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1984
BLAINE HOUSE
CONFERENCE ON AGING

A REPORT OF
CONFERENCE PROCEEDINGS
AND
RECOMMENDATIONS

MAINE COMMITTEE ON AGING

AND

BUREAU OF MAINE'S ELDERLY

MAINE DEPARTMENT OF HUMAN SERVICES

STATE HOUSE

AUGUSTA, MAINE 04333



# BLAINE HOUSE CONFERENCE ON AGING CO-SPONSORED BY

MAINE COMMITTEE ON AGING AND

BUREAU OF MAINE'S ELDERLY DEPARTMENT OF HUMAN SERVICES

STATE HOUSE - STATION 11 AUGUSTA, ME 04333

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November 1984

Governor Joseph Brennan State House - Station 1 Augusta, ME 04333

Dear Governor Brennan:

On September 19 and 20, the Maine Committee on Aging and the Bureau of Maine's Elderly sponsored the tenth Blaine House Conference on Aging. The conference was held at the Augusta Civic Center and was attended by 400 delegates. It is with pleasure that we transmit to you this account of the conference. We trust that you and the members of the 112th Legislature will find the enclosed recommendations worthy of consideration and action.

The resolutions passed by these delegates reflect careful consideration of the issues and a dedication to improving the quality of life of Maine's older population.

We anticipate your continued support for older people in Maine. The Maine Committee on Aging and the Bureau of Maine's Elderly look forward to working with you, the legislature and citizens in implementing many of the enclosed recommendations. Thank you.

Sincerely,

Patricia Riley, Director Bureau of Maine's Elderly Dept. of Human Services Margaret D. Russell, Chair Maine Committee on Aging

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INTRODUCTION AND OVERVIEW

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#### WHAT IS THE BLAINE HOUSE CONFERENCE ON AGING?

The Blaine House Conference on Aging is held every two years to formulate public policy direction for issues affecting older people in Maine. The Conference is attended by 400 older people from throughout the State, who are chosen in their local area.

Prior to the Conference, a planning committee is established composed of elderly representatives from statewide who determine areas of interest and concern to older people and plan and conference format.

The next step consists of developing working discussion papers by resource people familiar with the complexities and issues surrounding a topic. These papers are studied by the delegates prior to the conference and form the basis of workshop discussion. These papers are abstracted in this report.

During the Conference each workshop, chaired by a member of the Maine Committee on Aging, develops a series of resolutions designed to address some of the issues raised during the workshop. They outline legislative and administrative actions which need to be taken in the following two years to improve the quality of life for older people in Maine.

These resolutions are proposed by the delegates and are voted on during the workshop. Those resolutions which are passed by the workshops, as well as resolutions from the floor, are discussed and voted on by delegates on the second day of the Conference.

In an effort to more thoroughly address a limited number of resolutions, the Committee on Aging considers the priorities of the five area agencies on aging, along with the Committee's own goals and selects from the resolutions its top priorities for the upcoming legislative session.

The Blaine House Conference on Aging is a mutual effort of the Maine Committee on Aging, the Bureau of Maine's Elderly of the Department of Human Services, the area agencies on aging, other aging organizations and the older people of Maine. The enclosed report represents their concerns, interests and issues.

This report was prepared by the Maine Committee on Aging. Copies of this report and the full workshop discussion papers may be obtained by writing to the Maine Committee on Aging, State House - Station 11, Augusta, ME 04333

Address - Governor Joseph E. Brennan

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#### MAINE COMMITTEE ON AGING

# State House Station 11 Augusta, Maine 04333

local 289-3658 toll free 1-800-452-1912

Update on

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maret Russell

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1982 Blaine House Conference on Aging Resolutions

The Maine Committee on Aging is pleased to report this update of accomplishments from the 1982 Blaine House Conference on Aging. Because of many of your efforts, we can be proud of the progress made during this past year. It is imperative that we continue working together to address issues of concern to older citizens and to assure a strong advocacy voice for Maine's older people.

Many of the legislative accomplishments came directly from resolutions adopted by the 1982 Blaine House Conference on Aging. Other pieces of legislation came from resolutions passed by the 1981 Interim Conference on Aging or the 1980 Blaine House Conference on Aging. A summary from the six 1982 Blaine House Conference on Aging workshops follows

# I. Retirement/Employment Income

# Social Security

The 1982 Blaine House Conference on Aging resolved to support the 1981 White House Conference on Aging recommendations which opposed any reductions in benefits to Social Security recipients and encouraged the Administration to make every possible and fiscally responsible effort to maintain the current income protection provided by Social Security.

This resolution provided us with guidance as we advocated with our federal Congressional Delegation regarding proposed changes to Social Security. The following include some of the changes enacted by Congress in the Social Security Program:

- tax half of the annual Social Security benefit of gross income for an individual if more than \$25,000 or \$32,000 for a couple
- postpone the payment of the 1983 cost of living allowance to January 1984 and pay all future cost of living increases each January.

- increase the benefit amount in Supplemental Security Income by \$20 a month (\$30 for a couple) in July 1983 and delay the SSI cost of living increase to January 1984.
- bring all new federal employees hired on or after January 1, 1984 and all current members of Congress, the Vice- President and the President under Social Security.
- bring all employees of non-profit organizations under Social Security beginning January 1, 1984 and immediately prevent any more state and local governments from withdrawing their employees from Social Security.
- increase social security payroll taxes by 0.3% on employers and employees each in 1984 but provide a fully off-setting tax credit for employees to prevent any increase in actual tax payments.
- increase Social Security payroll taxes by 0.3% on employers and employees each in 1988.
- improve benefits for certain groups of divorced, disabled or surviving spouses.
- gradually raise the age at which full retirement benefits are paid from 65 begining in the year 2000 until it reaches age 67 in the year 2027. The age at which reduced retirement benefits are paid will remain 62.

#### II. Health Care Costs

# L.D. 1737 An Act to Limit Future Increases in the Cost of Hospital Care in Maine

This law establishes a Maine Health Care Finance Commission empowered to implement a mandatory prospective hospital payment system with hospital specific revenue limits. The intent of the legislation includes but is not limited to:

- 1. Appropriately limiting the rate of increase in the cost of hospital care;
- 2. Protecting the quality and accessibility of hospital care to the people by assuring the financial viability of an efficient and effective state hospital system; and
- 3. Assuring greater equity among purchasers, classes or purchasers, and payors.

# L.D. 1391 An Act to Require Hospitals to Provide Itemized Bills Upon Request

This bill requires that each hospital shall inform all

patients, or legal guardians, in writing at the time of the patient's discharge that it will provide an itemized bill upon request.

# L.D. 1542 An Act to Require Physicians, Chiropractors and Podiatrists to Post their Policy Regarding their Acceptance of Medicare Assignment

This bill requires allopathic physicians, osteopathic physicians, chiropractors, and podiatrists to post their policy regarding the acceptance of Medicare assignments.

Individuals eligible for Medicare pay an annual deductible fee, and 20% of the usual, reasonable and customary charges for covered services provided by a physician. The remaining 80% is paid by Medicare if the physician agrees to Medicare assignment. If the physician does not accept Medicare assignment, the individual must pay the annual deductible, the 20%, and whatever portion of the amount charged by the physician which is above the usual, reasonable and customary charge set by Medicare.

Whether or not the physician accepts assignments can make a significant difference in what health care costs the Medicare recipient.

## Bureau of Maine's Elderly - training to physicians

The Bureau of Maine's Elderly helped organize and participated in a four-hour session on Geriatric Medicine at the Annual Meeting of the Maine Medical Association. The Bureau is presently planning with physicians and other health and social work professionals a multi-disciplinary geriatric long term care institute to be held in the spring of 1984 in conjunction with Brown University Gerontology Center and Medical School. In addition, the Bureau is participating with Family Medicine Institute in developing a geriatric curriculum for the Maine/Dartmouth Family Practice Residency.

# III. Home Based Care

The 1982 Blaine House Conference on Aging established as its highest priority the continuation and expansion of the Home Based Care Program. The program has proven to be effective in providing an alternative to nursing home care. Over two-thirds of the elderly individuals served have been assessed as medically eligible to go to a nursing home. Home based care has been demonstrated to be cost effective and humane.

The 111th Legislature expanded the Home Based Care Program from the \$1.25 million originally funded by the 110th Legislature to \$4 million for the upcoming biennium, a 220% increase in the program. Although the Blaine House Conference, the Maine Committee on Aging, and the area

agencies on aging advocated for a \$6 million appropriation through an amendment offered by Senate President Gerard Conley, the increased appropriation reflects a strong commitment by the legislature to support the expansion of the program.

### Long Term Care Committee

Michael Petit, Commissioner of the Department of Human Services, has made the decision to expand the state's Long Term Care Committee to include consumers and representatives of provider organizations and area agencies on aging. This Committee will coordinate, advise and plan for matters related to Home Based Care and other long term care initiatives.

#### Personal Care Services standards

The Bureau of Maine's Elderly of the Department of Human Services has developed proposed standards guiding personal care services. The proposed standards should go to public hearing this fall.

#### IV. Alternative Living Arrangements

- 1. The Department of Human Services, Bureaus of Medical Services and Maine's Elderly, have initiated demonstration projects in Eastern and Southern Maine to conduct care management assessments of individuals entering boarding homes. It is the intent that these demonstrations provide information to guide the development of a statewide case management assessment program for those applying for residency in a boarding home.
- 2. The Part II budget for new and expanded services provided \$52,000 in additional funds to expand the Congregate Housing Program.
- 3. The Maine Committee on Aging convened a Task Force to study the licensing category of eating and lodging. The Task Force has representatives from the Department of Human Services Bureaus of Medical Services and Maine's Elderly, Legal Services for the Elderly, area agencies on aging, and citizens. The Task Force is in the middle of its work and intends to make its final recommendations by December 30, 1983.
- 4. The Bureau of Maine's Elderly has been working with the area agencies on aging and the Maine State Housing Authority on programs to assist individuals to construct accessory apartments in their homes. In this last session, the legislature provided funds to the Maine State Housing Authority to grant loans to assist in new construction or in the rehabilitation and

conversion of existing structures, and in developing accessory apartments. Funds are also available for home improvement programs and additional congregate housing units.

# V. Quality of Long Term Care: Incentives, Sanctions and Certification

- 1. As stated earlier, the Home Based Care Advisory Committee has been merged with the Department of Human Services' State Long Term Care Committee.
- 2. Legislation was passed during the past legislative session which allows the Superior Court to place into receivership long term care facilities when it is necessary for the residents' health and safety.

#### VI. Utilities

- 1. The Maine Committee on Aging has established a task force on telephone use and the elderly. The purpose of the task force is:
  - a. to establish a clear understanding of federal action relating to telephone service;
  - b. to analyze how this action might affect Maine's older citizens;
  - c. to establish a mechanism to keep Maine's elderly fully informed, answer questions, and provide guidance if appropriate;
  - d. to determine more precisely the nature of telephone use among the elderly in Maine;
  - e. to provide information on telephone use among the elderly to decision-makers such as the Public Utilities Commission, the Maine legislature, and members of Congress; and
  - f. to keep informed of both national and state proposals which address telephone service.

The Task Force has had its first meeting.

#### VII. Resolutions from the Floor

- 1. As directed by the 1982 Blaine House Conference on Aging, the Aging Network has tried to employ the term "care" management instead of "case" management.
- 2. The legislature provided additional funds to maintain legal services for the elderly. The funds will provide for one attorney to focus on the legal needs of the institu-

tionalized elderly, a paralegal, and funds for support services.

- 3. Legislation was enacted (L.D. 1328) which allows the judge to consider the age of the victim in determining a sentence.
- 4. The Maine Committee on Aging, the area agencies on aging and the Department of Human Services' Bureau & Maine's Elderly all expressed opposition to the referendum drive to index the State income tax retroactively.
- 5. The last session of the legislature provided \$200,000 of emergency supplemental appropriations to the Home Based Care Program in order to adequately care for elderly persons.

We thank you and other elderly citizens for making this past year a productive one. We look forward to advocating together again this year on policies and programs for older people.

# 1983 BLAINE HOUSE CONFERENCE ON AGING UPDATE

The Maine Committee on Aging and the Bureau of Maine's Elderly are pleased to provide the following accomplishments which were directed by the 1983 Blaine House Conference on Aging. None of these actions were accomplished independently. Support was provided by the American Association of Retired Persons, the Area Agencies on Aging and many other individuals and agencies, and it was this collective effort that enabled the many successful endeavors.

## I. Boarding Homes and Adult Foster Homes

Resolution: BE IT RESOLVED that the Blaine House Conference on Aging urge the legislature to remove the artificial ceiling on boarding home reimbursement but continue to reimburse based on reasonable cost for services provided to clients, and a more equitable appropriation be made to flat rate boarding homes and adult foster homes based again on reasonable cost for services provided.

Action: Although the artificial ceiling on boarding home reimbursement was not removed, the reimbursement rate to boarding homes and adult foster homes was increased last year by the Department of Human Services.

Resolution: BE IT RESOLVED that the Blaine House Conference on Aging urge the legislature to approve funding of the area agency on aging care management program as the central point of entry to the long term care system, to assure appropriate placement and adequate services for those applying for boarding and foster homes.

Action: L.D. 2388 An Act to Assure Appropriate
Placement and Service Provision to State
Assisted Residents of Boarding Homes and
Adult Foster Homes (sponsored by Sen. Bustin,
Kennebec; Rep. Kelleher, Bangor; Sen. Gill,
Cumberland; and Rep. Nelson, Portland)

Numerous advances have been made to improve the administration of the boarding home program. A major recommendation relating to residents is that there be a standardized assessment of residents' abilities, needs and independent living skills in order to determine care and services needed on an individual and population basis. Assessments are now provided to the mentally retarded and adult protective services population residing in boarding

homes and adult foster homes. This law expands the system, through community agencies, to state assisted mentally ill and elderly individuals and assures that each resident both receives services which maximize the ability to live independently and is appropriately placed. This initiative was a result of the 1983 Blaine House Conference on Aging resolution.

#### II. Mental Health

There were five resolutions dealing with mental health problems of the elderly which were passed at the 1983 Blaine House Conference on Aging.

Resolution: BE IT RESOLVED that emphasis be placed in training more doctors, nurses and social workers on diagnosis and treatment of the older patient and that a means to carry out this education be developed by the Community Mental Health Centers or other appropriate agencies.

Resolution: BE IT RESOLVED that general education on the needs and problems of and alternatives for the elderly be undertaken by the Bureau of Mental Health, Bureau of Maine's Elderly, Area Agencies on Aging, Community Mental Health Centers, and the Cooperative Extension Service and that appropriate measures be taken to coordinate these multi-agency educational efforts.

Resolution: BE IT RESOLVED that funds be provided which would be specifically targeted for coordinated, decentralized, inter-disciplinary on-going education and training programs, focused on geriatric mental health issues and the identification of community resources.

Resolution: BE IT RESOLVED that the state recognize the needs of these residents to receive an adequate multidisciplinary functional assessment and diagnosis, and that reimbursement be provided for development of psychiatric units in existing or new nursing homes and long term care facilities including (a) staff trained to manage and treat mental health problems, (b) an environment designed to suit these needs, and (c) a percentage of floating beds to be utilized for intermittent ICF (respite) care for elderly being cared for by their families in the community.

Resolution: BE IT RESOLVED that reimbursement for mental health services by trained paraprofessionals and professionals be made available for all mental health services that reach elderly people in their home, boarding homes, nursing homes, or other long term care facilities.

Action: The Bureau of Mental Health and the Bureau of Maine's Elderly established a task force to examine the mental health needs of Maine's older citizens. The Task Force recently developed its final report and presented it to the Bureau of Maine's Elderly and the Bureau of Mental Health for action.

