Centers should be encouraged to continue its training program for these personnel.

#47B. Content of Training Programs. There should be training programs in the following areas:

Gerontology and Mental Health. Where appropriate, operators and staff of adult foster care and boarding care facilities should receive training in the areas of gerontology and mental health.

Medications. There should be more adequate training, especially in large boarding care facilities, in the administration of medications.

Programs. Adult foster care and boarding care facility personnel and regional consultants employed by the Department of Human Services should receive training about the needs of residents and programs to meet those needs. Activity coordinators in boarding care facilities are in particular need of this training.

Risks. Training should be provided to help adult foster care and boarding care facility personnel understand that it is acceptable for residents to take risks and that increased independence of residents will not cause more work.

#47C. Training for Operators. The Department of Human Services should require an 80-hour course covering areas such as reimbursement policies, physical plant requirement, individual program planning and theories of normalization for operators of boarding care facilities. Operators should pay for the course out of pocket. The Department should reimburse operators for the course, only if they stay with facilities for a specified length of time. There should be a minimum number of hours of continuing education required for operators in certain subject areas, such as those above.

#47D. Qualifications of Operators. Qualifications for operators of boarding care facilities should be expanded to demonstrate commitment and determination

to achieve the goal of quality home-like environment which addresses the needs of consumers of long term care services. References from the local community should be used in the approval of operators.

MAJOR FINDING

The Task Force finds that the personnel of both adult foster care and boarding care facilities receive inadequate training.

ISSUES

Training:

Specifications in the licensing regulations of the Department of Human Services are vague with respect to the content and frequency of both orientation and in-service training programs in boarding care facilities.

The Department will not reimburse larger boarding care facilities for staff time while one staff person is engaged in orientation or in-service training and not actually delivering direct care. Smaller boarding care facilities and adult foster care facilities cannot pay substitute staff for regular staff who want to attend training courses. In addition, they cannot afford transportation and other training expenses.

Two areas of significant training needs are mental health and gerontology.

Qualifications:

The qualifications for operators of boarding care facilities are minimal. The operator must be over age 21; capable of making mature judgments; have no physical, mental, or personality disturbances which interfere with carrying out responsibilities; and not be addicted to drugs or alcohol. There are no educational or experience requirements. Nor are there any training obligations.

RECOMMENDATION #48: OTHER TRAINING AND MANPOWER ISSUES

#48A. Mental Health Professionals. Mental health professionals should receive training regarding the special mental health needs of elderly and other consumers of long term care services. The Bureau of Maine's Elderly, Department of Human Services, and the Bureau of Mental Health, Department of Mental Health and Corrections, should establish a training program about the special mental health needs of the elderly.

#48B. Consultants. The Department of Human Services should permit intermediate care facilities to engage the services of consultant physical, occupational and other therapists and mental health professionals for staff education and training about safety procedures and care of residents. The Department should recognize the importance of the role of social workers and other professionals in training aides in various long term care settings.

#48C. In-House Staff Development. The Department of Human Services should require administrators of long term care facilities and programs to provide regularly scheduled in-house staff development programs in which all employees should be required to participate, and should reimburse long term care facilities and programs for the costs of such programs.

#48D. Outside Continuing Education. The Department of HumanServices should reimburse long term care facilities and programs for permitting employees to have time off with pay to participate in continuing education programs outside of the facilities and programs. Transportation and, in some cases, respite care should be routine allowable costs for meeting staff training needs.

#48E. Prior Approval. The Department of Human Services should approve staff development plans, including in-house programs and outside continuing education programs, on an annual basis, and should not require prior approval for each course or session offered pursuant to the plans. (See also Recommendation #41.)

#48F. Manpower. Employee-client ratios should be based on assessments of client needs. The Department of Human Services and the Department of Mental Health and Corrections should appoint a study group (including a representative of the Governor's Commission on Mental Health Manpower) to determine adequate levels of manpower in residential facilities.

FOOTNOTES

1) The minimum wage was $2.90 per hour in 1979. It is $3.10 in 1980 and will be $3.35 in 1981.

2) America's Nursing Homes: Profit in Misery, AFL-CIO

PART EIGHT:
DISCRIMINATION AGAINST AND ADVOCACY ON BEHALF OF CONSUMERS OF LONG TERM CARE SERVICES

BACKGROUND

Recommendation #49 examines several issues relating to discrimination against consumers of long term care services. Recommendation #50 describes advocacy groups in Maine and recommends a bill of rights for residents of long term care facilities. Excerpts from a letter received by the Task Force cover many of the areas considered over the past year:

> "...I have a parent who is a patient at _____ ...If patients don't like the food on their trays, they go without food until the next meal...carrots, beets, same thing week after week...Then they go on an applesauce kick, they have it morning noon and night... _____ is a nice place to visit, not for staying. The place, beds, patients are clean. That's where the care stops. Some patients are ignored by the nurses if they are called too often..."

RECOMMENDATION #49: DISCRIMINATION AND RELATED ISSUES

#49A. Equal Services. The following actions should be taken to ensure that residents of intermediate care facilities receive equal services:

Residents. Each intermediate care facility should be required to provide equal services to all residents, regardless of their source of payment for services (Medicaid versus private funds) and their demand for services ("easy" versus "difficult" residents).

Individuals Seeking Admission. Each intermediate care facility which enters into a provider agreement with the Department of Human Services should be required to accept all individuals seeking admission on a first come, first served basis, subject to the conditions stated below.

Conditions. The requirements in the preceding two paragraphs, should be subject to the following conditions:

- Each intermediate care facility, including those which do not admit individuals who are eligible for Medicaid, should be required to keep residents who have exhausted their private funds and who have become eligible for Medicaid. Each provider agreement between the Department of Human Services and an intermediate care facility should stipulate that the facility cannot discharge residents because they have run out of funds. This stipulation should be consistent with the amount of time established for the private pay rate which the resident and the facility have agreed to in the admissions contract.

- Each intermediate care facility should be required to accept individuals eligible for Medicaid, provided that the facility is able to address adequately the long term care needs of these individuals, and provided, further, that the occupancy rate is at 95 percent or lower or there are two vacant beds in the facility, whichever is higher.

- Each intermediate care facility should be required to admit "difficult" residents, unless the facility can document that it is not able to address adequately the long term care needs of any such residents. In addition, each intermediate care facility should be prohibited from discharging a "difficult" resident without full documentation and adherence to residents' rights provisions concerning transfer and discharge.

Implementation. The recommendations in the preceding three paragraphs

should be carried out immediately through regulations promulgated by the Department of Human Services. The recommendations should be interim steps, which should remain in effect until the Legislature enacts a residents' rights act. (See Recommendation #50A)

#49B. Security Deposits. Intermediate care facilities should not require security deposits by individuals who are eligible for Medicaid at the time of application for admission. The Department of Human Services should reimburse facilities for the bad debts of these individuals.

#49C. Discharge to Hospital. Intermediate care facilities should be required to notify the Department of Human Services when a resident is discharged to a hospital and should request approval of reimbursement for the resident's bed for up to 15 days in any calendar year. The Department of Human Services should grant this approval.

#49D. Leave of Absence. Intermediate care facilities should not be required to obtain approval to hold the bed of a resident who takes a leave of absence for up to and including 24 days in any calendar year.

#49E. Residents of State Mental Health Institutes. The Governor should urge the Maine Congressional Delegation to support legislation to repeal a "limitation" clause in PL92-603, which prevents certain residents of the two state mental health institutes from receiving any monthly personal needs allowance under the Supplemental Security Income Program.

MAJOR FINDINGS

The Task Force finds that there are many incidents of discrimination by intermediate care facilities against individuals who are eligible for or receive Medicaid benefits; who require intensive care; and who are disoriented, disruptive or mentally ill. The Task Force also finds that there are mentally ill individuals in the two state mental health institutes who receive no allowances to meet their personal needs.

ISSUES

Private vs. Medicaid Residents:

According to figures available in 1978, 66 percent of all individuals admitted to intermediate care facilities pay with private funds. Only 15% of all residents of

these facilities pay with private funds.

Several facilities in Maine request that applicants assure prompt payment at the private rate for a period ranging from six months to two years, before converting to Medicaid status. In a few instances, applicants have found, after waiting for months for an available bed, that they are unable to enter a facility as a private pay resident for the period requested by the facility. In these few instances, the applicant is not admitted to the facility.

Some facilities decide that they will admit a certain percentage of private pay residents. This is done to ensure desired levels of income to the facilities.