A copy of the entire Task Force report will be available at the Conference. The recommendations from the Task Force and a synopsis of the report are enclosed in this package.

Action: The lllth Legislature amended the Appropriations Bill to provide funds to the Bureau of Mental Health to hire an Elderly Services Specialist. A total of \$30,000 is provided for a one year project to link and integrate mental health gerontological training with state institutes, community centers, nursing and boarding homes, primary health providers, area agencies on aging and universities; develop a range of preventive naturalhelping and home based care strategies; identify and develop material for an inventory of mental health resources; and to develop future resources for training and service provision.

#### III. Medicare

Resolution: BE IT RESOLVED that the sense of the 1983 Blaine House Conference on Aging be communicated to state and federal legislators that a system of financial and other incentives for doctors, hospitals and other providers be established that will have the effect of controlling or reducing medical costs.

Resolution: BE IT RESOLVED that the Blaine House Conference on Aging urge the Maine Committee on Aging and the Bureau of Maine's Elderly to impress on Congress the need to maintain current levels of financial and health care protection provided to the elderly and disabled through the Medicare Program.

BE IT FURTHER RESOLVED that no means test shall be imposed on premiums, eligibility or benefits; and

BE IT FURTHER RESOLVED that the Maine Committee on Aging and the Bureau of Maine's Elderly report back with progress in that regard at the 1984 Blaine House Conference on Aging.

Action: Sen. George Mitchell conducted statewide hearings last year on the future of the Medicare Program. The Maine Committee on Aging, Area Agencies on Aging, Commissioner Petit of the Department of Human Services, and others presented testimony on the Medicare Program. The Maine Committee on Aging testimony reflected the views of the Blaine House Conference on Aging.

# IV. Prescription Drugs and Drug Interaction

Resolution: BE IT RESOLVED that a pilot demonstration project be conducted under the leadership of the Maine Committee on Aging Ombudsman Program to establish independent drug review committees, similar to the Human Rights Committees in ICF-MR's, to review the medications of nursing home residents.

BE IT FURTHER RESOLVED that an evaluation of the project will be presented to the 1985 Blaine House Conference on Aging.

Resolution: BE IT RESOLVED that the Bureau of Maine's Elderly work with the Area Agencies on Aging to provide education on medication by means of all media so that consumers can fulfill their rights and responsibilities for their own health care.

Resolution: BE IT RESOLVED that the patient profile system be studied by the Maine Committee on Aging to see how its effectiveness could be maximized regarding over-the counter drugs, alcohol, and sharing of profiles with other pharmacies, the patient's physician, and the patient, while still maintaining patient confidentiality.

Action: The Department of Human Services, Bureau of Medical Services, implemented an Innovative Practices in Nursing Homes Program during the past year. Nursing homes throughout Maine competed for funds to create an innovative program in their nursing home. The Maine Committee on Aging staff participated in reviewing and ranking the proposals. One successful proposal was to establish a drug review process which includes drug free holidays. The results of this project will be reported to the 1985 Blaine House Conference on Aging.

Action: The Area Agencies on Aging have independently initiated consumer education materials on prescription drugs. Southern Maine Senior Citizens, in particular, have done a great deal of work on this subject and has distributed consumer information to consumers in its area.

#### V. Income Maintenance

Resolution: BE IT RESOLVED that Maine repeal 19 MRSA §219, which allows adult children in Maine to be held financially responsible for their dependent parents; and

BE IT FURTHER RESOLVED that the state explore tax credits, public education and other avenues to encourage families to assist with the care of their elderly, whether at home or in institutions.

Action: L.D. 2314 An Act to Repeal the Law Requiring Adult Children to Care for Parents According to Ability was passed by the Legislature.

This bill removes statutory provisions requiring adult children to provide care for their parents except that, in the event of the death of a person eligible for general assistance, the dead person's relatives, including his children, shall be responsible for burial costs.

Resolution: BE IT RESOLVED that the Blaine House Conference on Aging supports increases in benefits for recipients of SSI, AFDC and general assistance.

Action: The Maine Legislature last session increased the payment to AFDC recipients. Per directive of the Blaine House Conference on Aging, the Maine Committee on Aging supported these increases.

#### VI. Medicaid Waiver

WHEREAS, 32 other states have already been granted a Medicaid waiver to provide home based long term care; therefore

Resolution: BE IT RESOLVED that the State of Maine move expeditiously to apply for a Medicaid waiver to serve more people where they want to be served - in their own homes.

Action: On August 24th, the State of Maine, Department of Human Services, submitted an application for a Medicaid Waiver which will bring approximately \$4 million into the State for home services for over 1200 elderly citizens. The State is currently waiting to hear from the federal Department of Health and Human Services whether the Medicaid Waiver application will be granted.

## VII. Courthouse Accessibility

Resolution: BE IT RESOLVED that the 1983 Blaine House Conference on Aging endorses Question 2 on the November ballot, which will make all Maine courthouses accessible to every older Maine citizen; and

BE IT FURTHER RESOLVED that the Blaine House Conference on Aging urges all Maine citizens, particularly Maine's older citizens, to vote for Question 2 on the November ballot.

Action: Question 2 on the November ballot, which will make all Maine courthouses accessible to every Maine citizen, was successful.

# VIII. Home Based Care Funding

WHEREAS, the 1982 Blaine House Conference on Aging meeting voted as its "very highest priority" the funding of the Elderly Home Based Care Program at the \$6,000,000 level; and

WHEREAS, all those concerned about the elderly and their families greatly appreciate the \$4,000,000 actually approved by the Legislature in the Spring of 1983; and

WHEREAS, state government revenues seem to be ahead of budget projections; therefore

Resolution: BE IT RESOLVED that, if this trend continues, in order to better assist elderly people to achieve their single highest goal of staying in their own homes, the legislature be asked to increase funding for the Elderly Home Based Care Program to the needed \$6,000,000 level either through a Medicaid waiver or additional state revenues.

Action: Because of the demand for increased home based care funds as illustrated by the waiting lists at area agencies on aging, and because of the slow pace of the Medicaid proposal application, the Maine Committee on Aging pursued an amendment to the appropriations bill for increased funds to the Home Based Care Program. The legislature appropriated an additional \$750,000 to the Home Based Care Program to meet this increased demand.

# 1984 BLAINE HOUSE CONFERENCE ON AGING

The 1984 Blaine House Conference on Aging was attended by 400 delegates from throughout the State of Maine. The workshops focused on the following seven areas:

- I. The Effects of DRG's (Diagnostic-Related Groups) on Providing Quality
  Health Care Last year, Congress approved a fundamental change in
  Medicare by changing the method of payment to hospitals from a cost-based
  retrospective system of reimbursement to a payment system based on a predetermined price per discharge. The effect that this new hospital payment
  system will have on the elderly hospital patient and the quality of health
  care that they receive will be examined in this workshop.
- II. Medicare Supplemental Insurance: Too Much or Too Little? Medicare supplemental insurance is confusing to the elderly consumer as well as unsatisfactory in many instances in filling the gaps in Medicare coverage. Information related by Blue Cross/Blue Shield last year suggested that up to 90% of beneficiaries informally contacted had duplicate insurance. For individuals on a fixed income, this presents an unnecessary hardship. This workshop will focus on ways to address the confusing area of supplemental health insurance.
- II. Access to Long Term Care for Medicaid Eligible Consumers With the increased cost of nursing home care, many elderly consumers who require that intensive level of care cannot afford it and are forced to become Medicaid recipients. In many instances, elderly Medicaid recipients are denied access to needed care because of their source of payment. This workshop will discuss ways in which access to the long term care system can be insured regardless of an individual's payment source.
- IV. Increasing Employment Opportunities for Older Workers This workshop will focus on the role government, employers, employees and their unions can play in increasing the kind and number of work opportunities for older workers, educating about age discrimination and how to handle it, breaking down prejudices against older workers built on uninformed stereotypes, and improving the utility of special employment programs.
- V. Right to Medical Treatment/Right to Refuse Medical Treatment The complicated issues of whether everyone has a right to basic medical care regardless of income, age, and/or disability will be the topic of this workshop. Other questions that will be discussed relate to whether everyone, regardless of income, age or disability, has a right to every possible medical treatment, including high technology treatments like dialysis and organ transplants.

- VI. Improving Housing and Home Care Options In recent years, Maine has made substantial strides in some areas of home care including the creation of an innovative home based care program, state funding for a nursing and boarding home ombudsman program, substantial improvements in nursing home care and the creation of the residential service program to improve the boarding and foster home programs. Other aspects of the housing options available have not been carefully addressed. Among the latter are the questions of access and how to assure that Maine's elderly are properly protected from fraud, abuse and inappropriate care. Therefore, this workshop will focus on these four separate but related issues: protection in sale-lease-back transactions; need for a home care bill of rights; status of eating and lodging establishments; and state funded rental assistance.
- VII. Guardianship: Protecting the Elderly or Taking Away Their Legal Rights?

  The seriousness of the loss of rights where a guardianship is imposed weighed against the need for assistance and protection will be discussed in this workshop. Mechanisms for improving open participation in protective proceedings of third parties and the pros and cons of mandating less restrictive alternative philosophies in Maine's probate courts will be the key issues to be discussed.

#### MEMBERS OF THE MAINE COMMITTEE ON AGING

Margaret Russell, Augusta, Chair Alice Bourque, Biddeford David Brenerman, Portland Sen. Gerard Conley, Portland William Cunningham, Augusta E. Stuart Fergusson, No. Whitefield James Flanagan, Portland Fr. Valmont Gilbert, Augusta Norman Hall, Sanford John Joyce, Portland Mae Parker, Durham Wilfred Pombriant, Biddeford Louise White, Bangor

# MAINE COMMITTEE ON AGING STAFF

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II

BLAINE HOUSE CONFERENCE ON

AGING RESOLUTIONS

1984

#### RESOLUTIONS

#### 1984 BLAINE HOUSE CONFERENCE ON AGING

# The Effect of DRG's (Diagnostic-Related Groups) on Providing Quality Health Care

1. BE IT RESOLVED that the Maine Committee on Aging serve as the lead agency in organizing a task force to develop a state sponsored independent organization to monitor the accessibility, quality and integration of the entire continuum of health care in the State of Maine. The task force membership, in addition to representatives of consumer organizations, shall include all appropriate categories of providers who impact on the health care of Maine citizens, and report back to the Maine Committee on Aging by March 1, 1985.

BE IT FURTHER RESOLVED that consumer input be defined to include direct solicitation of patient/consumer opinion as well as consumer representation on the Task Force.

BE IT FURTHER RESOLVED that, in view of this effort, the Governor and the members of the state Congressional delegation be requested to express to the Health Care Finance Administration their strong objection to the federal government entering into a Professional Review Organization contract without review by the office of the Governor of the State of Maine.

- 2. BE IT RESOLVED that the Department of Human Services' Bureau of Medical Services develop a system, respecting the rights of clients for confidential records, for the collection and dissemination of data concerning all residents of long term care facilities and those assessed as nursing home eligible that is capable of tracking over time the medical status, functional abilities and nursing diagnoses of those residents, and that this system be given a high priority and sufficient funding to enable its completion by September 30, 1985. This data shall be responsive to the needs of the Health Care Finance Commission, nursing homes individually and collectively, state agencies and representatives of the aging network.
- 3. BE IT RESOLVED that the Maine Committee on Aging take the lead in developing a procedure to monitor denials of continuing stay in hospitals, denial of home health care benefits and long term care facility benefits, for referral to Legal Services for the Elderly, Inc., who would assist in appeals when appropriate and share this information with affected state and federal agencies and the Maine Congressional delegation. The Maine Committee on Aging would report back to the 1986 Blaine House Conference on Aging.

#### Medicare Supplemental Insurance: Too Much or Too Little?

- 1. BE IT RESOLVED that the Maine Committee on Aging and the Bureau of Maine's Elderly, in cooperation with other education and advocacy organizations, implement a public education program on Medicare and Medicare supplement insurance.
  - BE IT FURTHER RESOLVED that volunteers be trained and utilized to counsel senior citizens on problems they might have with their individual Medicare supplement insurance policies.
- 2. BE IT RESOLVED that the legislature investigate and make recommendations on the propriety, benefits, advertising and sales practices for limited benefit health insurance policies and all Medicare supplemental health policies sold within the State of Maine.
- 3. BE IT RESOLVED that the State of Maine be urged to require insurers and nonprofit hospital and medical service organizations to provide full pre-sale disclosure concerning the contents of health insurance policies and contracts.

## Access to Long Term Care for Medicaid Eligible Consumers

- 1. BE IT RESOLVED that the State of Maine should not impose any liens against people's property in administering the Medicaid program; and
  - BE IT FURTHER RESOLVED that state and federal Medicaid laws requiring resources to be determined as of the first day of the month should be amended to allow thirty days to reduce the resources to the limit allowed without losing eligibility; and
  - BE IT FURTHER RESOLVED that coordination be increased within the Bureaus of Income Maintenance and Medical Services and between the Bureaus, hospitals, and nursing homes to speed up the process of establishing eligibility of applicants for Medicaid.
- 2. BE IT RESOLVED that there be an act to prohibit discrimination against persons seeking access to services in long term care based on source of income, specifically included in but not limited to:
  - A) specified length of stay as a private pay resident as a requirement of admission be illegal
  - B) to forbid nursing homes from demanding any deposit from new nursing home residents as a guard against possible Medicaid denial

C) to prevent nursing homes from requiring that applicants who have not been adjudicated incompetent to be required to have a responsible party or be signed into the facility by a third party, and

BE IT FURTHER RESOLVED that public and private enforcement of the provisions be a part of this act, and include private right of action, and

BE IT FURTHER RESOLVED that the Maine Committee on Aging will work with the Department of Human Services to advocate for more nursing beds to be available to Medicaid eligible consumers.

- 3. BE IT RESOLVED that the Maine Committee on Aging investigate the regulatory and legislative possibilities with the view to requiring:
  - A) that Medicaid and private care patients receive the same care in non-discriminatory areas
  - B) that Medicaid be required to pay for and nursing homes be required to hold beds for Medicaid recipients for at least the number of days corresponding to the DRG.
  - C) that nursing homes remind patients and their families of the bed-hold regulations when the patient goes to the hospital.

## Increasing Employment Opportunities for Older Workers

- 1. BE IT RESOLVED that there be support for a uniform federal definition for enlarging criteria to 200% of poverty for qualifying for federal employment programs for people over the age of 55.
- 2. WHEREAS a federal court recently ruled that it was illegal under the Federal Age Discrimination in Employment Act (ADEA) to adopt maximum age limitations on apprenticeship programs and the Maine Human Rights Commission recently presented legislation to remove the age limitation on apprenticeship programs in the Maine Human Rights Act, therefore

BE IT RESOLVED that the Blaine House Conference supports this legislation.

- 3. BE IT RESOLVED that an educational committee be established for the purpose of informing the public on issues affecting older workers in Maine. The committee would:
  - 1. conduct a statewide conference for employers and employees;
  - 2. conduct a media campaign; and
  - 3. conduct an elder awareness program in Maine's elementary and secondary schools.

# Right to Medical Treatment/Right to Refuse Medical Treatment

1. BE IT RESOLVED by the Blaine House Conference on Aging that every competent adult citizen of the State of Maine has the basic human right to decide whether or not to seek or decline a fundamental humane level of medical care regardless of his/her income, age and/or disability, or any other characteristic; and

BE IT FURTHER RESOLVED that legislation be developed which guarantees that the written directives, such as those described in a living will, of a competent adult citizen of Maine regarding the use of extraordinary medical and life-sustaining procedures, when death is imminent and irreversible, shall be followed.

2. BE IT RESOLVED that the Maine Committee on Aging and the Bureau of Maine's Elderly initiate an educational campaign on the importance of the execution of a living will or the alternative of a durable power of attorney.

#### Improving Housing and Home Care Options

1. BE IT RESOLVED that the proposed Home Care Bill of Rights be accepted in principle and that the Home and Long Term Care Committee further develop the bill to insure protection of incapacitated adults, the development of a mechanism for client complaints and the distribution of the bill of rights to clients of home care; and

BE IT FURTHER RESOLVED that the Maine Committee on Aging develop a home care ombudsman program.

- 2. BE IT RESOLVED that the Blaine House Conference on Aging supports the concept of eating and lodging facilities as a viable housing option for older people and that the Bureau of Maine's Elderly be responsible for designing and implementing an effective means for acquainting owners, prospective owners and residents with licensing requirements and limitations, and for providing them with information concerning community resources.
- 3. BE IT RESOLVED that the Blaine House Conference on Aging supports legislation proposed by the Maine Home Equity Conversion Task Force to regulate residential sale/leaseback transactions.
- 4. BE IT RESOLVED that the State of Maine should fund a state rental assistance program utilizing the lowest interest financing money available first for elderly and congregate housing projects for low income elderly.

# Guardianship: Protecting the Elderly or Taking Away Their Rights?

- 1. BE IT RESOLVED that the Maine Probate Code be amended to assure that the least restrictive alternatives to guardianship are fully explored by the Probate Court through:
  - A) Requirement for a pre-guardianship report on the proposed ward's specific functional incapacities;
  - B) Mandatory appointment of an attorney and/or visitor for the proposed ward in all cases where a guardian ad litem is not appointed;
  - C) Presentation of a plan by the guardian which details implementation of the guardianship;
  - D) Mandatory review and reporting on the guardianship periodically, but no less than once every two years;
  - E) Development of a checklist by which the Probate Court will determine that alternatives to full guardianship have been reviewed, including:
    - 1. temporary quardianship;
    - 2. limited guardianship;
    - 3. single transaction court order;
    - 4. conservatorship alone;
    - 5. power of attorney.
- 2. BE IT RESOLVED that Maine should prevent unnecessary imposition or deprivation of rights of adults by:
  - A) expanding laws governing power of attorney including elaboration of the powers and accounting responsibility;
  - B) assist individuals in making advance arrangements for potential future incapacity;
  - C) provide public education regarding guardianship and legal incapacity, including production of a booklet and media presentations;
  - D) develop least restrictive alternatives for incapacitated persons.
- 3. BE IT RESOLVED that guardianship procedures provide due process by:
  - A) Improving notice through
    - providing notice to all immediate relatives of the prospective ward;

- 2. content to be changed to inform prospective ward of their rights;
- 3. service of notice be done on the ward in a humane way.
- B) Mandatory appointment of an attorney.
- C) Define evidence needed to prove standard of incapacity.

## Resolutions from the Floor

1. WHEREAS, the rules governing An Act to License Home Health Care Services, as currently proposed by the Department of Human Services, will, as demonstrated by ample public testimony, serve to increase the costs and limit the availability and range of providers of home care services, therefore

BE IT RESOLVED that the 1984 Blaine House Conference on Aging urge the legislature to repeal or amend as necessary 22 MRSA \$2141-2148 in order to provide specific assurances that licensure, if and when it is implemented, does not have the unintended negative impact of unduly increasing costs and/or eliminating categories of providers including, but not limited to, small proprietary agencies, nursing registries, visiting nurse associations and municipal health services.

2. WHEREAS, there is a pattern of de-appropriating funds from the Elderly Householders Property Tax and Rent Refund Program account, therefore;

BE IT RESOLVED that the Bureau of Taxation submit to the next legislature a proposal to amend the Elderly Householders Property Tax and Rent Refund Program to extend property tax relief to more elderly by:

- A) updating income eligibility levels for individuals and couples and provide for periodic review; and
- B) incorporating a sliding scale for refunds so as to eliminate the "in or out" feature of the current law.
- 3. BE IT RESOLVED that the 1984 Blaine House Conference on Aging request that Maine's Aging Network work cooperatively with the state agency responsible for consumer protection to develop and disseminate educational materials to help elderly citizens recognize and protect themselves against various types of consumer fraud.

4. WHEREAS, it is imperative that patients know the reason why the medicine is prescribed, and patients taking more than one medication (often as many as ten daily) become confused because the prescription label does not contain what the medication is for, therefore

BE IT RESOLVED that each Maine practicing doctor be required to provide with each prescription what the drug/medication is ordered for by including by name the symptom and/or anatomical area involved in treatment.

- 5. BE IT RESOLVED that a fitness council be set up to promote fitness and preventive medicine among senior citizens.
- 6. BE IT RESOLVED that the names of doctors who will accept Medicare assignment be published or otherwise made available (besides directory in agency) for senior citizens.
- 7. WHEREAS, a great number of older individuals are living alone in a home much larger in size than they require, and a home which is often a burden to maintain and pay the required costs such as heating and taxes and would desire and greatly benefit from the companionship of others in a single home dwelling through a program such as the Home Sharing demonstration program that has proven the extremely cost effective benefit of the home sharing concept, therefore

BE IT RESOLVED that the 1984 Blaine House Conference on Aging urge the Maine legislature to appropriate a minimum of \$200,000 to implement a statewide Maine Home Sharing Program beginning no later than July 1, 1985.

8. WHEREAS, dental health is an important component of general health for all populations and age groups, especially Maine's elderly citizens, the Maine Advisory Committee for Dental Health Promotion for the Elderly in conjunction with the Maine Department of Human Services, Office of Dental Health, submits the following resolution for endorsement by the Blaine House Conference:

BE IT RESOLVED that an immediate goal be to support a state legislative copayment dental program which requests funding for adult dental services under the Medicaid program; and

BE IT FURTHER RESOLVED that a sliding fee scale dental program or copayment dental program be established to make comprehensive dental care accessible to elderly citizens with limited economic resources, who would not be eligible for Medicaid dental benefits; and

BE IT FURTHER RESOLVED that a statewide dental health education program be established to focus on the special dental health characteristics and dental needs of Maine's elderly citizens to be coordinated and funded through the Maine Area Agencies on Aging with the assistance of the MDHS Office of Dental Health; and

BE IT FURTHER RESOLVED that all Maine intermediate care facilities be required under the Maine Licensing and Certification guidelines, rules and regulations to have a dental consultant and a periodic indepth review of dental health care provided for residents by on-site staff or dental professionals.

9. WHEREAS, the out-of-pocket expenses charged directly to elderly people under the Medicare Program are increasing at a rapid rate; and

WHEREAS it is always more desirable and less expensive to prevent an illness or disease than to treat and cure the disease, therefore

BE IT RESOLVED that the Blaine House Conference on Aging urge appropriate state officials and the legislature to study and test the concept of a social health maintenance organization in the hopes that those older people who so choose can support their Medicare coverage by emphasis on a program of health education and health maintenance.

- 10. BE IT RESOLVED that the legislature be urged to continue the Catastrophic Illness Program.
- 11. BE IT RESOLVED that the statewide service plans for elderly persons developed by the Departments of Human Services and Mental Health and Mental Retardation reflect an integrated approach incorporating input from regional mental health coordinating groups to guarantee accessible, coordinated and appropriate mental health services along a flexible continuum of care, ranging from in-home to institutional settings, determined not by diagnosis but by functional level of need.
- 12. BE IT RESOLVED that ongoing coordinated state and regional educational/training/consultation programs on aging and mental health be developed which would include training/consultation to boarding, foster and nursing homes as well as to hospitals and community mental health, social services, health and home health agencies serving Maine's elderly. Specifically, the Departments of Human Services and Mental Health and Mental Retardation, community mental health agencies and area agencies on aging should work together to develop and implement comprehensive focused mental health elderly education and consultation activities.
- 13. BE IT RESOLVED that the Advisory Committee on Mental Health Services to Elderly Persons, the Maine Committee on Aging, the Mental Health Advisory Council and the Maine Human Services Council should convene on a regular basis to determine how to best meet the needs of elderly persons with mental health problems, especially those who lack a natural support system. Activities should be identified that would enable these advisory groups to promote greater public awareness and sensitivity to the needs of the mentally ill. Strategies for developing state agency initiatives and legislative support for the Task Force on Mental Health Services to Elderly Persons recommendations should also be addressed.

- 14. BE IT RESOLVED that the 1984 Blaine House Conference on Aging, on behalf of people of all ages in Maine, supports an immediate and mutually verifiable freeze on the further research, development and deployment of all nuclear weapons by all nations.
- 15. BE IT RESOLVED that the five area agencies on aging in conjunction with the Bureau of Maine's Elderly and the Maine Committee on Aging be urged to spearhead specific community education programs in the areas of social and health related programs available to their constituents.
- 16. BE IT RESOLVED that the Blaine House Conference on Aging proposes a follow-up study on recommendations of the 1981 Status of Older Workers in Maine Government.
- 17. BE IT RESOLVED that the Blaine House Conference on Aging supports an amendment to the targeted job tax credit program that provides for the inclusion of older workers (50) as a designated element of the program.
- 18. BE IT RESOLVED that the Blaine House Conference on Aging support legislation in Maine to fund a total of \$90,000 to the nine Older American Volunteer Programs in Maine R.S.V.P., Foster Grandparents, Senior Companion.
- 19. BE IT RESOLVED that the 1984 Blaine House Conference on Aging request that Governor Joseph Brennan appoint to the Maine Job Training Council a person representing older worker concerns.
- 20. WHEREAS, partly as a response to a resolution passed at the 1983 Blaine House Conference on Aging, the Department of Human Services has applied for an elderly home care Medicaid waiver program for Maine, and

WHEREAS, the Medicaid home care waiver program will be a direct response to the desire of all elderly people (and their family members) to remain in their own homes with dignity and independence for as long as that is at all possible, therefore

BE IT RESOLVED that the Blaine House Conference on Aging urge the Maine Legislature to monitor the status of the application to the federal government for a Medicaid elderly home care program and to provide additional funding to serve those elderly individuals on waiting lists for home care should the waiver not be funded by the federal government, and

BE IT FURTHER RESOLVED that, if the elderly Medicaid home care program is funded by the federal government, that the legislature provide the required 30 percent non-federal state seed share of the program effective January 1, 1985, as well as any required start-up state funding for this critically required elderly in-home care support program.

- 21. BE IT RESOLVED that the Regular Session of the 112th Legislature authorize a legislative study on Social Service Transportation Issues to include representatives from the Department of Transportation, Bureau of Maine's Elderly, area agencies on aging, Maine Committeeon Aging, Bureau of Social Services and the Maine Human Services Council and other relevant parties. The Legislative Study should have as its responsibilities the review of current transportation studies that exist and the current transportation system with particular attention to funding adequacy. The Legislative Study should be authorized to recommend additional funding for social service transportation if funding inadequacy is found.
- 22. BE IT RESOLVED that the Blaine House Conference on Aging recommend to the Maine Congressional Delegation for presenting to the U.S. Congress that the Medicare system be reviewed and modified to realistically meet the health care needs of the aged, compatible with the current sociologic, scientific and fiscal needs of the country.
- 23. WHEREAS, a simple deferral of real estate taxes on residences of the elderly could be administered by the State at a modest cost while providing a great benefit to the elderly, therefore
  - BE IT RESOLVED that the Maine Committee on Aging study and seriously consider advocating for a real estate tax deferral program for the elderly of Maine.
- 24. BE IT RESOLVED that the first \$2,500 of assets be disregarded from determination of SSI eligibility.
- 25. BE IT RESOLVED that the state plans of the various bureaus of the Department of Human Services specifically address the needs of Maine's Indian population.
- 26. WHEREAS adequate affordable and accessible housing is basic to the independence of the elderly and since growing numbers of elderly are unable to afford such housing in the private market, therefore
  - BE IT RESOLVED that the Blaine House Conference on Aging urge the Congressional Delegation to reverse the Administration's trend toward abandoning federal housing programs for low income older people.
- 27. BE IT RESOLVED that the legislature improve Maine's elderly prescription drug program by expanding the number of drugs covered.

III.

MAINE COMMITTEE ON AGING PRIORITIES

#### MAINE COMMITTEE ON AGING PRIORITIES

The Maine Committee on Aging considered all of the resolutions passed by the 1984 Blaine House Conference on Aging which would require legislation to realize, either because they require statutory authority or they require funding. In discussing the resolutions requiring legislation, the Committee decided not to include on its legislative list those resolutions which they knew were being pursued legislatively by other parties. This reduced the list of legislative resolutions to a total of twelve. The Committee members then listed the twelve resolutions in order of priority. Combining these with the priorities set by the area agencies on aging, the following list of priorities for the upcoming legislative session was determined.

- 1. Amend procedure for determining eligibility for Medicaid, increased intra-Departmental coordination to speed establishment of eligibility, prohibit discrimination against persons seeking long term services based on source of income (Access to Long Term Care for Medicaid Eligible Recipients, Resolutions #1 and #2)
- 2. Enact "living will" legislation (Right to Medical Treatment, Resolution #1)
- 3. Conduct public education program on Medicare and Medicare supplement insurance, and trained volunteers to counsel senior citizens on their Medicare supplement insurance policies (Medicare Supplemental Insurance, Resolution #1)
- 4. Amend Maine Probate Code to assure consideration of least restrictive alternatives to guardianship, explore ways to prevent unnecessary imposition or deprivation of rights of adults, and provide for better due process procedures in guardianship proceedings (Guardianship, Resolutions #1, #2, and #3)
- 5. Establish a Home Care Bill of Rights, and develop a home care ombudsman in the Maine Committee on Aging (Housing and Home Care, Resolution #1)
- 6. Establish a system for collection and dissemination of data concerning all long term care facility residents and those assessed as nursing home eligible (Effect of DRG's, Resolution #2)
- 7. Investigation of limited benefit health insurance policies (Medicare Supplemental Insurance, Resolution #2)
- 8. Request state funding for Medicaid waiver match (Floor Resolution #20)
- 9. Repeal or amend An Act to License Home Health Care Services (Floor Resolution #1)
- 10. Amend the Elderly Householders Tax and Rent Refund Program by periodically reviewing and updating income eligibility levels and by establishing a sliding scale for refunds. (Floor Resolution #2)
- 11. Request state funding for Home Sharing Program
   (Floor Resolution #7)
- 12. Request state funding for a state rental assistance program (Housing and Home Care Options, Resolution #4)

The following legislative issues which were included as resolutions from the Blaine House Conference will be presented in bill form by other parties:

- Legislation proposed by the Maine Home Equity Conversion Task Force to regulate residential sale/leaseback transactions (Housing and Home Care Options, Resolution #2)
- Maine Human Rights Commission legislation to remove the age limitation on apprenticeship programs in the Maine Human Rights Act (Employment, Resolution #2)
- Request for funds for adult co-payment dental program under Medicaid Program and a sliding fee scale dental program or copayment dental program for elderly who would not be eligible for Medicaid dental benefits (will be submitted by the Maine Advisory cOmmittee for Dental Health Promotion for the Elderly) (Floor Resolution #8)
- Legislation to fund a total of \$90,000 for nine Older Americans Volunteer Programs in Maine (Floor Resolution #18)

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WORKSHOP DISCUSSION PAPERS (ABSTRACTS)

### The Effects of DRG's (Diagnostic-Related Groups) on Providing Quality Health Care

Chair: E. Stuart Fergusson, Member, Maine Committee on Aging

Resource People: Francis McGinty, Maine Health Care Finance Commission

Ron Thurston, Maine Health Care Association Craig Young, M.D., Maine Medical Association Warren Kessler, Kennebec Valley Medical Center

Staff: Romaine Turyn, Maine Committee on Aging

Delegates:

Madeline Smith Edgar Carey

Rita Noel Maggie Smith

John Brown Lew Palmer

Sadie Mitchell Elenora Favre

Laura Griffin Edith Stephenson

Elinor Harvey Andrew McSween

Jeanne Denny Muriel Scott

Elaine Fuller Louise Flanders

Alta Clark Susan Belles

Julie Lacomb Rollin Ives

Patricia Wallstrom Elizabeth Gibson

Marilyn Chiddix Leona Brown

Bernice Jenuskevice Phyllis Bracy

George Forbes Richard Lippenscott

Joan Settin Richard Baldwin

Laurel Atkinson Ouentin Johnson

Susan Brown Laura Cathcart

Irene Pike

Gerald Billings

Merton Perkins

Alma Abbott

# Abstract of Workshop Paper on THE EFFECT OF DRG'S (DIAGNOSTIC RELATED GROUPS ON PROVIDING QUALITY HEALTH CARE

(copies of full text available from Maine Committee on Aging)

#### BACKGROUND

Last year, Congress enacted what has been termed "the most significant health care legislation since the inception of Medicare in 1965." This legislation, called the Prospective Payment System, altered Medicare's traditional method of payment to hospitals, which had been a cost-based retrospective system of reimbursement. The new system, aimed at curbing rapid growth in Medicare hospital costs, will have payments based on a predetermined price per discharge. That is, each Medicare hospital patient will be assigned to a "diagnostic related group (DRG)" based on the condition that was principally responsible for his or her admission. There are 467 DRG's, each having a specific monetary value assigned to it, allowing for geographic adjustments. There are also three special categories for cases falling outside the regular groups. The hospital will get paid a fixed amount of money for the total care of a particual condition. (Under the old system, the hospital was paid retrospectively based on its costs; thus there was no incentive to cut costs.) If the cost to care for a Medicare patient is more than the DRG pays, the hospital must absorb the loss, if less, the hospital keeps the difference as profit.