The Task Force believes that, ethically, it is wrong for Medicaid residents to be denied access to facilities. The Task Force also believes that under no circumstances should Medicaid residents receive less care than private pay residents. The Task Force understands that high occupancy rates contribute to the incidence of discrimination. However, it firmly believes that access to needed long term care services must be a right of all individuals, regardless of income.

Security Deposits Required:

A few facilities have written into their Medicaid admission contracts a security deposit to be paid in advance of admission. There are some individuals who believe deposits are illegal and contrary to federal regulation and the provider agreement. Others suggest that the practice should be encouraged, so that the money can be used to cover costs when a resident is discharged to a hospital and the facility is unable to obtain prior approval to hold the bed.

Residents Requiring Intensive Care:

Residents in intermediate care facilities are evaluated for a level of care in order to determine if prior approval of additional nursing staff is warranted. As a result of this, it is extremely difficult to place a Medicaid resident who requires intensive care because it may mean an additional burden on existing staff. Even with prior approval for additional staff, there are still facilities which are reluctant to accept residents needing intensive care. Some facilities prefer, for obvious reasons, to confine admissions to the persons needing little care or a moderate amount of care. Thus the person requiring large

amounts of direct nursing time may end up in less desirable homes.

"Difficult" Residents:

There are some individuals who are "difficult" for intermediate care facilities to care for. They are often disoriented, disruptive, or mentally ill. There are differing opinions about what responsibility intermediate care facilities have for these individuals.

Some people argue that part of being sick, elderly, or handicapped is anger about loss of control and identity. This sense of loss frequently results in complaining or other disruptive behavior. These people believe that facilities are equally responsible for serving "difficult" residents as they are for serving "easy" residents. Others argue that abusive individuals should not be admitted or should be discharged in order to protect other residents from harm.

Discrimination Related to Discharge:

It is not an uncommon practice for a facility to take advantage of the language in the State's licensing and certification regulations which gives facilities an option of requesting prior authorization for reimbursement to hold a bed for a hospitalized patient if there is no other available bed in the facility. This loophole has been used to discharge a difficult resident or one whose private funds have been exhausted. It is particularly convenient if the resident becomes ill and needs hospitalization. Unfortunately, in some instances the resident is sent for a diagnostic evaluation in what appears to be an excuse to discharge.

A common complaint relayed to the Nursing/Boarding Home Ombudsman Program is that Medicaid patients who complain about their treatment are told, "you can always leave if you don't like it here." Given the unavailability of nursing home beds, this in effect translates into a take it or leave it attitude and a disregard of the residents' rights to express grievances.

Problems Not Considered Discrimination:

There are several potential problems of Medicaid recipients that are not necessarily considered discrimination. These are problems which result from the structure of the Medicaid program itself and thereby deny benefits, services or choices that are available to those who can afford to pay for their care.

One problem is that there are some small facilities with 100 percent Medicaid population which have fewer services, less staff and lower quality of food and services than comparable facilities which have a mix of private and Medicaid residents.

Another problem is that many needed services are not available to Medicaid residents, because the State does not cover the services under its Medicaid Program. These services include dental care, eye care and mental health services provided by certain professionals. In addition, many services are covered under the State's Medicaid Program, but are simply not available to many Medicaid residents. These services include physical and occupational therapy and mental health services provided by psychiatrists. Facilities have policies outlining the services they are willing and able to provide and the types of residents they will accept. Some facilities are not capable of providing the quality of services necessary for residents requiring special skilled care. This is not discrimination.

A third problem is that Medicaid residents are often segregated to Medicaid wings or second floor accommodations in large, four-bed rooms.

Finally, Medicaid residents experience problems relating to leaves of absence. Under federal regulations, Medicaid residents are allowed 18 days leave of absence from a facility. A "leave of absence" means a period of time of 24 hours or more. In Maine prior authorization by the Department of Human Services is required for a facility to hold a bed of any resident who is on leave of absence for any number of days up to and including 18 days in any calendar year. The Department will only allow overnight leaves <u>without prior authorization</u>. This is based on a premise that any resident who can leave the facility for an extended period of time does not need nursing care. The Department thus fails to promote increased family contact, with an aim toward meeting the residents' social and emotional needs, and to test his ability to function in the least restrictive environment. Testimony presented during the regional hearings of the Task Force strongly reinforces the perceptions in this area.

Attorney General's Opinion:

On March 18, 1980, the chairman of the Task Force wrote to the Attorney General and asked for his legal opinion regarding possible discriminatory effects of the Medicaid Program on both individuals whose care in intermediate

care facilities is paid for by the Medicaid Program and individuals who pay for the care with private funds. The Attorney General's response of May 13, 1980, is included in this Report as Appendix

There are around 30 residents residing at Augusta and Bangor Mental Health Institutes who receive no allowance of any kind. The Task Force received testimony that a "limitation" clause in PL 92-603 states that residents of public institutions are not eligible to receive the personal needs allowance under the Supplemental Security Income Program.

Residents of Psychiatric Facilities:

The 30 individuals live in parts of the two institutes which are licensed as intermediate care facilities, but they are not classified as requiring nursing care and are, therefore, not eligible for Medicaid. Consequently, these individuals are not eligible for Supplemental Security Income or Veterans benefits. The result is that they have no discretionary spending money. If these individuals lived in any facility other than a state institution, they would receive the monthly personal needs allowance.

RECOMMENDATION #50: ADVOCACY

#50A. Residents' Rights. The Governor should submit legislation to the 110th Maine State Legislature in January 1981, to establish in law a long term care residents' rights act. The legislation should:

Affirm Rights. Not give individuals special rights, but should affirm basic rights which can be eroded by misunderstanding, administrative convenience, or neglect;

Apply to all Residents. Apply to all residents of state institutions, skilled nursing facilities, intermediate care facilities, boarding care facilities (including group homes and transitional living facilities), adult foster care facilities, and eating and lodging places with long term residents; and

Consolidate other Laws. Consolidate existing laws relating to rights of various groups which receive long term care services.

#50B. Funding. The Governor should recommend to the 110th Maine State Legislature that:

Ombudsman Program. There should be increased funding for the Nursing Home and Boarding Home Ombudsman Program of the Maine Committee on Aging; and

Chronically Mentally Ill. There should be an appropriation to the Office of Advocacy, Department of Mental Health and Corrections, to provide to chronically mentally ill individuals who reside in the community advocacy services, through contracts between the Office and private agencies.

#50C. Role of Advocates. Agencies providing advocacy services for consumers of long term care services should carry out the following roles:

Coordination. They should meet periodically to discuss goals and areas of mutual concern.

Self-Advocacy. They should assist in the development of "self-advocacy."

Family Support Groups. They should encourage the organization of family support groups.

Case Management. Advocacy to fill in gaps in services should be one function of the case management process. Agencies providing advocacy services should not be required to be part of case management teams. However, they should be able to serve as case managers, if the State enters into contracts with them to do so. (See Recommendation #29.)

MAJOR FINDING

The Task Force finds that even though there are several groups which advocate on behalf of consumers of long term care services, many consumers have no one to advocate on their behalf. Individuals who are chronically mentally ill and residents of intermediate care, boarding care and adult foster care facilities are the two groups of consumers with the greatest need for advocacy.

ADVOCACY: DESCRIPTION AND ISSUES

Residents' Rights:

The Nursing Home/Boarding Home Ombudsman Program receives around 200 complaints about intermediate and boarding care facilities each year. Fourteen percent of the complaints investigated relate to alleged violations of residents' rights. Seventy-five percent of these complaints are validated. Complaints of alleged verbal and physical abuse are, for the most part, not verified. It appears that, at times, fear of retaliation prevents validation of complaints.

In addition, the Office of Advocacy, Department of Mental Health and Corrections, investigates grievances of Department clients who reside in state institutions or other facilities "administered" by the Department.

Seldom has a license been revoked or a conditional license imposed for repeated violations of residents' rights. Given the current survey process focus on physical plant, written policy, staffing patterns, review of records, liability of the facility and professional staff, and the need to comply with federal requirements, the rights of residents are submerged and, essentially, unenforceable.

The residents of intermediate and boarding care facilities, in most instances, have had no process for self-advocacy. Residents' councils can provide this opportunity. A residents' council is an organization of residents within a facility which provides the residents with input into their day-to-day activities and with a grievance mechanism, which identifies for administration and staff the problems the residents experience, and which seeks to resolve the problems within the facility.

Not all facilities have a residents' council. Some facilities have been reluctant to allow more than a token council, run and controlled by staff of the facility. Other facilities have refused to allow the formation of a residents' council, using the excuse that many residents are not alert or that there would be too much demand on staff time.

34 MRSA § 2146 requires a residents' council, if requested by a mentally retarded client of the Bureau of Mental Retardation, Department of Mental Health and Corrections. For a residents' council to be effective, it must be clear to the residents that they have rights. 34 MRSA § 2145 requires the Bureau to actively seek out and inform clients about their rights, but this has not occurred.

Appendix F includes a Residents' Bill of Rights proposed by the Ad Hoc Committee on Residents' Rights and accepted in principle by the full Task Force.

Advocacy:

In recent years, several organizations have begun to provide services to individuals who need long term care services. There are two types of advocacy: "client advocacy" and "systems advocacy." The first involves protection by an interested third party - the advocate - of an individual's health, welfare, and rights. The second involves fighting for changes in the system of long term care services, which will improve the circumstances of a large number of individuals. Both state agencies and private organizations are involved in advocacy.

A few organizations (Legal Services for the Elderly, Inc. and the Handicapped Rights Project) provide legal services to individuals who need long term care services. Legal services encompass both systems and client advocacy.

Some individuals believe there is duplication and lack of coordination among agencies providing advocacy services to long term care clients. There are three groups serving as advocates for the mentally ill, and five groups serving as advocates for the physically disabled.

Others do not believe that there is duplication because legal mandates for advocacy services are limited to specific groups and problems; expertise of the advocacy groups is usually limited to narrow interests; advocacy groups are forced to cooperate and coordinate activities, as a result of the limited number of advocates trying to help an overwhelmingly large number of clients.

The Task Force believes that, overall, there is lack of advocacy services. The large number of professional

advocacy groups does not mean that there is an over-abundance of advocates. There do appear to be enough paid, professional advocates for the elderly and developmentally disabled individuals. There also appear to be enough paid, professional advocates for physically disabled individuals, even though there is a distribution problem, with the majority of them located in the greater Portland area. However, there are very few advocates for chronically mentally disabled individuals or for residents of intermediate, boarding care and adult foster care facilities.

Charts VI through IX describe the advocacy services available in Maine for elderly, physically disabled, chronically mentally ill and mentally retarded individuals.

CHART VI. ADVOCACY SERVICES FOR ELDERLY INDIVIDUALS

Name of Agency	Type of Advocacy	State Enabling Legislation	# of Staff
Maine Committee on Aging	Systems & client advocacy for elderly individuals	22 MRSA§5112, sub-§ 2, states that the Committee on Aging "shall have the power and duty to serve as an advocate on behalf of older people, promoting and assisting activities designed to meet at the national, state and local levels the problems of older people. The Committee shall serve as an ombudsman on behalf of individual citizens and older people as a class in matters under the jurisdiction of Maine State Government."	3 staff members, including 2 professionals and not including Ombudsman (see below).
Nursing Home/ Boarding Home Ombudsman Program*	Systems & client advocacy for residents of skilled nursing, intermediate care, & boarding care facilities	Also under 22 MRSA§5112 and under the federal Older Americans Act amendments of 1978, the Maine Committee on Aging--through its Nursing Home/Boarding Home Ombudsman Program--is authorized to: "enter onto the premises of any boarding care...and any nursing home facility...in order to investigate complaints concerning those facilities"; and to permit "up to 25 persons, including committee members, staff of the committee and other citizens, to carry out this function of the committee."	1 paid ombudsman 22 volunteers
Legal Services for the Elderly, Inc.	Legal advocacy for elderly individuals with legal problems	There is no state enabling legislation. This is a private, nonprofit agency.	4 attorneys
Area Agencies on Aging	Systems & client advocacy for elderly individuals residing in the areas.	22 MRSA§5118 requires the 5 area agencies on aging to develop plans which "provide for the initiation, expansion or improvement of social services in the area covered by the plan."	

*Administratively, the Nursing Home/Boarding Home Ombudsman Program is under the Maine Committee on Aging.

CHART VII. ADVOCACY SERVICES FOR PHYSICALLY DISABLED INDIVIDUALS

Name of Agency	Type of Advocacy	State Enabling Legislation
ALPHA I	Systems & client advocacy for individuals who are severely physically disabled, as a result of spinal cord injuries, polio, multiple sclerosis, spina bifida, cerebral palsy, or muscular dystrophy	There is no state enabling legislation. This is a private, nonprofit organization based in South Portland.
Handicapped Rights Project	Legal advocacy for 1500 clients of Bureau of Rehabilitation	There is no state enabling legislation. This is a private, nonprofit organization based at the University of Southern Maine.
Southern Maine Association for the Handicapped	Systems & client advocacy for individuals who are physically disabled	There is no state enabling legislation. This is a private, nonprofit organization.
Maine Association of the Deaf	Systems & client advocacy for individuals who are deaf	There is no state enabling legislation. This is a private, nonprofit organization based in Portland, Maine.
Consumer Advisory Council	Systems advocacy for clients of Bureau of Rehabilitation	There is no state enabling legislation. This was established by the Bureau of Rehabilitation, Department of Human Services, in April 1979, in response to federal requirements under the Rehabilitation Act of 1973, as amended, to develop plans for considering views of its constituency.

CHART VIII. ADVOCACY SERVICES FOR CHRONICALLY MENTALLY ILL INDIVIDUALS

Name of Agency	Type of Advocacy	State Enabling Legislation
Office of Advocacy	Systems & client advocacy for all clients of the Department of Mental Health & Corrections	34 MRSA§1-A establishes an Office of Advocacy within the Department of Mental Health and Corrections "to investigate the claims and grievances of clients of the Department, and to advocate for compliance by any institution, other facility or agency administered by the Department with all laws, administrative rules and regulations, and institutional and other policies relating to the rights and dignity of these clients. § 1-A provides that the functions of the office shall be to: -- "receive or refer complaints made by clients..., intercede on behalf of these clients in the initiation of grievance procedures..."; -- "keep itself informed about all laws, administrative rules and regulations and institutional and other policies relating the rights and dignity of these clients and about relevant legal decisions...; and -- "make and publish reports necessary to the performance of functions..."
Community Support Services Project	Systems Advocacy for individuals discharged from Augusta & Bangor Mental Health Institutes	There is no state enabling legislation. This is a 3-year demonstration project, funded by the National Institute for Mental Health.
Alliance for the Mentally Retarded	Systems & client advocacy for mentally ill individuals & their families	There is no state enabling legislation. This is a private, nonprofit group recently organized in the greater Portland area. Its members are relatives of individuals who are mentally ill.

CHART IX. ADVOCACY SERVICES FOR MENTALLY RETARDED INDIVIDUALS

Name of Agency	Type of Advocacy	State Enabling Legislation
Office of Advocacy	Systems & client advocacy for all clients of the Department of Mental Health & Corrections	34 MRSA§1-A establishes an Office of Advocacy within the Department of Mental Health and Corrections "to investigate the claims and grievances of clients of the Department, and to advocate for compliance by any institution, other facility or agency administered by the Department with all laws, administrative rules and regulations, and other policies relating to the rights and dignity of these clients. § 1-A provides that the functions of the office shall be to: -- "receive or refer complaints made by clients..., intercede on behalf of these clients with officials..., or assist these clients in the initiation of grievance procedures..."; -- "keep itself informed about all laws, administrative rules and regulations and institutional and other policies relating to the rights and dignity of these clients and about relevant legal decisions...; and -- "make and publish reports necessary to the performance of functions..."
Advocates for the Developmentally Disabled	Systems & client advocacy for individuals with all types of developmental disabilities	Enacted by the Maine State Legislature in 1979, 22 MRSA§3551 requires the Governor to "designate an agency, independent of any state or private agency which provides treatment, services, or habilitation to persons with developmental disabilities, to serve as the Protection and Advocacy Agency for the Developmentally Disabled in Maine pursuant to the United States Code, Title 42, Sections 6001 through 6012. The agency so designated shall have the authority to pursue legal, administrative and other appropriate remedies to assure the welfare and protect the rights of persons with developmental disabilities." The Governor designated Advocates for the Developmental Disabled pursuant to §3551. This is a private, nonprofit agency which was established in 1973.