Since the hospital is paid for each admission under the new reimbursement system, there are strong incentives to increase admissions and reduce the costs of caring for each patient by reducing services and shortening the individual's hospital stay. Therefore, the DRG system will encourage hospitals to:

- manage their case mix (the relative proportion of patients with a specific diagnosis or disease treated at the hospital);
- develop new relationships with their medical staff; and
- evaluate different treatment protocols prescribed by physicians for patients in the same DRG.

As a result, because hospitals can keep the difference between treatment costs and the DRG payment, they are encouraged to introduce technologies and management techniques that monitor and control costs. From a management perspective, the prospective system is designed to compel hospitals to behave more efficiently.

The DRG for an individual patient is determined after the patient's discharge from the hospital, based on such information as the principal diagnosis, any secondary diagnoses, the patient's age and sex. The determination is made by the Medicare fiscal intermediary.

This prospective pricing system applies only to inpatient care provided to Medicare patients. Outpatient care rendered to Medicare beneficiaries will continue to be reimbursed under the retrospective cost-based system, although this is expected to change in the near future.

DRG's remain a controversial issue. Major concerns relate to the system's inability to distinquish the various levels of illness or patient severity; its potential manipulation by hospitals seeking higher payment levels (called DRG creep); and its inability to capture the true resources consumed in the treatment of a case.

Under the prospective payment system, the responsibility for maintaining quality of care is delegated to Peer Review Organizations (PRO's). PRO's are authorized under the 1982 law which created the new reimbursement system and are defined as bodies "composed of a substantial number of licensed doctors of medicine or osteopathy engaged in the practice of medicine or surgery in the area", or "a body which has available to it, by arrangement or otherwise, the services of a sufficient number of physicians engaged in the practice of medicine or surgery."

#### PRO's will be required to review:

- the diagnostic information provided by the hospital for purposes of payment (DRG verification);
- the completeness, adequacy and quality of care;
- the appropriateness of admissions and discharges; and
- the appropriateness of care provided to "outlier" cases (cases that don't fall within the 467 DRG groups).

#### ISSUES RELATING TO THE PROSPECTIVE PAYMENT SYSTEM

Prospective payment has been in effect only since October 1, 1983. It will not be fully implemented until 1986, and its effect on the quality of hospital services, as well as the availability and quality of nursing home services and home care services, is not yet fully known. As advocates for the elderly, the Maine Committee on Aging and the Bureau of Maine's Elderly assert that it is critical that the effects of this new system be closely monitored and that we continue to educate ourselves and consumers about the workings of the system.

# COMMENTS FROM FRANCIS MCGINTY, EXECUTIVE DIRECTOR, MAINE HEALTH CARE FINANCE COMMISSION

The Executive Director of the Maine Health Care Finance Commission, Frank McGinty states that "the prospective payment system implementation will cause irreparable injury to many of our

nation's hospitals and those they serve." The Maine Health Care Finance Commission was established last year by the Maine legislature to develop and implement a prospective payment system to meet Maine's unique needs and which incorporates all payors (private insurance and Medicaid in addition to Medicare). Because Maine has chosen to create its own system, Mr. McGinty "does not believe there is reason to be concerned that the accessibility or quality of the services available to the citizens of Maine will be diminished by the implementation of the DRG system. The prospective payment system we have chosen to establish in Maine is not only fundamentally different than the Medicare system, but it also envelops the Medicare payment system and . . . negates many of its most potentially damaging characteristics."

Mr. McGinty asserts that "it is clear that any incentives for hospitals to become more efficient (as a result of the Medicare prospective payment system) are substantially weakened if they are free to shift any losses incurred in the provision of care to Medicare beneficiaries to other payors by increasing their charges to them.

"The payment system creates extraordinary rewards for hospitals which admit Medicare beneficiaries in greater numbers and harshly penalizes hospitals which act to reduce such admissions. (Such incentives) will inevitably increase the rate at which Medicare beneficiaries are admitted to hospitals at a time when reducing that rate must be an important part of any effective response to the Medicare Program's financial problems.

"The establishment of a Professional Review Organization (PRO) is highly unlikely to be an effective counterweight to these pressures.

"Maine's system will negate many of the potentially damaging characteristics of the Medicare DRG system. Maine's system begins with a determination of each hospital's financial requirements, the total amount it needs in order to continue to provide services of acceptable quality to those it serves. Maine's system guarantees each hospital that it will receive an amount equal to its financial requirements. The hospital will receive no more or less than the amount it was determined to need.

"If there is a threat to Maine hospitals and those they serve arising from the Medicare payment system, it is in the very real potential for the system to become the vehicle by which the Federal government attemps to shift its bona fide obligations to others."

#### COMMENTS FROM RON THURSTON, MAINE HEALTH CARE ASSOCIATION

The Maine Health Care Association, an association of 112 nursing homes in Maine, states that the prospective payment system provides an incentive to hospitals to make sure the physician has the most accurate diagnosis possible so that it does not lose revenues by recording a diagnosis that might entitle it to a different level of reimbursement.

"It clearly, however, provides an incentive for the earliest possible discharge, because the hospital will receive the same revenue regardless of the patient's stay. Hospitals in Maine are of course faced with double incentives to reduce length of stay since they are also facing revenue limits in the aggregate as a result of the work of the Health Care Finance Commission. These aggregate limits may have a greater impact on admission decisions then DRG's."

In contrast to Mr. McGinty's statement, the Maine Health Care Association believes that "there are two forces at work on hospitals which clearly provide incentives to reduce and control access to care. One could argue in the extreme that controlling access to hospital care could result in improvement in the patient's health status. Hospitals are sometimes not very healthy places to be. At the other extreme, of course, they are absolutely essential to our survival. The key is to determine the difference between when they are vital and when they are harmful. (There is) no organized way to determine that on a statewide basis without the presence of a physician-directed review organization which has as its mission the assurance of a minimum quality of hospital care for all Maine citizens.

"Physicians are the gatekeepers of hospital care. Yet there is no mechanism to assure on a statewide basis, let alone a system-wide basis, the provision of a minimal standard of qualtiy. That is this state's single most important health policy issue. The Blaine House Conference on Aging should call on the health policy makers of this state to immediately create and find funding for a statewide physician directed and accountable quality assurance organization." This recommendation is contrary to the opinion expressed earlier in this paper by Mr. McGinty.

"With regards to the questions of nursing homes' experience with DRG's, it has been limited. (The Maine Health Care Association has) interacted with the Department (of Human Services) in the hopeful development of a clinical data system. The unavailability of clinical data on nursing home patients is a fundamental flaw in the evaluation of the effect of DRG's on nursing home patients. Without data we can merely speculate and hypothesize.

"Finally (the Maine Health Care Association) has been concerned for some time over the unavailability of the skilled nursing level of care for most Maine residents. It is unavailable as a Medicare benefit both because of a lack of beds and because of what we believe to be unreasonable determinations of the Medicare definition of skilled care by our fiscal intermediary.

### COMMENTS FROM CRAIG W. YOUNG, M.D., PRESIDENT, MAINE MEDICAL ASSOCIATION

The Maine Medical Association's President, Dr. Craig Young, submitted a discussion paper from which we have quoted below:

"DRG's are a bureaucrat's answer to try and reduce future hospital health care cost. It is a treatment of a 'sympton' (high cost of medical care) rather than a cure for the 'disease' (finding out why the cost is so high).

"The real reason that hospital costs are rising are these:

- A. Over-regulation: A full 50% of the medical care dollar goes toward meeting bureaucratic controls, regulations and bookkeeping.
- B. Lack of competition: Certificate of need legislation developed with the intent of preventing unnecessary duplication has such low trigger thresholds that it, in fact, guarantees monopolies and high cost of care.
- C. Defensive medicine: A tort system which allows extravagant damage awards, most of which never sees the injured person's pocket.

"Not only is the DRG not the answer to controlling cost, it will in both the short and long run reduce the quality of care. Have physicians experienced the impact of DRG's on the health care system? Not yet, of course, because it is too early.

"The PRO is another bureaucratic boundoggle. The PRO was designed to police hospitals who try to get around the DRG system by checking to see that admissions have not gone up from prior years. The PRO's are basically a joke since an honest effort to try and oversee the effect of DRG's is not rewarded."

#### DRG RELATED ISSUES

Although the following issues relating to DRG's were not addressed by any of the three discussion papers included earlier, we feel that they are of significant importance and must be raised for discussion.

#### A. Vertical Integration

The new prospective payment system presents real incentives to hospitals to search aggressively for nursing home placements to avoid alternate placement days and to reduce patients' length of stay by placing them in a long term care arrangement.

To improve their access to providers of long term care (nursing homes, home health agencies), hospitals may buy nursing homes and home health agencies. This is called "vertical integration."

Patricia Nemore, staff attorney for the National Senior Citizens Law Center, states that hospitals, "especially the for-profits, will potentially gain tremendously from vertical integration. For example, a hospital can discharge a patient earlier than the average length of stay for that patient's DRG, thereby making money on that discharge. If the patient goes directly from the hospital to a nursing home owned by the same corporation, full payments for nursing home services will begin immediately, and the corporation will make money providing that level of care."

Ms. Nemore goes on to say that "obviously such an arrangement has serious implications for the patient's freedom of choice of providers. If the patient does not want to go to the hospital's nursing home, or to whatever facility the hospital recommends, the options may be rather limited. First, the patient can ask the attending physician to state that continued inpatient hospital care is needed. A second possible option for the Medicare patient not wishing to go to the nursing home designated by the hospital is to find an alternative facility. This can be extremely difficult as very few nursing homes now participate in the Medicare program. Those facilities that do participate in Medicare are not evenly distributed throughout the country. In Maine, only about 3% of the total nursing home care provided is in Medicarecertified nursing homes. Should the patient be fortunate enough to find a Medicare-certified SNF, there would still be obstacles. Even if an about-to-be discharged hospital patient found a nursing home bed in a suitable facility, Medicare might not pay for the stay.

#### B. Contracts Between Hospitals and Nursing Homes

Hospitals have also showed interest in developing contractual arrangements between hospitals and nursing homes which would guarantee bed availability by having the hospital pay a nursing home to reserve a specified number of beds. These arrangements will potentially limit patient freedom of choice. The contracting option presents some additional questions, as follows:

1. Will the amount a hospital pays be the full private rate or only some "standby" amount that is more than a nursing home would receive if a bed were empty?

- When does a patient become the sole responsibility of a nursing home, and how long will a hospital pay for a patient?
- 3. Will a hospital pay the full private rate after a patient's admission to a nursing home or only the difference between a private rate and a third-party payment?
- 4. Who will control hospital discharges to a nursing home and what role will a patient and the physician play in this decision?
- 5. Who will determine when another bed becomes available to a hospital once a hospital's reserved beds are full? Will the hospital play a part in a nursing home's discharge decisions?

#### C. Further Limitations on Access for Medicaid Recipients

The preferred treatment of hospital patients under almost any of these arrangements between nursing homes and hospitals is likely to reduce further the availability of beds for Medicaid recipients. Medicaid recipients may find it harder to obtain and keep nursing home beds.

#### D. Swing-Bed Facilities

Small rural hospitals have an additional option for increasing access to nursing home beds. Section 904 of Public Law No. 96-499, the Omnibus Budget Reconciliation Act of 1980, authorizes hospitals in areas with shortages of nursing home beds to provide skilled and intermediate care services, which are reimbursed at the appropriate rate.

#### CONCLUSION

Although the Maine Committee on Aging and the Bureau of Maine's Elderly continue to hear concerns that the DRG prospective payment system will dramatically affect the quality of care available to Maine's older citizens and that its effects are already being felt, the resource persons selected for this workshop do not overwhelmingly provide support for those concerns at this time.

Questions remain as to how advocates for the elderly should best monitor the new prospective payment system. We know that the health care system is experiencing dramatic change, but our concern remains how these changes will affect the quality of care available to Maine's older citizens.

#### Questions for discussion

- 1. How can the elderly advocacy network in Maine best monitor the effects of the new prospective payment system for hospitals? What plans does the Health Care Finance Commission have for monitoring the DRG system in Maine?
- 2. Who is addressing the shortage of skilled nursing facility beds pointed out by Ron Thurston and Trish Lemore? Can the elderly advocacy network play a role in this SNF shortage issue? If so, what role?
- 3. Is there or is there not a need for a statewide physician directed and accountable quality assurance organization to monitor implementation of DRG's?
- 4. Should the Department of Human Services develop a clinical data system on nursing home residents?
- 5. Are hospitals in Maine planning on purchasing nursing homes and home health agencies to allow for vertical integration? What is the Department of Human Services' and the Health Care Finance Commission's opinion of vertical integration?

### Medicare Supplemental Insurance: Too Much or Too Little?

Chairs: Alice Bourque, Maine Committee on Aging David Brenerman, Maine Committee on Aging

Resource People: Tom Record, Bureau of Insurance

James McKenna, Assistant Attorney General Jadine O'Brien, Blue Cross/Blue Shield Tom Bagley, retired insurance professional

Valerie Kilhenny, Health Insurance Assoc. of America Aaron Wilmont, Health Care Finance Administration

Staff: Natalie Dunlap, Bureau of Maine's Elderly

Delegates:

Richard Cooley Nina Byron

Frank Cameron Lorraine Bonney

Hugh Hoag Richard Simmons

Rosie Clark Doris Poulin

Jim Fletcher Charles Wright

Ross Connors Barbara Glen

Josephine Gould Michael Tyson

Grover McLaughlin Hildegard Butler

Joseph Morin Esther O'Briwn

Everett Baxter Velana Dainys

Marion Robertson Virginia Zulieve

Greta Connors Carol Mercer

Edgar Brown Guy Scarpino

Evangeline LaChance James Elias

Flora Nason Phillip Macy

Gordon Mansir

Jerry Wirthman

Eunice Lambert

Sarah Stevens

Dan Lowe

#### Abstract of Workshop Paper on

# MEDICARE SUPPLEMENTAL INSURANCE: TOO MUCH OR TOO LITTLE?

(Copies of full text available from Maine Committee on Aging)

#### Introduction

Although the aged represent only about 10% of the nation's population, they account for over 25% of all personal health expenditures. In addition, those over age 65 pay more out of pocket for their medical care today than they did in 1965 when the Medicare program began. From a high of 50% in 1969, Medicare now pays for only 38% of the total medical bill of the nation's elderly. The rest is paid either by the elderly patient, by various publicly financed medical assistance programs such as Medicaid, or by private health insurance.