CHART IX. CONTINUED

Name of Agency	Type of Advocacy	State Enabling Legislation
State Planning and Advisory Council on Developmental Disabilities	Systems advocacy for individuals with all types of developmental disabilities	34 MRSA§2614 requires the Governor to establish a State Planning and Advisory Council on Developmental Disabilities. Even though no reference is made to advocacy under this law, some of the Council's activities can be considered advocacy.
Committee on Problems of the Mentally Retarded	Systems advocacy for mentally retarded individuals	34 MRSA§2613 requires the establishment of a 12-member Maine Committee on Problems of the Mentally Retarded. The Committee is required "to act in an advisory capacity" to the Commissioner of Mental Health and Corrections and the Bureau of Mental Retardation "in assessing present programs, planning future programs and in developing means to meet the needs of the retarded in Maine." Thus, it appears that under the law the Committee is engaged in systems advocacy. However, the Committee has not been an active advocate in recent years.
Maine Association for Retarded Citizens	Systems & client advocacy for mentally retarded individuals	There is no state enabling legislation. This is a private, nonprofit organization with several local organizations around Maine.
Consumer Advisory Council	Systems & client advocacy for class members involved in Pineland Consent Decree	There is no state enabling legislation. The Consumer Advisory Council was established in July, 1978, to represent class members involved in the Pineland Consent Decree. The Council will exist for an indefinite period of time.
Handicapped Rights Project	Legal advocacy for 1500 clients of the Bureau of Rehabilitation	There is no state enabling legislation. This is a private, nonprofit agency, based at the University of Southern Maine.

APPENDICES

APPENDIX A

OFFICE OF
THE GOVERNOR

NO. 11FY 79/80

AN ORDER ESTABLISHING THE GOVERNOR'S TASK FORCE ON LONG TERM CARE FOR ADULTS

WHEREAS, over 10,000 elderly persons and hundreds of developmentally disabled, mentally ill and other adults reside in nursing and boarding homes in the State of Maine; and

WHEREAS, the persons who are 75 years of age or older represent the most rapidly growing segment of Maine's population, and 75 percent of the residents in nursing homes are 75 or older; and

WHEREAS, a U.S. Senate Subcommittee on Long Term Care has concluded that 30 percent of the low income elderly persons would not be there if other services had been available at the time those persons entered the nursing homes; and

WHEREAS, payments made to nursing homes under the State Medicaid Program increased by 182 percent from $18.7 million in 1974 to $52.7 million in 1978; and

WHEREAS, there are diverse and diverging planning efforts relating to long term care for Maine citizens, which need to be coordinated:

NOW, THEREFORE, I, JOSEPH E. BRENNAN, Governor of the State of Maine, establish a Governor's Task Force on Long Term Care for Adults to examine the needs of dependent and semi-dependent adults in the State and to make recommendations for improving the services provided to meet these needs.

Membership

There shall be 32 voting members on the full Task Force. Twenty-three of these members shall be state legislators, private sector providers and other members of the general public appointed by the Governor. Nine of these members shall be state employees invited to participate by the Commissioner of Human Services.

The Governor may invite other interested Maine citizens to serve as nonvoting members on subcommittees of the full Task Force.

The Commissioner may invite other appropriate state and federal officials to participate on the Task Force or any of its subcommittees as nonvoting members.

Executive Order (cont)

Responsibilities

The responsibilities of the Task Force shall be:

1. to identify and examine the plans developed by various public and private agencies and groups to meet the long term needs of dependent and semi-dependent adults;

2. to determine which aspects of the various plans do the most to enable these adults to make as many decisions as possible about their own lives and to reside in the least restrictive, yet safe, settings available;

3. to complete a comprehensive review of statutes, regulations, policies and financing which driect and affect the provision of services to meet the long term needs of these adults, with an emphasis on improving the coordination of the administration of long term care services by various state agencies;

4. to make recommendations to the Governor for more fully meeting the long term needs of Maine's dependent and semi-dependent adults, including a plan for administrative action and a plan for action by the 110th Maine State Legislature;

5. to hold public hearings during the development of these recommendations; and

6. to build public awareness of the problems and issues involved in the particular substantive area to be examined.

Administration

1. The Department of Human Services shall provide clerical staff support services for the Task Force, making use of any federal funds which become available for this purpose.

2. The Department of Human Services shall reimburse members of the Task Force for actual and reasonable mileage, lodging and meal expenses directly related to the activities of the Task Force.

3. The Final Report and recommendations shall be submitted by the Task Force on or before Labor Day, 1980.

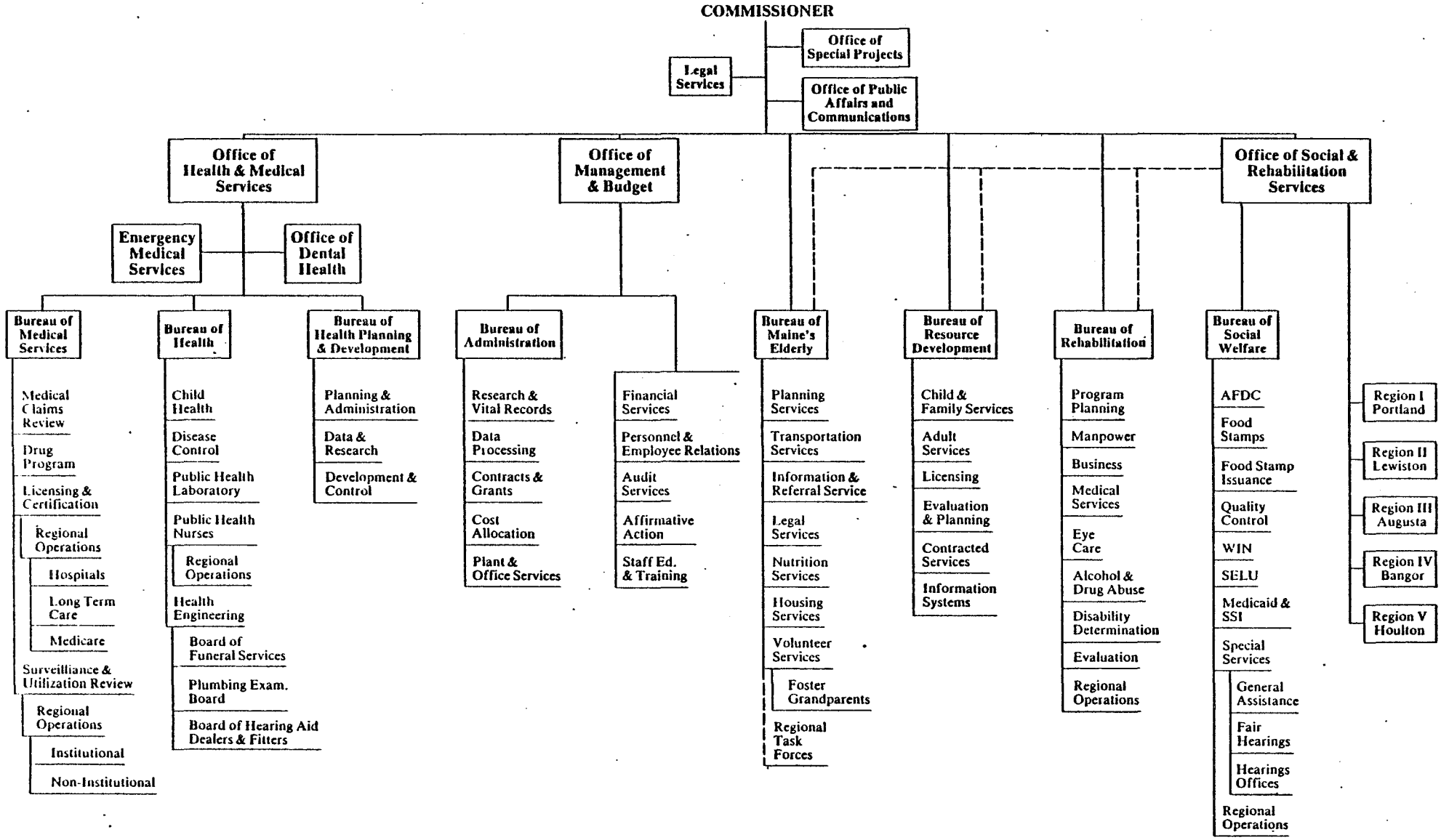
4. This Executive Order shall terminate with the submission of the Final Report and recommendations.

Joseph E. Brennan

JOSEPH E. BRENNAN, Governor

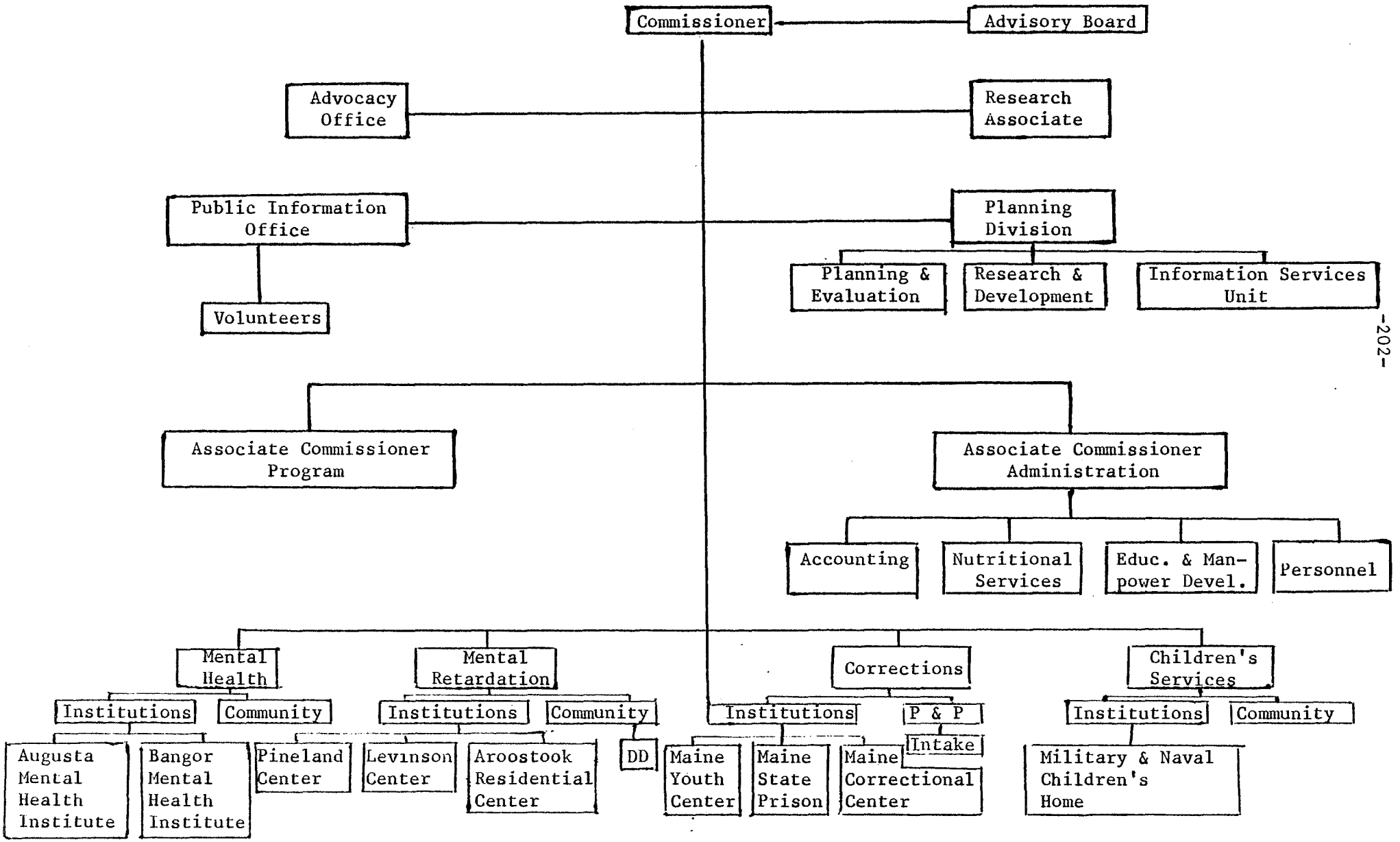
APPENDIX B

Maine Department of Human Services
Organizational Chart
November, 1979



APPENDIX C

Department of Mental Health and Corrections



CASE MANAGEMENT SYSTEMS DEVELOPED IN OTHER STATES

1. Triage, Inc. - Connecticut.

Approach: Initiated in 1975 by a home health agency, Triage is a private, nonprofit organization, run by a board of directors representing providers, elderly consumers, and state officials. Triage is staffed by nurse clinical assessment techniques. In the home, each client is assessed, including physical and mental health needs, as well as a history if the individual's social needs such as housing, transportation, finances, etc. The information is organized into a client record using the Weed's problem-oriented charting approach. The plan of care is developed and the team arranges for services and monitors the client's need on a regular basis to ensure that services are appropriate.

Funding/ Costs: Triage currently functions with several Medicare Waivers, including waivers of restrictions on receiving home health care (i.e., 3-day prior hospitalization rule, the 100 visit limit, the homebound requirement, and the skilled nursing definition). Triage has 198 contracts with providers who are required to submit monthly reports detailing client data, service provided and instruction given while the client is active. Services provided have been at a cost comparable to that spent on medical services alone at the national level.

2. The Alternative Program (TAP) - Utah.

Purposes: The purposes of this case management model are:

- To prevent the inappropriate, premature admission of elderly individuals to nursing homes.
- To provide options for elderly individuals normally admitted to nursing homes.
- To eventually turn over to each area agency on aging the overall operation and management of TAP in two years.

Approach: The Division of Aging in the State of Utah developed the TAP Program which creates, through area agencies on aging, assessment teams who review client needs and provide alternatives, as appropriate. The Division of Aging provides

funds to area agencies on aging and maintains individual assessment and case plans on each individual being considered for admission to a nursing home. Case plans from area agencies are reviewed and services are authorized if approved within seven days after they are received from area agencies. The area agency is responsible for the initial assessment of clients; to develop case plans; to arrange and coordinate services; to follow up on contacts; to reassess within 180 days the initial assessment and every 180 days, thereafter, unless the case plan calls for more frequent assessment; and to file reimbursement requests. The program more than met its first year objective to reduce by 12 per month the number of individuals admitted to nursing homes.

Funding/ Costs: Funding consists of pure state funds. There was an initial $200,00 state appropriation. TAP saved $735,000 in the first year. Per client per day costs have been $4.31 compared to $28-60 per client per day in a nursing home. The program may also charge a fee based on family income.

3. ACCESS (Assessment of Community Care)-Monroe County, New York.

Purpose: The purpose of this case management model is to test the cost effectiveness of a centralized unit responsible for all aspects of long term care for elderly individuals in Monroe County, New York. Located in Rochester, the ACCESS unit develps and coordinates community services; administers long term care funds; approves all Medicaid payments for institutional and community long term care services; and collects data.

Approach: ACCESS is the single point of entry to the long term care network. ACCESS staff provide each client with a comprehensive needs assessment, assistance in planning and obtaining either community or institutional services and ongoing monitoring of the appropriateness of the services. Private pay individuals may voluntarily use ACCESS services.

Funding/ Costs: ACCESS is an HEW Section 1115 demonstration project. Per day costs are $22.80 compared to $45.00 in skilled nursing care facilities.

4. Alternative Health Services Project (AHS)-Georgia.

Purpose: The purpose of this case management model is to test the cost effectiveness and health impact of three alternatives to nursing home care for individuals who would otherwise be placed in institutions because no other options were available in the community. The three services being tested are:

- Home delivered services - including skilled health care and social support services such as homemakers, chore and transportation;
- Alternative living services - including sheltered housing provided by a foster home, boarding home or congregate facility which includes room, board and personal care assistance; and
- Adult day rehabilitation - including a central facility providing health and social rehabilitation services to restore or maintain the client's optimal level of functioning.

Approach: In a 17-county demonstration area, the project serves clients who are Medicaid eligible, over 50 years of age and who either reside in a nursing home or meet the State Medicaid eligibility requirements for nursing home care.

Funding/ Costs: AHS received an HEW demonstration grant under Section 1115 of the Social Security Act. A preliminary analysis of the AHS indicates that the average monthly cost of AHS services is $162, compared to the estimated average monthly cost of Medicaid of $500 for nursing home care.

5. Community Care Organization Project (CCO)-Wisconsin.

Purpose: The purpose of this case management model is to test the effectiveness of a community-wide system for providing disabled adults a package of health and social services to enable them to remain in the community.

Approach: Three sites were established statewide. The CCO is an administrative and management unit which develops contracts with local service providers and coordinates and funds all

services for its clients. First, the CCO staff assess the clients' long term care needs. Then they plan, obtain, and monitor the services required to maintain the individual in the community.