Medicare was never designed to cover the total cost of providing medical care for the elderly. It was intended to serve as a core health insurance program which the elderly poor could augment with Medicaid, and other senior citizens, depending on their needs and resources, could augment through private health insurance.

The private health insurance industry has been successful in designing and marketing policies which supplement the coverage provided by Medicare. The need for these Medicare supplement policies is fostered by the complex and often inadequate benefit structure of the Medicare program itself.

These gaps in Medicare coverage and the complexities of the Medicare program have created confusion and often abuse in the medical insurance marketplace, and the victim is the elderly consumer. Frequently, they are seriously misinformed regarding the type of coverage they are buying. In addition to purchasing insurance policies specifically designed to supplement Medicare, they buy nursing home, cancer, home care, accident and intensive care hospital policies, and more - policies which they probably don't need and will probably never use.

#### Background

The federally-enacted "Baucus amendments" urged states to increase regulatory requirements, to establish minimum standards for Medicare supplement contracts, to require disclosure materials to be used in the sales process, to require summary pages on policies, and to establish "free-look" or review standards.

Maine's Public Law 1981, Chapter 605 of the laws of Maine and promulgation of Maine Insurance Rule Chapter 270 by Maine's Bureau of Insurance were intended to provide for the reasonable standardization of coverage the simplication of terms and benefits of Medicare supplement policies and to facilitate public understanding and comparison of such policies. The regulations established the following:

- 1. Standard definitions and terms.
- 2. Minimum standards were set which must be met by all Medicare supplement health insurance policies sold in Maine.
- 3. It is unlawful for insurnace agents to represent or imply that the policy, insurer, agent or broker is sponsored by or affiliated with the Government.
- 4. An outline of coverage must be provided by insurance agents at the time application is made to the consumer.

#### Current Problems

#### I. Consumer Awareness

Regulations, consumer education material and policy disclosure are helpful to consumers but do not, of course, solve all problems. If people do not understand Medicare's benefits, they will not be able to identify a health insurnace policy which effectively deals with the "gaps" in Medicare or determine whether coverage in addition to a Medicare supplement policy, such as cancer or nursing home insurance, may be necessary.

All of the resource people that considered this issue for the 1984 Blaine House Conference on Aging came to the same conclusion: the need for increased consumer awareness.

#### A. Maine Bureau of Insurance

Before the law and regulations were in force, there were a multitude of poor policies on the market. Since the Bureau of Insurance has to approve them according to the minimum standards, there are about 30 policies marketed in Maine.

The Bureau of Insurance feels that the largest problem and the one of most serious concern to them is "the purchase of substantially duplicative Medicare supplement insurance by senior citizens who are unaware of the terms of their coverage or who simply believe that 'more policies must be better.'"

"It has become apparent to the Maine Bureau of Insurance that elderly persons have little ready access to information regarding specific sources of Medicare supplement policies or of the various provisions of available products. They normally only have information regarding Medicare and Medicare supplement

insurance generally and specific information regarding a particular product for which they are being solicited.

"In order to help address this problem, the Maine Bureau of Insurance has developed a policy comparison chart summarizing the benefits and costs of those Medicare supplements most commonly sold in Maine. (The chart is available from the Bureau of Insurance.)

#### B. Health Insurance Association of America

Education of the consumer was highlighted by the Health Insurance Association of America as a means to address the current misunderstandings that exist.

#### C. Maine Medicare B, Blue Shield of Massachusetts

The problem of beneficiaries with duplicate coverage was again pointed out. Most particularly, the situation where low income people who are eligible for Medicaid don't realize that they do not need additional insurance because Medicaid pays almost all costs, including long term nursing care. As this representative pointed out, "one recurring problem I have observed is the beneficiary with Medicare, Medicaid, and Companion Plan They still retain their Companion Plan because they afraid that Medicaid will end and leave them with no supplemental coverage. It is my understanding that Companion Plan will not terminate but "suspend" coverage and will reinstate the policy if and when Medicaid coverage terminates. I would assume it to be the responsibility of the Medicaid representatives to inform the beneficiaries of this fact and to instruct them to notify Companion Plan of their Medicaid eligibility, or better yet, to make the call for them." (In response to this, the Maine Department of Human Services informed us that they encourage Medicaid recipients to retain their private health insurance policies to assure that those policies pay before Medicaid pays.)

#### D. Blue Cross/Blue Shield of Maine

Blue Cross/Blue Shield of Maine agreed that "a comprehensive and coordinated effort must be undertaken to solve the health insurance puzzle." Some projects which Blue Cross/Blue Shield is aware of and which are worth exploring include one developed by Blue Cross and Blue Shield of Rhode Island. The "Medicare Volunteer Program" trains senior volunteers to help others understand the "ins and outs" of Medicare. Volunteers are located in senior centers and meal sites and also make home visits to provide counseling.

The Amsden Project, an innovative program in New Hampshire which uses volunteers to help elderly residents with their Medicare problems, has won national recognition. It operates with the assistance of over one hundred volunteers at almost two dozen sites.

A short while back the Maine Committee on Aging proposed an innovative Health Insurance Information Network. (See Maine's Responses.)

Blue Cross and Blue Shield of Maine stands ready to share in both the development and cost of such a project, if it is undertaken with similar assurances of cooperation from all other interested parties.

#### E. Health Insurance Agent, Retired

A retired private health insurance agent who has counseled elderly concerning their Medicare supplement insurnace coverage emphatically stated that "a person with Medicare only needs one Medicare supplemental policy." Consumers Union agreed, and they recommended in the June 1984 issue of Consumer Reports that "the elderly (should) augment Medicare coverage with a Medicare supplement policy. But buy only one. Purchasing more than one policy will usually lead only to duplicate coverage and a waste of money."

He also expresses grave concerns about the marketing of nursing home insurance which is currently taking place in Maine.

#### F. Consumer and Antitrust Division, Maine Attorney General's Office

The Consumer and Antitrust Division of Maine's Attorney General's Office suggested two solutions to fraudulent Medicare supplemental insurance sales. First is "a vigorous enforcement of our current consumer protection laws. However, this is an area notoriously difficult to police. Insurance sales are often made in the home by insurance agents using high-pressure tactics. It is very difficult to pin down exactly which misrepresentations different sellers are using." Consumer education seems to be an even more fruitful response to consumer fraud."

#### II. Limited Coverage Health Policies

Elderly consumers are sometimes asked to purchase insurance policies which provide limited protection for specific expenses, such as hospital confinement(known as hospital indemnity policies) or nursing home care or for specific "dread" diseases such as cancer.

Limited coverage health policies are <u>not</u> covered by the law and regulations governing Medicare supplemental insurance policies

because they are not Medicare supplement insurance.

#### A. Dread disease policies

The most prevalent kind of limited policy is cancer insurance. Because most benefits are targeted to paying hospital costs, dread disease policies do not provide cost effective insurance protection for senior citizens.

#### B. Nursing Home or Long Term Care Insurance

As many elderly have become painfully aware, Medicare was not designed to address the need for long term care. Though it covers up to 100 days of care in a skilled nursing facility, users of Medicare average only about 27 days of covered care peryear. Medicare claim criteria are extremely restrictive, and only a small portion of all nursing home beds are certified for Medicare. In 1980, only 1.5% of the elderly's nursing home expenditures were paid by private health insurance. However, 59% of the nation's elderly own an insurance policy that covers nursing home care.

The greatest problem, and the primary reason that elderly purchase relatively useless nursing home insurance, is that they do not understand the long term care system and what type of nursing home Medicare will pay for. Most of the elderly who purchase nursing home insurance believe they are buying a policy that will pay for nursing home coverage below the skilled level. Usually they are wrong. Most elderly who utilize nursing home care use intermediate care facility services, not skilled nursing facility services.

Long term care is the most significant service not covered by medicare. Little or no private health insurance exists to relieve this burden. The result is that many elderly needing long term care spend their resources and end up on Medicaid.

Currently there is much discussion about what should be done to fill the huge gap in Medicare that relates to nursing home coverage. Two approaches have been suggested. One is that Medicare expand its coverage to include intermediate care facility and custodial (boarding home) care. The other is that private insurance policies for nursing home care be marketed which would pay for care in a nursing home for up to three years after a 90-day waiting period.

A third and more realistic approach might be for Maine's Bureau of Insurance to regulate the sale of nursing home insurance more closely through the promulgation of regulations setting minimum standards for certification of nursing home

insurance.

#### C. Hospital Indemnity Policies

Indemnity policies usually pay a fixed amount of money for each day of hospitalization, such as \$50 or \$100 a day. Indemnity policies are attractive to the elderly because they pay in addition to other insurance held by the policy holder. However, benefits are not structured to reflect the actual charges for hospital care. With the average cost per day of hospital care at \$262, the usual indemnity policy pays only \$50-100 per day. This is not any real financial protection for the aged patient.

Additionally, and probably one of the most important facts that is overlooked, is that a person might suffer from a long debilitating illness which only entails a few days in the hospital. The per hospital day dollars that the policy pays will not contribute much assistance to a long recuperation at home.

#### Other States' Responses

#### I. Consumer Awareness

# A. <u>Senior Health Insurance Benefit Advisors (SHIBA)</u>, <u>Washington State Insurance Commission</u>

SHIBA is an acronym for Senior Health Insurance Benefit Advisors, a program created in 1979 by the Washington State Insurance Commission. The intent of the program is to recruit, train and organize senior volunteers to serve as teachers, advocates and resource people to other senior citizens in the problem areas of Medicare and Medigap Insurance. In 1983, SHIBA had a staff of 204 volunteers who, after training, respond to questions from and provide counsel to senior citizens concerning Medicare supplement insurance.

In 1983, Washington's SHIBA program received 8,290 telephone inquiries, had 7,286 face-to-face counseling sessions, filed 50 complaints with Washington's Consumer Protection Division, took part in 186 training sessions, and gave 254 talks to senior organizations.

#### B. Medigap Hotline, Wisconsin

The Wisconsin Medigap Hotline is a statewide toll free telephone number which Wisconsin senior citizens can call for information and counseling regarding private health insurance in addition to Medicare. A key to the success is the Wisconsin Medigap Hotline is the Hotline's ability to advise on the various insurance policies and

their comprehensiveness because the Hotline has copies of <u>all</u> Medicare supplements sold in Wisconsin. Without the <u>ability</u> to see the policy under discussion, a telephone counseling service could not run effectively.

#### II. Limited Coverage Health Policies

#### A. Dread Disease

A few states totally prohibit the sale of dread disease policies. Several consumer advocacy groups recommend that senior citizens not purchase limited policies.

Some states' responses are as follows:

<u>Connecticut</u> - specified disease policies, riders and benefits issued on an individual or group basis were banned.

New Jersey - bans the sale of specified disease policies.

- Massachusetts dread disease policies can be sold but they cannot limit their coverage to any single disease such as cancer. Each policy must have a maximum benefit of no less than \$10,000, and they cannot be sold to anyone over 65 yeras of age.
- California A dread disease policy must have a maximum limit of at least \$10,000 or a series of minimum benefits such as \$50 a day for the first 12 days of hospitalization with no elimination periods, deductibles or coinsurance factors and \$30 per day for each day of continuous hospitalization.
- New York Prohibits the sale of specified disease policies or coverage for procedures or treatment unique to specified diseases.

#### B. Long Term Care Insurance

We know of no state that has limited the sale of long term care insurance per se or has presented specific minimum standards for long term care insurance to date. Most states have promulgated minimum standards for Medicare supplement insurance which only set minimum for skilled nursing facility care.

#### C. Hospital Indemnity Policies

Some states have promulgated regulations that establish minimum daily hospital benefits.

#### D. Other Issues

Because many Medicare supplement and indemnity policies are advertised heavily in the media, some states have passed laws to regulate the advertising to assure that ads are not misleading or misrepresent the product being marketed.

#### What Has Maine Done So Far

The state law and regulations described earlier in this paper have gone a long way in addressing some of the major problems with the content of the policies marketed by standardizing terms and requiring minimum standards for policies sold in Maine. The problem of lack of elderly consumer awareness about the various issues concerning Medicare supplemental policies still exists, as do abusive sales practices and scare tactics.

The Maine Committee on Aging attempted to address the information and counseling need in 1982 through the development of a proposal for a "Health Insurance Information Network." The proposal was presented as follows:

A health insurance analyst located in each of the five area agencies on aging would be able to provide analysis and information services via telephone contact and individual person-to-person contacts.

The Maine Committee on Aging proposal sought funding from private sources, including Unionmutial and Blue Cross/Blue Shield of Maine. However, no private funds were made available. A VISTA position was sought through ACTION but was also denied. State funds were never sought.

#### QUESTIONS

#### Consumer Awareness

- 1. How can the consumer become better informed about the various issues relating to Medicare supplement insurance? A consumer hotline? A volunteer counseling program?
- 2. Are pamphlets useful in informing elderly on the issues? Newsletters? Public service announcements?
- 3. How should current information, such as the Bureau of Insurance's Policy Comparison Chart, be distributed to assure widest distribution among Maine's elderly?

#### Limited Benefit Insurance

- 1. Should Maine prohibit the sale of "dread disease" policies such as cancer insurance?
- 2. Should the Bureau of Insurance promulgate regulations to set minimum standards for nursing home insurance policies sold in Maine?
- 3. Should Maine become involved in regulating advertising that relates to health insurance to assure that it is not mis-leading or misrepresenting facts?
- 4. Should Maine set minimum standards for hospital indemnity policies?

### Access to Long Term Care for Medicaid Eligible Consumers

Chairs: Wilfred Pombriant, Maine Committee on Aging

Resource People: Toby Edelman, National Senior Citizens Law Center

Anthony Forgione, Maine Health Care Association Marina Thibeau, Esq., Legal Services for the Elderly

Isabella Tighe, Bureau of Medical Services
Joseph Wannemacher, Assistant Attorney General

Staff: Jill Duson, Maine Committee on Aging

Delegates:

Anthony Wedge Methyl Hutchins

Elizabeth Knight Gladys Babb

Violet Francis Hugh Montgomery

Gordon Browne George Pauk

Paul LeVecque Maxine Boure

Robert Armstrong Thelma Pray

Arthur Flemming Clyde Bartlett

Charles Alexander William Mccue

Carl Rogers John Hanna

Ann Padilla Sylvia West

Alberta Eaton Phyllis Jones

Minnie Lee Gartley Joanne Miller

Charles Thomas Leo Seneca

Loretta Belle Rush Roy Jones

Dick Cleaves William Inlow

Laura Murray

Marjory Blood

Thelma Boynton

Mildred Dickson

Lucy Burgess

### Abstract of Workshop Paper on ACCESS TO LONG TERM CARE FOR MEDICAID ELIGIBLE CONSUMERS

(copies of full text available from Maine Committee on Aging)

Medicaid recipients and other poor people who want and need nursing home care often have difficulty getting and keeping a bed in a long term care facility. Discrimination by nursing home providers occurs, in large part, because facilities are able to charge private-pay residents higher rates than those paid by Medicaid for identical services.