Funding/ Costs: The CCO project received an HEW Section 1115 Medicaid Waiver. For the entire CCO client population, the average per diem cost for an individual is $2.22 higher than nursing home care.

6. Nursing Home Pre-Admission Screening Program - Virginia.

Purpose: The purpose of this case management model is to test the effectiveness of a pre-admission screening program in reducing the flow of elderly and disabled individuals into nursing homes and in promoting more appropriate utilization of both institutional and community long term care services.

Approach: Any nursing home applicant who is eligible for Medicaid or who will be eligible within 90 days of nursing home admission must be screened by the local health department before he or she can enter a nursing home. If the screening committee decides that available community services can meet the individual's needs, Medicaid cannot reimburse for the care should the individual decide to enter an institution.

Funding/ Costs: There are no new funding sources for this program. Funding depends on existing community services available under Titles XVIII, XIX and XX of the Social Security Act and Titles III and VII of the Older Americans Act. No new federal or state financing sources have been developed. No cost data available to date.

7. Long Term Home Health Care Program: Nursing Home Without Walls - New York.

Purpose: The purpose of this case management model is to obtain Medicaid reimbursement for 10 additional services not normally covered under the New York State Medicaid Plan: home maintenance, nurtition/education services, respiratory therapy, respite care, social day care, transportation, congregate meals, moving assistance, housing improvement, and medical/social services.

Approach: Providers of nursing home without walls may be certified home health agencies, public or private nonprofit nursing homes or hospitals. Prospective providers submit applications to the New York State Commissioner of Health who approves or denies their participation in the program after thoroughly assessing the adequacy of their personnel, facilities, services, policies, and financial procedures. All providers must offer nursing, home health aide, personal care and homemaker services, therapy, audiology, medical social work, nutritional services and medical supplies and equipment. The local social services department works with the provider agency to provide each client with a needs assessment and an individually tailored package of services to prevent institutionalization.

Funding/ Costs: A Section 1115 Waiver from the U.S. Department of Health and Human Services reimburses for all services needed by a client, up to a maximum monthly cost of 75 percent of the monthly Medicaid reimbursement rate for an equivalent level of institutional care.

8. Service Management - Pennsylvania.

Purposes: The purposes of this case management model are:

- To give area agencies on aging the responsibility and authority to coordinate services for individual elderly clients. A process which is an extension of the area agency on aging's mandate to coordinate services for the elderly was established.
- To facilitate access to a complete array of services, ranging from home care to institutional care.
- To facilitate choice of services that are most appropriate for the individual's unique conditions and concerns.
- To ensure that integrated delivery of services to each individual is achieved.
- To ensure that there is periodic review of the appropriateness of the services being provided.

Approach:

First, there is an initial broad-based standardized assessment of the individual's current functioning. Next, a written service plan is created and agreement made between the individual and worker, regarding the individual's problems identified, goals to be achieved and services to be pursued. Next, the worker arranges for services, as planned. Soon, the worker follws up to confirm that service has begun. Finally, and on an ongoing basis there is reassessment at a scheduled time to reexamine client's functioning and to change the service plan and services, consistent with current needs.

The essentials of Service Management are:

- There must be a full array of services.

- Each client in the system must have one agency responsible for service management.

- It follows that all agencies in the system must recognize the responsibility of the designated agency to perform service management on behalf of the individual.

- One agency in the system must be accountable for the entire system. Its accountability can be based either on external mandate or mutual agreement of agencies on the system.

SUMMARY OF CASE MANAGEMENT APPROACHES

IN OTHER STATES

Project	Waiver Granted by Federal Government		Direct Service Provider Does Case Management	Team Assessment Is Part of Case Management
	1115 Medicaid Waiver	222 Medicare Waiver		
Triage (Connecticut)	No	Yes	No	Yes
The Alternatives Program (Utah)	No	No	No	Yes
ACCESS (Monroe County, New York)	Yes	No	No	No
Alternative Health Services Project (Georgia)	Yes	No	No	Yes
Community Care Organization Project (Wisconsin)	Yes	No	No	No
Nursing Home Preadmission Screening Program (Virginia)	No	No	Yes	Yes
Nursing Home Without Walls (New York)	Yes	No	Yes	Yes
Service Management (Pennsylvania)	No	No	Yes	Yes

ICHARD S. COHEN
ATTORNEY GENERAL

STEPHEN L. DIAMOND
JOHN S. GLEASON
JOHN M. R. PATERSON
ROBERT J. STOLT
DEPUTY ATTORNEYS GENERAL

STATE OF MAINE
DEPARTMENT OF THE ATTORNEY GENERAL
AUGUSTA, MAINE 04333

May 13, 1980

Peter Mills, Sr., Chairman
Governor's Task Force on
Long-Term Care for Adults
c/o Department of Human Services
State House, Station 11
Augusta, Maine 04333

Dear Mr. Mills:

This letter is in response to your request of March 18, 1980, on behalf of the Governor's Task Force on Long-Term Care for Adults, for a legal opinion from this office on questions pertaining to reimbursement to long-term care facilities under the Medicaid Program administered by the Department of Human Services (hereinafter Department).1/

The questions raised focus on the effect on prices and patient admissions resulting from the role of the Department as the sole agency which establishes standards for long-term health care facilities, licenses them, and pays, pursuant to its own regulations, for the care for approximately 85% of the State's long-term health care clients. While we believe many of the issues raised by the Task Force to be policy matters which must be addressed by the Legislature or administrative officials, we shall endeavor to clarify the legal framework within which such issues may be examined.

1. Statutory and regulatory background of long-term health care. Title XIX of the Social Security Act (42 U.S.C. § 1396, et seq.) authorizes the Department of Health, Education and Welfare (now Department of Health and Human Resources) to

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1/ Since the Medicaid Program covers nursing home care and not boarding home care, this letter addresses your questions only insofar as they pertain to nursing home reimbursement.

provide substantial funding to states which have approved plans for medical assistance programs. 42 U.S.C. § 1396a(a) specifically details the elements required in order for a state medical assistance program to be approved by HEW. The program must be in effect state-wide, 42 U.S.C. § 1396a(a)(1), and a single state agency must administer or supervise its administration. 42 U.S.C. § 1396a(a)(5). The plan must also provide that the state health agency establish and maintain standards for institutions providing care to Medicaid recipients. 42 U.S.C. § 1396a(a)(9). Payment for long-term care facilities is required to be made by the State Medicaid Agency "on a reasonable cost related basis, as determined in accordance with methods and standards which shall be developed by the State on the basis of cost-finding methods approved and verified by the Secretary [of HEW]." 42 U.S.C. § 1396a(a)(13)(E) and 42 CFR § 447.273. The plan, moreover, must specify items of expense which are allowable costs. 42 CFR § 447.278.

At the State level, 22 M.R.S.A. § 3173 designates and authorizes the Department as the agency administering the medical assistance program. This section, as well as 22 M.R.S.A. § 42(1), empowers the Department to promulgate all necessary and proper rules for the administration of a medical assistance program. 22 M.R.S.A. § 1708(2) mandates that nursing home reimbursement by the Department be on a cost-related basis in accordance with accounting and auditing standards and procedures established by the Department. The Department is also mandated to be the licensing agency for long-term care facilities pursuant to 22 M.R.S.A. § 1811, et seq.

2. Regulation of price by State. You have raised general concerns, first of all, in regard to the situation created by the reimbursement for nursing home services by the Department at rates established pursuant to agency regulation when this purchase of services accounts for approximately 85% of the market. While recognizing that the current reimbursement methodology utilized by the Department has been approved by HEW, you question whether the overall process is legally infirm, particularly in regard to the effect on competition.

Four major statutes, two federal and two state, prohibit anticompetitive practices. 15 U.S.C. § 1 and 10 M.R.S.A. § 1101 prohibit contracts, combinations and conspiracies in restraint of trade. 15 U.S.C. § 45, et seq. and 5 M.R.S.A. § 206, et seq. prohibit unfair methods of competition. While the question of whether the Department's reimbursement scheme involves unlawful, anticompetitive practices raises factual issues which cannot be resolved in the context of this opinion, we shall set out the legal framework in which such a question would have to be considered.