"Providers" in the private sector, and Medicaid providers dealing with non-Medicaid patients, can charge whatever the market will bear. It is always to their financial advantage to fill a bed with a private pay rather than a Medicaid patient - if a private pay resident is available.

Medicaid provides a floor - of income to the provider, of services to the recipient. Providers are also businessmen, and they would like to make more money.

The State and Federal governments have an interest in spreading the benefit of scarce resources as broadly as possible, thus paying as small a portion of the available funds as possible to get the job done.

This paper will discuss several factors which act to limit the availability of nursing home services for low income applicants for admission and the ability of individuals without private pay resources to avoid inappropriate discharge from a facility. This discussion will include a focus on specific Medicaid eligibility regulations and industry policies which impact on low income persons in need of nursing home care. This document represents a compilation of brief papers submitted by the workshop resource persons together with materials excerpted from a report prepared by the U.S. General Accounting Office entitled "Medicaid and Nursing Home Care: Cost Increases and the Need for Services are Creating Problems for the States and the Elderly," GAO/IPE-84-1, October 21, 1983.

#### THE MEDICAID PROGRAM - POLICIES WHICH AFFECT ACCESS TO CARE

#### A. The Transfer of Assets Rule

In 1981, Congress established a penalty to be imposed on people who transferred assets to others in exhange for less than fair market value for the purpose of becoming eligible for Medicaid.

In 1982, Congress amended the transfer of assets law to give the states several options in the operation of Medicaid programs. States can now choose to impose liens on the homes of institutionalized Medicaid recipients to recover for the costs of their care and

apparently can penalize such people for transferring their homes in exchange for less than fair market value. Maine has, so far, not exercised these options.

#### B. First Day of the Month Rule

Beginning in August, 1983, Maine determined Medicaid eligibility by counting the assets an individual owned in the first moment of the first day of the month. If he met other standards and owned less than \$1500.00 of assets in that moment, he was eligible for Medicaid for the whole month. However, the rule works in reverse to deny Medicaid (including nursing home) benefits to many elderly people. If the individual's assets exceeded \$1500.00 in the first moment of the first day, even by as little as one dollar, then that individual is ineligible for the whole month.

#### C. Six Month Budget Period

Maine currently requires calculation of spenddowns for "medically needy" individuals to be extended over six months. This creates a hardship for many elderly people whose incomes are fixed and received monthly, whose expenses are paid monthly, and whose need for medical attention is relatively constant. These people are required to use up six months' worth of excess income (i.e., the spenddowns) for medical bills before Medicaid will step in and cover the rest.

#### THE NURSING HOME INDUSTRY

A study by the National Citizens' Coalition for Nursing Home Reform (NCCNHR) and information from the National Senior Citizens Law Center lead to the conclusion that nursing homes act in several ways to make access more difficult for Medicaid patients.

According to the survey findings, nursing homes have taken steps to reduce access by preventing initial admission for Medicaid eligibles, discharging from their facilities former private pay patients once they become Medicaid-eligible because they have exhausted their resources, limiting the number of beds a facility has certified for Medicaid participation, requiring patients to demonstrate that they have sufficient resources to pay privately for a specified period of time, requiring as a condition of admission that patients have a "responsible party" sign a contract as a means of insuring payment, and requiring "security deposits" of large sums as a requirement for admission as a Medicaid recipient.

# FEDERAL LAWS AND STATE ACTIONS INTENDED TO REDUCE ACCESS PROBLEMS FOR MEDICAID RESIDENTS

Several federal laws prohibit discrimination against Medicaid nursing home patients.

According to the NCCNHR study cited above, several states have passed their own legislation making it illegal to discriminate in admitting Medicaid eligible applicants or by transferring private pay patients once they become Medicaid eligible patients. These states include Connecticut, Massachusetts, Michigan, Minnesota, New Jersey, New York and Ohio. Maine has a statute prohibiting discrimination against Medicaid residents by forbidding discharge or transfer of a resident because he or she switches from private paying status to Medicaid, but it does not address the problem of first achieving admittance to a nursing home.

#### DISCRIMINATORY PRACTICES

Provider discrimination against poor people takes many forms. Admission presents the first barrier to access to care.

#### POLICIES WHICH PREVENT ADMISSION OF LOW INCOME RESIDENTS

One common practice is requiring applicants for admission to sign private pay duration of stay contracts which obligate residents to remain private pay for specified periods, usually ranging from several months to several years, before the facility will "accept" Medicaid payments on the resident's behalf.

A few Maine nursing homes have demanded substantial <u>cash</u> deposits before agreeing to admit persons whose eligibility for Medicaid has not yet been determined, to guard against the possibility that Medicaid will be denied and the resident will have no other source of money.

A third practice requires applicants to have a co-signor, often called "responsible party," who becomes legally and financially responsible for paying for nursing home care. This practice, however, creates an almost insurmountable hardship for individuals in need of care who do not have a third party willing to take on this role of responsible party.

#### PROVIDER CONTRACTS

Two other facility practices manipulate Medicaid provider contracts with the state agency in order to limit the number of Medicaid beds that are theoretically available to recipients:

- A. <u>distinct part certification</u> is Medicaid certification of a single wing or floor, instead of an entire facility; and
- B. <u>limited bed</u> provider agreements certify fewer than all the certifiable beds in a facility.

#### WAITING LISTS

Nursing homes also often tell applicants that there is a waiting list for a Medicaid bed. The invisible waiting list story is frequently a ruse for delaying the admission of a Medicaid eligible resident while giving priority to potential private-pay residents.

#### DISCHARGING MEDICAID RESIDENTS

Once in a nursing home as a Medicaid recipient, a resident is not guaranteed continue stay. A nursing home may choose to transfer or discharge a resident whom it no longer wants to keep.

Maine regulation permits payment for Medicaid-covered services to nursing homes, even if the Medicaid resident is temporarily out of the home. This usually occurs when the resident needs hospital care for a short period but will need to return to the home. This benefit to the resident is often ignored by the nursing home so as to discharge an unprofitable Medicaid resident to a hospital and then refuse to readmit that resident when the need for acute care ends.

#### FINDING A SOLUTION - STATE REMEDIES

Remedies to Medicaid discrimination are usually found at the state level, since the federal Medicaid law imposes no obligations on facilities to provide care for specific residents.

State remedies enacted to date have been varied in method and purpose. Most early remedies were general and addressed nursing homes voluntarily participating in the Medicaid program.

Most recent state efforts address specific manifestations of discrimination and, interestingly, have typically come from the same states that made the initial efforts to outlaw discrimination.

#### WHAT DOES THE BLAINE HOUSE CONFERENCE ON AGING RECOMMEND?

- 1. Should Maine adopt any of the liens or transfer-of-asset penalty options offered by Congress?
- 2. Should the State's regulation requiring assets to be counted as of the first day of the month be repealed and replaced by a regulation granting coverage for each day that an applicant meets all the eligibility standards?
- 3. Should classification and income-maintenance procedures be reviewed and amended as necessary to prevent long delays in establishing eligibility for nursing home assistance?

- 4. Should Maine amend its regulations to shorten the spenddown budget period to one or two months?
- 5. Should Maine adopt regulations explicitly stating that nursing home contracts requiring a specified length of stay as a private pay resident are discriminatory and violate federal and state laws?
- 6. Should Maine adopt regulations forbidding nursing homes from demanding any deposit from new nursing home residents as a guard against possible Medicaid denial?
- 7. Should Maine adopt regulations stating that nursing home contracts requiring that applicants who have not been adjudicated incompetent must be signed into the facility by a third party violate federal and state laws?
- 8. Should Maine adopt regulations clarifying "responsible party" and prohibiting a facility from refusing admission to anyone who does not have relatives or friends to serve as the "responsible party"?
- 9. Should Maine adopt regulations requiring nursing homes to admit people in the order of their applications without regard to their sources of payment, and establishing monitoring procedures to force compliance?
- 10. Should the state require nursing homes to explain the bed-hold policy to residents and/or responsible relatives and to request such bed-holds for the residents whenever appropriate?

### Increasing Employment Opportunities for Older Workers

Chairs: William Cunningham, Maine Committee on Aging

Resource People: Francia Davis, Maine Human Rights Commission

Rita Gerke, Cooperative Extension Service

Gale Gibson, U.S. Department of Labor

Eileen Lonsdale, Western Older Citizens Council

Joseph Cody

Leonard Nilson, Maine Department of Labor

Staff: Doris Russell, Bureau of Maine's Elderly

Delegates:

Anita Wiles Anne O'Neil

Agnes Tierney Paul Eric Dilberg

Rose McKenna Roberta Strout

Nancy Rines Helen Goodine

Patricia McDonough Erwin Szawlowski

Peter Coe Evelyn Bonney

Earle Potter Viola McGilvery

Tina Gilbert Wilfred Ferland

Bob Frates Dorothy Adickes

Faylene Webster Raeburn MacDonald

Richard Woodworth Roland Castonguay

Georgette Berube Gordon Mansir

Donald Stewart Winnifred Black

Marjorie Osgood

Anne Hathaway

Carl Kirkpatrick

Jacqueline Rogers

Gary Locke

Nat Shed

# Abstract of Workshop Paper on <u>Increasing Employment Opportunities for Older Workers</u> (Copies of the full text are available from the Maine Committee on Aging)

Since a Blaine House House Conference on Aging last dealt with the topic of employment for older workers in a workshop in 1982, there have been two events worth noting in the area of increasing job opportunities for older workers.

First, the Senior Community Service Employment Program (SCSEP) the Older American Jobs Act Title V jobs program administered in Maine by the Department of Human Services, Bureau of Maine's Elderly and four other sponsors, was expanded with funding for an additional 43 subsidized jobs state-wide, bringing the total for all of Maine to 388. Under this program low-income persons age 55 and over are hired into part-time community service jobs with the understanding that the sponsors will make the efforts that are necessary to see that annually 15% of the program enrollees find unsubsidized jobs.

The second development to note was the passage of the Joint Training and Partnership Act (JTPA), successor to the Comprehensive Employment and Training Act (CETA), in 1982 with a percentage of its appropriation set aside for the training for jobs in the private sector of workers 55 years of age and older with poverty level income.

JTPA is bringing \$241,198 into the state for the older worker part of its program for the year running from July 1, 1984 to June 30, 1985. The key components of this program administered by the Bureau of Maine's Elderly are in place state-wide at the area agencies on aging and JTPA training deliverers. They are: worker counselor/job developer staff in each of the regions;
2) specialized training arranged for by the area agency and its JTPA staff to meet the varying needs of different groups of individuals in the target population; 3) training for employers to make sure they understand demographics, the need for older workers in the workforce, misconceptions about older workers, and discriminatory practices and to provide technical assistance on such matters as benefit packages and the structuring of flexible work schedules and parttime and shared jobs; and 4) a special innovative pilot project to train a small group of eligible older workers in how to set up a small business as an independent contractor to provide services such as minor repairs, chore services, window washing, lawn mowing, snow shoveling and the like.

Thanks to a Blaine House Conference on Aging resolution, Maine also has a law forbidding mandatory retirement in either the public or private sector. We also enjoy an active Human Rights Commission.

In spite of all this, older people who are seeking work right now continue to report difficulties and continue to be under-represented in the work force. For example, Maine State Government is one of the largest employers in the State, but, as of 1981, only 17% of its employees were 55 and over and only 2% age 65 and over. And the Human Rights Commission which has been processing complaints filed on the basis of age since the statute was passed in 1971 reports, "...a dramatic increase in the age cases filed...from 74 cases filed in the previous year to 137 cased filed this past year... an 85.1% increase. This number represents 34 percent of the yearly case load of the agency."

The Maine Job Service which defines an older worker as anyone 45 years of age or older reports that out of the 80,300 applicants who came into Job Services offices last year, 10,200 were in the older worker category. Placement rate for the older workers was 19% whereas for all age groups it was 22%. In addition the State Department of Labor estimates that only 3,300 individuals in the over 55 labor force are currently available and seeking employment. It is generally assumed that for every unemployed older person looking for work, there are more who want work but have grown discouraged and given up looking. Further, older workers tend to remain unemployed longer than their younger counterparts and therefore exhaust unemployment benefits.

The Job Service also reports that "...there is a continued reluctance by employers to hire them (older workers) because of the perennial myths that they are:

- 1. Over qualified and would not be satisfied with this type of work.
- 2. Probably would not have much longer to work anyway.
- 3. Would expect a salary greater than what the employer is willing to offer.
- 4. Probably doesn't need the work as badly as a younger person does."

The 1981 Bureau of Maine's Elderly and Maine Human Rights Commission study, (The Status of Older Workers in Maine State Government: Analysis and Recommendations) states, "Unlike other discriminatory behavior, age discrimination results more from a lack of understanding than from emotional bias, and it appears to be based on the acceptance of beliefs about the effects of age and the aging process that are not universally valid...Among these commonly held beliefs are ones which maintain that older people are rigid in their thinking and not easily changed; that their health is deteriorating and so, therefore, is their usefulness; that they are slowing down and their productivity declining; that their intelligence is diminishing and they cannot be creative or innovating in their thinking."

The Maine Human Rights Commission also calls attention to the particular problems of older women, "Sex-based job segregation affects all women workers but has a particularly harsh effect on older women." It points out that "even women who succeed in finding jobs later in life or who have been working for years, face difficulties on the job. Both age and sex bias is reflected in the payment older women receive from their work. The wage gap widens as women age: while the average woman earns 59¢ for every dollar earned by a man, the ratio drops to 55¢ to the dollar for women over 45."

In recent testimony before a special hearing of the Joint Economic Committee chaired by Representative Olympia Snowe, Eileen Lonsdale, Support Services Director of Western Older Citizens, Council, one of the five Maine area agencies on aging, adds to this picture in a discussion of wage disparity between what men and women earn in one area in Maine. She reported that the mean income for full and part-time workers in Androscoggin County, which includes Lewiston and Auburn, indicates the following:

Men \$9,808 Women \$4,444

The mean income for full-time employment:

Men \$13,133 Women \$8,862

The mean family income in Andorscoggin County by age categories:

45-54 \$21,441

55-64 \$17,331

65+ \$10,111

Source: Bureau of Labor Statistics

While there is no breakdown by sex by age, clearly women receive lower wages, regardless of age. In this area with few exceptions, women work in female-dominated jobs which pay a disproportionately low wage regardless of the responsibilities and experience. Until that changes, jobs will make little difference in the attainment of a decent standard of living for women.

Ms. Lonsdale also said that, "The Senior Community Service Employment Program and the more recent JTPA have not solved the special problems and barriers that older women face...Analyzing statistical reports from four out of five SCSEP programs in Maine, out of a total of 383 workers, 73% were women. In all but one of the programs, the average wage was \$3.35...perpetuating poverty for people 55 and over and also doing little or nothing to assist these women to build up a retirement income...The concept of the Senior Community Employment Program is a good one because it utilizes the skills of older workers, provides some training new skills, and places older workers in Community Service jobs which allow them to

make a contribution to the community. The clear problem is that it does little to raise the standard of living of the older person..."

The problems faced by older workers in Maine as elsewhere are:

- discrimination on the basis of age fed by unfounded prejudices against older workers that are built on ignorance and unfortunate stereotypes; and discrimination on the basis of sex;
- inadequate job opportunities, a situation that has its origins in at least the following factors: 1) rigidity in personnel practices in both the public and private sector; 2) a limited job market in rural areas which make up a large part of Maine; and 3) a high unemployment rate state-wide;
- . low wages that may not be fair compensation or in jobs that don't tap the kinds and degree of experience, knowledge and skills of older workers, especially older women.