A fundamental issue underlying your inquiry is whether the antitrust laws apply to conduct of the State or State officials. For many years following the United States Supreme Court decision in Parker v. Brown, 317 U.S. 371 (1943), it was commonly believed that a State or State official would not be held liable for violation of the antitrust laws, although a private person acting pursuant to a State policy of non-competition could, under certain circumstances, be held liable. Recent cases lend support to the proposition that action by the State or by a State official may at least be nullified as violative of the antitrust laws if such action promotes an uncompetitive policy which has not been clearly articulated and affirmatively expressed by the State Legislature. Rice v. Alcoholic Beverage Control Appeals Board, 21 Cal. 3rd 431, 579 P.2d 479 (1976). It is even clearer that a private person acting pursuant to State policy will not be immune from application of the antitrust law unless that policy is both "clearly articulated" by the State acting as sovereign and is "actively supervised by the State itself." California Liquor Dealers v. Midcal Aluminum, 48 USLW 4238, U.S. , (1980). Therefore, it may be argued that a policy of noncompetition adopted by a State official or department as a discretionary exercise of general duties does not confer immunity from the antitrust laws, but rather that a specific policy of noncompetition must first be adopted by clear, unambiguous legislative action.

However, any claim that the Department's reimbursement practices violate antitrust law would encounter significant hurdles. First, it would have to be established that the anti-trust laws with their statutorily prescribed remedies will be directly applied to the State or State officials as they are currently applied to private individuals. Second, anticompetitive practices would have to be factually demonstrated. Third, it would have to be shown that such practices were not contemplated by state or federal laws governing the reimbursement of nursing homes by the Department. In the final analysis, then, while factual questions preclude us from definitively resolving this issue, we believe that an antitrust claim predicated on the Department's reimbursement scheme would be difficult to sustain.

A further issue raised is whether there is any conflict of interest generated by the various functions performed by the Department. The common law in Maine holds that "perfect fidelity" in the exercise of their powers and duties is required of public officials. Lesieur v. The Inhabitants of Rumford, 113 Me. 317, 93 A. 838 (1915). However, we see no violation of that doctrine here, where all the functions performed by Department officials are those which are within their powers and duties as mandated by state law in furtherance of federal requirements.

3. Effect on private patients. Secondly, you have raised more specific concerns regarding the impact of the present Medicaid nursing home reimbursement methods on private pay patients. One issue focuses on the absence of direct control by the state over rates charged to non-Medicaid patients.

The Legislature may distinguish between classifications if it is not done arbitrarily and is based upon a proper distinction. Prudential Insurance Company of America v. Insurance Commissioner, 293 A.2d 529 (Me. 1972). Inequality of treatment is not forbidden if it rests upon an actual difference bearing some relation to a proper public purpose which is sought to be accomplished by such discrimination. State v. National Advertising Company, 387 A.2d 745 (Me. 1978). Here, the Legislature has authorized the Department to promulgate rules necessary to carry out the Medicaid Program. As noted above, federal law requires that such regulation include a reimbursement system for facilities providing nursing home care to program recipients. The Department lacks authority to regulate prices for non-Medicaid patients since this control is not a necessary element of the Medicaid Program and the Legislature has not otherwise delegated such authority to the Department. It is the view of this office that the setting of prices for Medicaid patients in the absence of comparable regulation for non-Medicaid patients is rationally related to the administration of a medical assistance program as well as to the goal of achieving compliance with federal requirements, thereby securing the funding necessary to maintain a program of medical assistance for the needy.

The second issue relative to private pay patients is the potential for private pay patients having to absorb some of the costs of Medicaid patients' care. In our view, the problem, if a reality, is primarily a policy matter for the Congress and for the State Legislature. 2/ We would note that the requirement under federal law that nursing homes be reimbursed on a reasonable cost related basis was enacted with the intent, in part, that underpayments resulting from the former flat rate payments system be obviated and that non-Medicaid patients not be obliged to absorb the cost of Medicaid patients' care. See 41 FED. REG. 27300 (July 1, 1976). However, federal law does not require

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2/ To the extent that it might give rise to a legal claim, that claim would be grounded in the antitrust laws. The difficulties of successfully bringing such a claim are discussed in the previous section.

states to pay all costs of nursing home care rendered to Medicaid recipients and, indeed, places a number of limitations on reimbursement. See, e.g., 42 CFR §§ 447.35, 447.284, 447.316. Moreover, states are accorded great latitude in dispensing available welfare funds. Dandridge v. Williams, 397 U.S. 471 (1969).

4. Effect on Medicaid patients. Finally, you raised concerns pertaining to the impact of the present system on admission policies of certain nursing homes relative to Medicaid eligible individuals. You have correctly noted that the State would be in non-compliance with federal law if its fee structure were insufficient to enlist an adequate number of providers to participate in the Medicaid Program. See 42 CFR § 447.204. The question of compliance with § 447.204 is also a factual question which cannot be resolved in the context of an Attorney General's opinion.

If exclusion of Medicaid patients is in fact occurring, whether or not at a level indicative of non-compliance with 42 CFR § 447.204, or if homes are requiring residents to be private paying residents for certain periods of time, there may be remedies other than increasing Medicaid payment rates. For example, the Commonwealth of Massachusetts has successfully pursued court action under its consumer protection laws and has restrained nursing homes from engaging in such practices. Moreover, providers who join together to boycott, or to threaten to boycott, the Medicaid Program in order to secure higher reimbursement may be liable for violations of antitrust law.

In summary,we see no basis for concluding, given the information presently available to us, that the current nursing home reimbursement system under the Medicaid Program is violative of any laws. Rather, in the absence of any inconsistency with state or federal law, the particular reimbursement methodology chosen by the Department is a matter of policy. It should be noted that both federal Medicaid regulations (42 CFR § 447.205) and the Maine Administrative Procedure Act (5 M.R.S.A. § 8001, et seq.) provide facilities with the opportunity to review and to comment on reimbursement policies.

I hope this information is helpful. Please feel free to call on me if I can be of any further service.

Sincerely,

RICHARD S. COHEN
Attorney General

RSC/ec

APPENDIX F

FINAL DRAFT

Be it enacted by the People of the State of Maine, as follows:

Sec. 1. 22 MRSA c. 404 is enacted to read:

Chapter 404

Residents Rights Act of 1980

§1763. Legislative intent and findings; rights of residents.

1. Articulation of Rights. It is the intent of the legislature to articulate rights of all residents of long term care facilities in Maine. Each resident of a long term care facility or her authorized representative shall have and may exercise all the rights enjoyed by citizens of this State and of the United States and the rights enumerated in this chapter without restraints, interference, coercion, discrimination, or reprisal in any form or manner whatsoever. Each resident of a long term care facility shall have the right to be treated at all times with courtesy and respect and full recognition of her dignity and individuality. Each resident of a long term care facility shall have the right to adequate and appropriate medical treatment and care and to other services that comprise necessary and apprropriate care without regard to age, race, national origin, color, religion, sex, handicap, or source of payment for care.

2. Intent of Act. It is the clear, unequivocal intent of this Act to guarantee individual dignity, liberty, pursuit of happiness and the protection of the civil and legal rights of residents of long term care facilities. Nothing in §1765 shall be construed to permit

infringement on the rights of other residents.

§1764. Definitions.

As used in this chapter, unless the context otherwise indicates, the following terms have the following meanings;

1. Abuse. "Abuse" shall mean any physical or mental injury or sexual mistreatment inflicted on a resident other than by accidental means in a facility.

2. Administrator. "Administrator" means the person responsible for the overall care of residents and management of the facility.

3. Authorized representative. "Authorized representative" means any person, other than those prohibited by law or regulation, who has been designated in writing by a competent and informed resident or court of appropriate jurisdiction to act on the resident's behalf to the extent indicated in writing.

4. Department. "Department" shall mean the department of state government which has the primary responsibility for the resident in question.

5. Commissioner. "Commissioner" shall mean the commissioner of the department of state government which has the primary responsibility for the resident in question.

6. Long term care facility. "Long term care facility" means any facility which is certified or licensed as a federal or state health or residential facility, excluding short term acute care hospital beds.

7. Neglect. "Neglect" means a failure of a facility to provide adequate medical or personal care or maintenance or supervision or protection, which failure results in physical or mental injury to a resident or in the deterioration of a resident's physical or mental condition.

8. Physical restraint. "Physical restraint" means any article, device, or garment that interferes with the free movement of the resident which the resident cannot remove easily and which is used against the will of the resident for the purpose of controlling the behavior of the resident against harm to himself or others. Safety devices such as bed rails, soft ties or straps (that do not tie the hands or feet) and trays that are used in formative or protective situations to achieve proper body position and balance, proper circulation with allowance for change of position and mobility shall not be consider restraints. Totally enclosed cribs or barred or locked enclosures shall be considered restraints.