How to confront these problems and to help bring about changes that will benefit older workers, giving them productive work and increased purchasing power and paving the way for the ever increasing numbers of older people who will be needed in the workforce as the population continues to be comprised of more and more older people are the challenges to the economy as a whole and the aging network in particular. There must be actions that government, employers, employees and their unions can take in the following areas right now:

- increasing the kind and number of work opportunities (e.g. through part-time jobs and flexible schedules);
- educating about age discrimination and how to handle it;
- breaking down prejudices against older workers built on ignorance and stereotypes;
- improving the utility of special programs like SCSEP and JTPA.

If that is the case, which of the above should be addressed, by whom, and how?

## Right to Medical Treatment/ Right to Refuse Medical Treatment

Chairs: Rep. John Joyce, Maine Committee on Aging Mae Parker, Maine Committee on Aging

Resource People: Phyllis Brown, Maine Health Care Association Edward David, M.D., Maine Medical Association Alexander McPhedran, M.D., Maine-Dartmouth

Family Practice Residency

Herbert Paris, Regional Memorial Hospital Gordon Smith, Maine Medical Association

Robert Robinson, Esq.

Estelle Lavoie, Preti, Flaherty & Beliveau

Staff: Kate McHaney, Maine Committee on Aging Trish Riley, Bureau of Maine's Elderly

Delegates:

Joseph Smaha George Knight

Beatrice Dorbacker Evelyn Brown

Buddy Murray Henry Tinkham

Agnes Flaherty Lawrence Harpe

June Perkins Lillian Beal

Margaret Jones Clyde Harvell

Barbara Niss Carol Timberlake

James Gorman Eloise Moreau

Dr. Paul Pfeiffer Virginia Bradbury

John Shaw Reid Bruce

Andrew Kaufmann Shirley Orss

Doris Baxter Elizabeth Weaver

Ann Sparling

Marie Dow

Jackie Hodgkins

Ruth Pendleton

Ruby Young

Roger Newton

Abstract of Workshop Paper on

<u>Right to Medical Treatment/Right to Refuse Medical Treatment</u>

(Copies of full text are available from the Maine Committee on Aging)

#### Introduction

Our society stands at the threshold of being forced to make some critical decisions about health care for citizens. Questions demanding answers are: Who will receive health care? What health care will be received? How will we pay for the health care? How much should we pay for health care? Who will pay for the health care of those who cannot afford the price? Who should be entitled to what services? What are the limits on health care possibilities? The answers to these tough questions must be reconciled with so many disciplines: medicine, nursing, law, ethics, philosophy, economics, psychology, theology. They must reflect sound medical judgment and a firm legal base, and also not offend our traditions of self-determination, social justice and equality.

#### A. The Right to Health Care

#### 1. Equal Access to Equal Care?

The first set of issues for debate involve the basic right to health care. Who is entitled to health care in this country and who will pay for the health care of the poor? First we should acknowledge that in a strict legal sense there is no constitutional right or entitlement to health care. Our development of social programs designed to assure that medical care would be available to everyone were based on notions of social justice and equality.

Today most people agree that our nation's total health care bill has become astronomical and that technological health care capabilities daily become more extraordinary. Also, most experts seem to agree that the simultaneous increases in both per capita consumption cost of medical care coupled with the ever increasingly extraordinary treatment capabilities of modern medicine threaten the ability of our current system to provide equal access to equal medical care.

It is conceivable that under the best system of regulatory control of health care costs imaginable, America might not be able to afford its health care bill. But what is "too expensive"? Must limits be set? If so, why? Where?

# 2. The High Cost of Equal Care: Do We Need to Set Limits? Are We Already Setting Limits?

Health care literature has begun to abound with articles about cost containment, limiting availability of services and the rationing of health care To advocates of social justice, the idea of rationing conjures up the spectre of discriminatory images. To most, however, the notion that each of us would be entitled to every conceivable medical treatment, organ transplant or innumerable other (and perhaps as yet unimagined) technological devices to postpone death, at government expense, if needed, seems to stretch the tolerable limits of the cost/benefit ration.

Are we willing to publicly admit as a nation that our concept of equal access to equal care is not infinite? With all the public attention and demand for action on health care cost containment, it can be argued that our nation has already implicitly called on those who lead and govern to set aside the notion of equality in health care. The Administration has proposals that increase the out-of-pocket cost of Medicare to an elderly person. Under these proposals some elderly persons will be unable to meet these higher out-of-pocket expenses and will be denied medical services because of their income. Another example of rationing already occurring is called geographic rationing. Regulations that deny the purchase of certain expensive technological equipment for a certain geographic location may deny access to such services to those low income persons who do not have the means to travel distances to receive the treatment.

Under the recently enacted Medicare prospective reimbursement system for hospitals which plans to pay hospitals based on the types of procedures that are performed, rationing becomes a real issue. Another hidden rationing of health care can occur if physicians choose not to accept Medicare assignment. The elderly patient is faced with larger medical bills than are allowable under Medicare if they choose to receive services from a non-participating physician. In another area, some nursing homes now refuse admission if the source of payment is Medicaid, clearly denying access to long term health care for those who cannot afford that care.

#### 3. The Medical Profession and Rationing

There are other less formal, but even more hidden ways that health care is rationed. Physicians are called upon to make decisions as to how aggressively to evaluate a patient's problems and how aggressively to treat them. Such decisions represent the reality that some medical care is available to some and not to others of like circumstances. Furthermore, physicians are indeed "flying by the seat of their pants" because some of the treatment/non-treatment decisions involve complex legal and ethical problems, as well as concepts of social justice and medicine.

#### 4. The Need for Policy Guidelines

So far, we have failed to develop consistent guidelines, standards and procedures for when faced with treatment/non-treatment issues, and to make a decision as to what class of professionals are the proper line-drawers. Doctors by virture of their medical knowledge of the pros and cons of receiving treatment are qualified to have the major input into the line-drawing process but not to answer the question of whether society should allow or disallow a treatment based on allocation of resource factors or based on societal value to a certain quality of life. Public debate on this may be tedious and take long, but it is essential if arbitrariness and discrimination and differing personal, moral and religious values are to be challenged and debated.

The questions we need to be asking are: How can a way be found to develop guidelines, standards and procedures for drawing lines? Who should develop these standards?

#### B. Our Ethical Choices in Dying - Who Decides?

Once we have rules and guidelines for broad categories of patient classifications as to who is entitled to what health care, we still face an additional layer of problems in applying the guidelines to individual patients. Also, the intent of general guidelines cannot be to encompass every conceivable circumstance. We, therefore, are faced with who decides medical treatment in individual cases, particularly in situations of terminal or hopeless illness.

# 1. The Increasing Importance of Decisional Control of Medical Treatment Decisions

Our technological capabilities place us in a new era of doctor/patient relationships. While many patients in debilitated physical or mental conditions or terminal or hopeless illness situations are trying to bring their own personal values and ideas about quality of life to bear on the treatment they want to receive, the health care profession as a whole seems to see no need for change in the way decisions are made. The profession confidently proclaims that at least for competent persons the issue of "who decides?" is well settled both in medical practice and in the law and the rule of patient autonomy and self-determination is alive and well and carefully adhered to by physicians.

#### 2. Patient Self-Determination and the Doctrine of Informed Consent

The law has attempted to deal very concretely with the patient's right to control medical care. Usually a person's right to refuse treatment will be respected by the courts unless contrary to a compelling state interest. Also, the doctrine of informed consent on its face is very straightforward. It is a legal doctrine that requires disclosure by the doctor of information about any given procedure to the patient such that the patient can give his consent to the procedure. We cannot nevertheless be lulled into believing that the practical and legal machinery already exists to

deal with our difficult ethical choices. The doctrine of informed consent will not protect patient self-determination in making treatment decisions in terminally and hopelessly ill situations.

# 3. Patient Self-Determination and Incompetent Patients

When a patient is incompetent and a surrogate decision-maker is involved, the goals of patient self-determination and the necessity of informed consent are not changed. Patient self-determination is even more essential because many of the situations where patients are incompetent involve terminal or hopeless illness and/or very debilitated patients. At this point where the ethical choices become most critical patient self-determination becomes both more difficult to carry out and to assure.

Parties have frequently turned to the courts when there is disagreement on a life and death decision among guardians, families and doctors and health care institutions. In general the health care system does not want to have to resort to slow, painstaking and sometimes ineffective court procedures to resolve differences of opinion. Many advocates do not want to leave resolution of disputes to the medical profession itself including its "ethics" committees which cannot be guaranteed to be free of self-interest in protecting the medical sphere from outside interference. Some combination of approaches that allows us to remain true to the values of self-determination and the rights, best interests and personal preferences of the patient is essential.

The most widely touted mechanism for expressing preferences for treatment during terminal illness is the so-called "natural death These statutes provide for the execution of some kind of advance directive to the physician, as a means of trying to preserve self-determination for patients who may lose their decision making capacity. A living will is another type of patient-initiated advance directive. Whether the directive must follow a particular format laid out in a statute or is a typical living will, where the language is more the patient's own, all these advance directives are formal written authorizations to health care professionals to withhold or withdraw life-sustaining medical treatment from an adult patient with a terminal condition. Legislation simply gives the document legal effect and requires a physician to abide by the patient's wishes if expressed in a properly executed document. vance directive legislation has been legislatively sanctioned in many different states under names such as Natural Death Act, Right to Treatment Act, Rights of the Terminally Ill. A model uniform law on advance directives has been recently adopted by the National Conference on Uniform State Laws.

There are other mechanisms for patient-initiated advance directives to physicians. One is the durable power of attorney for medical decision-making. Many states have general durable power of attorney statutes, including Maine. Advocates of advance directives have argued that this statute can apply to decisions regarding health care as well.

The perfect mechanism seems not to exist. Opponents charge that the confusion and vagueness that surrounds definitions of "terminal condition", "life-sustaining procedures", "extraordinary treatment", and "imminent death", forces a conclusion that advance directive legislation is inherently unsound. They also argue that statutes do not contain enough protections for terminally ill patients. Patients may not make the same decision about withholding or withdrawing treatment when faced with death as they might in a more healthy state. Physicians argue that they are not adequately protected from lawsuits for complying with a patient's wishes. They also argue that advance directive legislation could make it risky to exercise proper discretion and withdraw or withhold treatment from an incompetent person unable to state his own preferences who had not issued an advance directive.

Proponents say that, if we do not choose to direct our care in the event of incompetence, legislation recognizing the validity and binding nature of advance directives or proxy does not force us to do so. Such a procedure is entirely voluntary.

There is enormous controversy over the concepts of advance directives and proxy designations. On the other hand, such patient directives are the only available mechanisms we have. Despite their inperfections, they provide some measure of protection.

#### Conclusion

The issues that have been presented here are complex, difficult and semmingly impossibly interwoven. We need to debate the parameters, if any, of our rights to health care. The ethical choices in dying evoke emotional and psychological responses in professional and lay people alike that complicate the process of determining answers. But we must have public debate, informed input and development of uniform standards to assist medicine, law, families, and surrogate decision-makers in their difficult choices. We must debate the need to reaffirm patient self-determination and explore ways to assure this precious principle. Self-determination is nowhere more important than in health care, and the personal control that all of us wish to assert in our own processes of dying.

## Improving Housing and Home Care Options

Chairs: Fr. Valmont Gilbert, Maine Committee on Aging

Louise White, Maine Committee on Aging

Resource People: Barbara Alexander, Esq.

Cheryl Ciechomski, Patient Care of Northern

New England

Don Hoxie, Bureau of Health

Amox Orcutt, Farmers Home Administration Catherine Cobb, Bureau of Medical Services

Staff: Anne Gardner, Bureau of Maine's Elderly

Delegates:

Evelyn Sapiel Lucille Kelley

Mickey Friedman Geneva Kirk

Marjorie Bither Jude Walsh

Beulah Bean Kaye Flanagan

Christine Boisvert Marilyn Paige

Margaret Fournier Laurence Gross

Kathy Goodwin Adams Phyllis Gray

Tom Endres Ed Ciampa

Anne Pringle Clair Lewis

Waldo Gilpatrick Mary Jane Cleveland

Maxine Boure Emily Pratt

Margaret Mortenson Donald Kenney

Hilton Power Louise Kenney

Eunice Crowley Madeleine Freeman

Hope Richardson Roger Higgins

Raymond Thuotte Isabelle Morrison

Lew O'Brien Doris Fowle

Janet Kimball

Mary Hardy

#### Abstract of Workshop Paper on

Improving Housing and Home Care Options

(Copies of full text are available from the Maine Center on Aging)

In recent years Maine has developed several programs whose aim is to assure appropriate care and protection to those elderly who are the most vulnerable, both in terms of the services they require and in terms of the limitations imposed by their fixed or dwindling incomes. A component crucial to the success of all these programs is the housing in which the elderly are living. It is this component, that we address in four different ways today.

# I. Home Equity Conversion Sale/Leaseback

In October, 1982, the Department of Human Services, Bureau of Maine's Elderly in conjunction with a Maine Home Equity Conversion Task Force was granted \$152,000 by the Department of Health and Human Services to develop a variety of home equity conversion plans to aid elderly people faced with loss of home ownership and possibly inappropriate placement in institutional settings.

Older people in Maine own nearly \$3 billion of home equity, most free of any mortgage. Many want to remain in the homes they own, but find themselves cash poor and often unable to afford taxes, insurance, home maintenance and other costs. The Elderly Householders Tax and Rent Refund Program serves only a small portion of the elderly and then only with a refund up to \$400/year.

Of several alternatives for equity conversion developed and evaluated by the task force, the sale/leaseback is the arrangement which seems to hold the most immediate promise. It is a transaction in which a homeowner can sell his/her home to a buyer in exchange for payment and the opportunity to become a tenant in that house (i.e. to sell and lease back residency). The buyer generally makes an initial downpayment and the remainder of the purchase price is paid to the seller in monthly installments over a period of time (e.g. 15 years). The older homeowner is then responsible for taxes, insurance and home maintenance costs. The seller/tenant transfers title in exchange for the right to rent back the house, usually for her lifetime.

This is not a new concept. Sale/leasebacks happen in Maine today. However, there is no protection for the buyer or seller and as the task force heard at consumer forums throughout the state, elderly homeowners have been victimized by sale/leaseback transactions.

Because no current Maine laws adequately protect either the buyer or the seller in a sale/leaseback transaction, the Home Equity Conversion Task Force drafted legislation to remedy the lack of protection in such transactions.

## The Residential Sale/Leaseback Statute

The draft legislation establishes minimum standards for all residential sale/leaseback transactions in Maine. It has the dual purpose of providing a blueprint for parties entering into the transaction and providing a framework against which conflicting interests may be weighed in the event of a breakdown in the agreement. The bill requires the buyer or the seller to disclose specific information including:

- The terms of the lease and process for exercising any renewal.
- · The down payment, sale price, and how it is to be paid.
- The amount of the monthly rent payment and the conditions, if any, under which that amount may be increased or decreased.
- · Responsibilities for taxes, insurance, maintenance, etc.

In addition to these disclosures the draft statute

- Provides a 20 day period during which either party may cancel the agreement of sale.
- Requires that the sale/leaseback agreement contains a
  warning regarding failure to provide for the purchase
  of an annuity as a means of protecting the future financial
  stability of the transaction.
- Requires that the lease be recorded prior to the deed and any mortgage as a means of protecting the life residency of the seller's leasehold interest.
- Provides for enforcement of the bill through private right of action or the Attorney General's Office pursuant to the Unfair Trade Practices Act, without creating any new bureaucracy.
- Requires that the sale/leaseback agreement contain a warning to the parties regarding the need to seek out comprehensive counseling services before finalizing a residential sale/ leaseback transaction.

QUESTION: Is such legislation necessary? If so, what should it include?