9. Title XVIII. "Title XVIII" means Title XVIII of the federal Social Security Act as now or hereafter amended.

10. Title XIX. "Title XIX" means Title XIX of the federal Social Security Act as now or hereafter amended.

§1765. Rights and basic protections of residents of long term care facilities.

1. Humane care. Each resident shall have a right to dignified treatment and humane care which conforms to Title XVIII, Title XIX or applicable state laws and regulations.

2. Environment. Each resident shall have a right to dignified treatment and humane care which conforms to Title XVIII, Title XIX or applicable state laws and regulations.

3. Medical information and care.

a. Each resident shall have a right to obtain from the facility the name and any specialty of any physician or other person responsible for the resident's care or coordination of care.

b. Each resident shall have a right to seek services of any

physician, including physicians who are not on the staff of the facility. If the cost of the physician's services is to be met under a federally supported program, the physician shall meet the federal laws and regulations governing such services.

c. Each resident shall have a right to obtain from her attending physician complete and current information concerning her medical diagnosis, treatment, and prognosis communicated in terms the resident can reasonably be expected to understand, unless there is a documented medical contraindication to this disclosure.

d. Each resident shall have a right to participate, to the greatest extent possible, in the development of her annual indivdiual plan of care. This plan shall be reviewed quarterly. Each resident shall have a right to refuse any element of such a plan.

e. Each resident shall have a right to review, in the presence of a member of the staff of the facility, and a right to copies of all medical records at reasonable times and reasonable cost.

4. Privacy. Each resident shall have a right to reasonable privacy. This right shall not be limited in any way except in the case of emergency or unless there is a documented medical contraindication. All efforts shall be made to provide privacy during medical examinations and treatment and when a resident is involved in the care of personal and bodily needs. Any reasonable request for privacy shall be honored. If both a husband and wife are residents of the same facility, they shall have the right to share a room within the capacity of the facility.

5. Communication and visitation. Each resident shall have a right to private communications and visitations.

a. Each resident shall have a right to communicate privately by mail and telephone. The administrator of the facility shall assure that correspondence is conveniently received and mailed and that telephones for public use are accessible to residents.

b. Each resident shall have a right to unimpeded, private visitation and association within and outside of the facility at reasonable hours. Each resident shall have a right to refuse or terminate any visit. Nothing in this provision shall be construed to permit infringement on other residents' rights to privacy.

6. Practice of religion. Each resident shall have a right to religious freedom and practice.

7. Personal property. Each resident shall have a right to retain and use personal clothing and possessions in a secure manner. The number and use of personal possessions may be limited or held for safety reasons or when the number and use infringe on the rights of other residents. Any such limitations and the basis therefore shall be documented in the resident's medical record.

8. Personal financial affairs. Each resident shall have a right to manage personal financial affairs unless a conservator or representative payee has been appointed or unless she has been adjudicated incompetent and had a guardian appointed. At least quarterly, the facility shall give a full accounting of all holdings on deposit with the facility and any financial transactions made on the resident's behalf should a facility accept a written delegation of this responsibility in conformance with state laws and regulations.

9. Transfers. Each resident shall have a right to be free from involuntary transfer except in the following situations:

a. The resident's attending physician determines that failure to transfer the resident would threaten the health or safety of the resident or others, and documents that determination in the resident's medical record;

b. The facility voluntarily or involuntarily ceases to cooperate or participate in the program which reimburses for residents' care;

c. Non-payment of allowable fees has occurred. The conversion to Medicaid eligibility due to exhaustion of personal financial resources or from Medicare to Medicaid does not constitute non-payment of fees under this section.

d. When the findings of a medical necessity review determine that the resident no longer requires the level of care providedat the facility.

The facility must notify the resident, or the resident's authorized representative, and attending physician at least fifteen days before an intrafacility transfer and at least thirty days before any other transfer, except as specified in sub-sections 9 (a), (b), (c), and (d) of this section. This notice must be in writing and contain the reasons for the proposed transfer, the effective date of the proposed transfer, and the location to which the facility proposed to transfer the resident.

10. Statement of services. Each resident or their authorized representative shall be informed, at the time of admission and quarterly during her stay, with a written notice of the facility's basic daily and monthly rate and a written statement of all facility services,

including any extra charges for services not covered under Medicare or Medicaid or by the facility's basic daily or monthly rate. The facility must inform each resident or her authorized representative in writing at least thirty days in advance of the effective date of any changes in rates or the services that these rates cover. Each resident shall have a right to choose the pharmacy of her choice and the right to receive pharmaceutical supplies and services in the community when they conform to the facility's system of distribution.

11. Medical research. Each resident shall have a right to be free from serving as a medical research subject without prior written, informed consent.

12. Medications. Each resident shall have a right to refuse medication unless involuntary administration of medication is approved by a guardian appointed in a separate competency hearing and given the authority to approve medication. The resident must be informed of the consequences of refusal to take medication, and the refusal and its reasons must be documented in the resident's medical record. Emergency situations characterized by a sudden, serious change in the resident's condition which creates an imminent danger to self or other are the only exceptions. In no event shall administration of medication be used as punishment or for the convenience of staff and the use of all medication shall be documented in the appropriate medical records.

13. Physical restraint. Each resident shall have a right to be free from unnecessary physical restraints. Physical restraints shall be employed only in emergencies to protect the resident from imminent injury to herself or others. Restraints shall not be employed as punishment, for the convenience of staff, or as a

substitute for habilitative or rehabilitative services. Restraints shall impose the least possible restrictions as consistent with their purpose.

14. Abuse or neglect. Each resident shall have a right to be free from abuse or neglect at all times. Each resident shall have a right to be free from harm inflicted by other residents.

§1766. Waiver of rights. Only a resident or his guardian may waiver the rights enumerated in this chapter.

§1767. Violations; liability for violations

1. Alleged violations reported and investigated. Any alleged violation of a resident's rights shall be reported immediately to the department and the Attorney General's office representing that department. The department shall designate a bureau, division, office or agency within the department to conduct an investigation of each alleged violation, except the bureau, division, office or agency so designated will not be responsible for licensing or certifying long term care facilities or other residential facilities. The department shall submit a written report of findings and results of the investigation to the administrator of the facility in which the residents rights were allegedly violated and to the commissioner of the department within five working days after the report of the alleged incident(s).

2. Liability for violation. Any person who has intentionally violated or abused any right or privilege of residents provided by this act shall be liable for damages as determined by law. The intentional violation of the provisions of this act shall be punishable as a Class E crime, punishable by imprisonment not to exceed six months or a fine as provided in Title 17-A §1301 or under applicable criminal

law. Civil damages may be awarded for negligent or intentional violations of this Act.

§1768. Notice of rights. Each resident and her authorized representative shall promptly receive from the department a written copy of this Act. Each resident shall be promptly informed by the department in clear language of the legal rights of residents of long term care facilities. A copy of this act shall be posted in each long term care facility in Maine. Facilities shall give each resident and their authorized representative a copy of this act at the time of admission to the facility. If a resident is unable to read the act, it shall be communicated to her in a manner the resident understands.

§1769. Residents advisory council. Each facility shall assist residents to establish a residents advisory council. The administrator shall designate a member of the facility staff to coordinate the establishment of and render assistance to the council. No employee or representative of a facility shall be a member of any such council. The council shall meet at least once each month with the staff coordinator who shall provide assistance to the council in preparing and disseminating a report of each meeting to residents, the administrator, and the staff. Records of the council meetings will be maintained in the facility.

The residents advisory council may communicate to the administrator the opinions and concerns of the residents. The council shall review procedures for implementing residents rights, facility responsibilities, and make recommendations for changes or additions which would strengthen the facility's policies and procedures as they affect residents' rights and facility responsibilities.

The council shall be a forum for obtaining and disseminating information, soliciting and adopting recommendations for facility programming and improvement, and early identification of and recommendations for orderly resolution of residents' problems.

The council may serve as an in-house grievance committee for residents concerns relating to this Act.

§1770. Department responsibilities. The department which has jurisdiction shall prescribe in regulations the minimum standards which must be included in the facility admissions contracts. The minimum standards shall include at least the requirement that contracts are written in understandable language and are printed in not less than twelve-point type.

All facilities which are reimbursed with public funds shall have contracts approved by and filed with the department which has jurisdiction

§1771. Denial of admissions. Facilities shall not deny any person admission solely because they are receiving public assistance.

§1772. Regulations. The department shall have the authority to promulgate regulations for this chapter.