#### H. Long Term Care and Housing

In 1981 Maine recognized the inequity of funding for home and community-based services as compared to institutional services and the Legislature enacted An Act to Require the Department of Human Services to Provide Home Based Care As An Alternative to Nursing Home Care (hereafter referred to as the Home Based Care Program). The law and its corresponding biannual appropriation of \$1,080,625 for services to elderly clients provided state funding to assist individuals eligible for or at risk of institutionalization in nursing or boarding homes to be served in their homes and communities with the provision of needed services.

The Home Based Care Program, a 100% State funded program, was sufficiently successful in its first year to warrant continuation by Maine's Legislature with a substantially increased appropriation of \$3,370,315 for the FY 84-85 biennium. There is also potential for even more clients to be served in their homes should Maine's application for a Medicaid Waiver be approved.

In addition, in October 1983, as a result of the Act to License Home Health Care Services, Commissioner of Human Services Michael R. Petit formed the Home and Long Term Care Committee. A policy statement was translated into a Bill of Rights for Home and Long Term Care. A draft of the proposed Home and Long Term Care Bill of Rights follows. Some questions or issues that arise include:

- 1. Do you feel that this Bill of Rights will be a useful consumer tool?
- 2. How should this Bill of Rights be distributed? Should this distribution be mandatory?
- 3. What do you think should happen if a person's rights are violated?
- 4. Do you believe that having a Bill of Rights for Home Care will help to ensure quality care?
- 5. Are there responsibilities that go hand in hand with those rights?

#### Home Care

#### Bill of Rights

# Introduction

You have chosen to remain at home in spite of frailities or difficulties that mean you will need help with some of the activities you would ordinarily do yourself. You are in familiar surroundings, living in the environment of your choice.

Home and long term care is defined as one or more services provided in the home on a sustained or intermittent basis to enable individuals, whose functional capacities are impaired, to be maintained at their maximum levels of psychological and physical well being. Such care should include services that promote, restore, maintain or minimize the effects of illness and/or disability.

Workers from home and long term care services that come into your home will do all that they can to honor your decision to stay at home and your desire to make decisions for yourself. There are times when a person has a legal guardian. If you have a legal guardian, the guardian may help with decisions or make decisions depending on the court's decision about your care and/or give permission to release information.

A great deal has been written about the Rights of patients in hospitals and of clients in nursing homes. Following is a list of Rights for persons who are receiving care from home and long-term care providers. While the following rights apply to all types of setting for care, hospital, nursing home or your home, Rights for home care have never been specifically highlighted. The rights that you have in your home are the same as those in an institution. These Rights will tell you what is due you when services are provided.

You never have to give up your rights. When you exercise one of your rights, it should be with consideration of other people's Rights.

You, the client, have the right to the following:

- · Considerate and respectful care
- Request and receive information about your health and social service status by those who care for you, in language that you will understand
- · Participate in the planning of your care at home
- · Accept or decline services, to the extent permitted by law, and to be informed of the probable effects of these actions
- · Be informed of the home and social services available to them
- Receive quality services
- · Live and die with dignity
- · Refuse to participate in surveys, studies and/or experiments
- · Look at your health and social service record
- Expect that all communications and records pertaining to your care will be treated as confidential
- Tell the people caring for you about any problem, complaint or suggestion you may have
- Know what services will be provided, how much they will cost and who will pay for the services.
- Be free from unlawful restraint, from abuse, from scolding and from punishment during your care
- Examine and receive explanation of your bill or statement of services regardless of the source of payment.

# Responsibilities

In accepting home care services:

- It is reasonable for the home care agency to expect that you will cooperate in carrying out the plan of care in which you have participated including payment, medical treatments, activities and other items listed on your plan and otherwise make a reasonable use of resources allocated to you.

#### WHERE TO GET MORE INFORMATION OR HELP

Throughout the system of federal, state and private programs through which you are being helped to stay at home, there are individuals and organizations from whom you can request information or help with a difficult situation. We suggest starting with one of the following:

Home Care Director of your Area Agency on Aging

Adult Protective Services

Bureau of Maine's Elderly

Maine Committee on Aging

Legal Services for the Elderly, Inc.

(all of the above will have addresses and telephone numbers and a brief explanation of the agency)

# [II. <u>EATING AND LODGING PLACES</u> - An Alternative Housing Option or Unlicensed Boarding Homes?

In May of 1983, the Maine Committee on Aging convened a task force to examine eating and lodging places with long term residents.

# Initial Concerns of the Eating and Lodging Task Force:

- The Nursing and Boarding Home Ombudsman Program has on occasion received complaints from or on behalf of people living in facilities licensed as eating and lodging places. The Ombudsman Program has no statutory authority to investigate such complaints.
- 2. Some facilities which failed to receive a license to operate as a boarding or nursing home because of physical plant, budgetary or other limitation have been able to receive a license and operate as an eating and lodging place.
- 3. Eating and Lodging Facilities offer a homelike environment with meals for many older people who can no longer remain in their own homes or apartments but who do not need the type of assistance in daily living or supervision that is available in a boarding home. However, some current residents of eating and lodging facilities may require a level of care the facility cannot provide.
- 4. Some eating and lodging facilities are operating beyond their licenses by administering medications.

# Activities of the Eating and Lodging Task Force:

- 1. Identified 38 licensed eating and lodging places out of the 400 in Maine as having long term residents.
- 2. Worked with the Fire Marshall's Office and Division of Health Engineering to strengthen the fire safety regulations.
- 3. Conducted a survey of thirty-two owners of eating and lodging facilities with long term residents and of ninty-one residents of these facilities. Some preliminary findings include:
  - -52% of the residents are over the age of 75 and 66% are over the age of 54.
  - -13 of the 32 facilities indicated that they administer medications for some of their residents.
  - -Over half of the residents had lived in their eating and lodging residence for a year or less although 5% had lived there for 15 or more years and 35% had lived there for between two and three years.

# Questions Before the Blaine House Conference:

- 1. Should there be a separate licensing category for eating and lodging places with long term residents?
- 2. Who should have jurisdiction over such facilities within the Department of Human Services, the Bureau of Medical Services, Division of Residential Services or the Bureau of Health's Division of Health Engineering.
- 3. Should the Nursing and Boarding Home Ombudsman's Program enabling statute be amended to broaden it's scope to include eating and lodging facilities?

4. Should a program be undertaken and by whom to educate eating and lodging owners about community resources available to assist them in assessing the care needs of their residents.

# IV. State Funded Rental Assistance Program for Elderly and Congregate Housing Financed by the Farmers Home Administration

While in recent years most of the traditional federal housing programs for the elderly have been eliminated or severely reduced, the Farmers Home Administration continues to offer one percent mortgage financing for housing developments for the elderly. In the past, Farmers Home Administration combined its one percent mortgage financing program with a rental assistance program so that tenants paid only 25%-30% of their income, not the full \$325 for rent.

Because of federal cut backs few new Farmers Home Administration projects in Maine subsidize tentant's rents. It has been proposed that Maine fund a state rental assistance program for Farmers Home Administration elderly and congregate housing projects for the low income.

Each project would be approximately 24 units in size and cost approximately \$1.1 million to construct, to be financed by Farmers Home Administration. As a condition of granting a loan, Farmers Home Administration would accept a State form of rental assistance for the benefit of the tenants in the project provided the following conditions could be met:

- A. The State of Maine would invest a principal amount of approximately \$500,000 which would generate interest income to fund 24 rental assistance (RA) units (a typical project) for a period of 20 years. Development of four to six projects would mean an initial state investment of up to \$3 million.
- B. The funds invested and earnings therefrom must be sufficient to pay out the expected amount needed without depleting the principal amount which would be returned to the State of Maine at the end of the 20-year period.
- C. The mechanics of the monthly subsidy would be administered consistent with the present Farmers Home Administration Rental Assistance Program.
- D. The selection of who would receive the projects subsidized by the State would be similar to the previous successful State of Maine Congregate Demonstration Program review process.

The obvious advantage to the State would be that Federal funds would be utilized to construct modern new congregate facilities in areas that otherwise could not afford such a facility.

QUESTION: Should the State enact a state rental assistance program for Farmers Home Administration elderly and congregate housing projects for individuals of low income.

# Guardianship: Protecting the Elderly or Taking Away Their Legal Rights?

Chair: Norman Hall, Maine Committee on Aging

Resource People: Thomas Bancroft, Dept. of Human Services

Ellen Kandoian, Esq. Univ. of Me. Law School Christopher Leighton, Assistant Attorney General

Hon. James E. Mitchell, Probate Judge

Neville Woodruff, Esq., Legal Services for the

Elderly

Staff: Tim Vogel, Legal Services for the Elderly

Delegates:

Mary Lee Fowler William Ard

Joyce Saldivar Fred Sterns

Kathy Valcourt Danial Hickey

Will Callendar Ruth Eaton

Donna Grant Susan DeRose

Susan Ainslie Selma Black

Gary Remal Susan Eldridge

Karen Gershman Stephen Simonds

Pam Allen David Howe

Louise Murchison Frema Grant

Helen Burney William McKeagney

George Catterson Edna Chandler

Mickey Friedman Mickey O'Malley

Don Lambert

Gerald McGilvery

Marion Collins

Beulah Bean

Irene Lindsay

#### Abstract of Workshop Paper on

Issues in Guardianship
Protecting Elderly or Taking Away Their Legal Rights?

(Copies of full text are available from the Maine Committee on Aging)

#### Introduction

Many elders assume that some day they will need to be placed under guardianship; dutiful children assume at some point a responsibility to become guardians. The self-concept of older persons and society's view of the elderly are epitomized by the functioning of the State's guardianship laws.

The infringements on the rights of the person made a ward are considerable. A quardian is charged with taking care of the ward's clothing, furniture, vehicles and personal effects; generally has the power to consent to treatment of the ward; is responsible for giving approval for the provision of professional services; can sign whatever releases may be required for the ward's treatment and consequently invade the ward's right of privacy in profound ways; may compel support from those with a duty toward the ward; is charged with the responsibility of conserving all of the ward's estate which is not required to meet his or her present needs; and must report on the ward's condition as required by the court. Simultaneously, the ward loses his or her right to marry, to enter contracts, to make gifts, to sell property, to choose his or her own clothing, furnishings, personal effects and, most critically, place of abode. Indeed, it is this last right which is probably at the heart of most disputes over the imposition of a quardianship. A quardian may place his or her ward in a nursing home despite the well-founded and vehement objections of the ward.

Despite the fact that Maine recently revised its guardianship laws, there is little evidence that they are being utilized specifically to enlarge protections for the ward and to avoid unnecessary restrictions on the exercise of his or her rights.

#### Least Restrictive Alternative

Maine's guardianship law implicitly accepts the philosophy of "least restrictive alternative." Adult Protective Services (DHS) articulates the principle as the core of its public charge. Although this philosophy is seldom used in the private guardianship context, it is the basis of APS policy for the conduct of its public guardianship function.

While APS can carefully consider the needs of its clients for varying levels of protective services, the much more common private quardianship (97% of the total) is implemented without strict regard

to a philosophy and without access to the full range of professional resources available to APS. The overwhelming majority of doctors, discharge planners, social workers and others who may be involved at initial states of inquiry know little or nothing about alternatives less restrictive than guardianship. In fact, the overwhelming majority of persons who become guardians are untrained in the social sciences or, more specifically, as caregivers or decisionmakers.

### Participation In The Probate Hearing

The second issue for consideration is involvement of the potential ward and others in the process of determining whether or not a guardianship is necessary. Current law (at 18-A M.R.S.A. §5-303(b) allows for the participation of a visitor, an attorney and the ward, but such participation is not required.

While the extent of participation in the guardianship process by concerned others has not been documented, observers agree that the ward seldom appears and that he or she is seldom represented. In general guardianship "hearings" are not hearings at all but rather the ratification of legal papers which have been properly prepared and filed.

Elderly advocates believe the prospective ward should participate in the proceeding unless a physician documents that participation would be seriously detrimental to the health and well-being of his or her patient. The ward's participation should be secured even in those cases where the ward does not wish to participate in or contest the guardianship because it is imperative, for the future, that the ward understands the nature of the protective arrangement which is being designed for his or her benefit.

Regardless of the ward's participation at the hearing, there must be other third parties involved in order to make the hearing process meaningful and to assure a thorough inquiry into the nature and extent of incapacity such that unnecessary and/or excessively restrictive protective arrangements are not granted.

The statute allows for a person to choose a lawyer to represent him. Again, in most cases, this does not happen. Not only does the potential ward not participate in the hearing but he does not have an attorney at the hearing to advocate on his behalf.

Other potential actors in guardianship proceedings are guardians ad litem and visitors. The guardian ad litem is a person who may be appointed by the court upon the filing of a guardianship petition to

represent the potential ward in the proceeding, unless the latter has his or her own counsel. Given that a guardian ad litem need not be an attorney, it is clear that a potential ward may be without representation of his own interests and that the court will not decide the case after hearing two adversarial views. A visitor, if appointed, is the eyes and ears of the court and should provide it a thorough evaluation of the prospective ward's present and contemplated living circumstances.

It is very unclear what the relationships and overlapping functions among attorneys, guardians ad litem and visitors are. What is clear are the functions that need to occur. Both sides of every story must be put before the court as much in a protective proceeding as in any other. Regardless of the fact that most people who petition the court to be named guardians are well—intentioned, a guardianship, by its terms, deprives the ward of almost all of his civil rights. For that reason, full consideration of the points of view of both the potential ward and the petitioner and the evidence of incapacity, are essential to the court. If the petitioner can be assured of having his views and evidence presented by a lawyer, the ward requires and deserves the same protection. Additional costs should not be allowed to be posed as barriers to this process.

#### Due Process Concerns

Current Maine probate procedure calls for service of the petition for guardianship "in hand" upon the alleged incapacitated person in order to commence the guardianship process. This is the only notice which the person must receive. At present, the notice is a "General Notice of Beginning of a Formal Probate Proceeding," the same notice used for all proceedings in that court. It does not tell the prospective ward that a guardianship is being sought, the potential curtailment of rights which might be involved, appropriate steps which might be taken to contest or question the guardianship or where the ward might intelligently look for legal or other assistance.

No standard of proof is currently specified for a finding of incapacity and the appropriateness of appointing of a guardian. Because institutionalization is a potential consequence of a guardian-ship, it is suggested that proof be "beyond a reasonable doubt" or at least the somewhat lesser standard of "clear and convincing evidence."

Finally, although present laws give the probate courts authority to obtain status reports on the ward's well-being and financial

condition, those reports are not routinely requested. An annual report on the ward's current living status, of treatment, exercise of limited rights and current financial situation should be submitted on an annual basis, automatically. It could provide the basis for terminating guardianships which are no longer needed and, in some cases, for making a change of the guardian or in the ward's current place of abode.

A guardianship should only be imposed following a finding of functional incapacity. A physician's statement usually forms the basis of a finding of incapacity but often such evaluations are not based on meaningful and current information about the prospective ward's condition. A finding of functional incapacity must reflect specific findings with respect to the prospective ward's mental status, self-care abilities and current level of physical functioning. Focus on only one of these elements should not be deemed sufficient for the imposition of a guardianship. A conclusory statement by a physician that a person is incapacitated and unable to care for him or her self should likewise be deemed unacceptable.

#### Questions

- 1. Should the Maine Probate Code be amended to require broadened participation by alleged incapacitated persons and attorneys acting on their behalf in guardianship proceedings? Should a visitor be appointed in every case?
- 2. Should a mechanism be adopted for assuring that all appropriate considerations of less restrictive alternatives have taken place as part of the probate proceeding?
- 3. Should due process protections relating to notice, burden of proof, standard of incapacity and regular reports on the status of the ward be strengthened in the Maine Probate Code?
- 4. Should these issues be presented to the public at large? If so, what are appropriate ways for presenting them?

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STATEMENTS OF SPEAKERS

# BLAINE HOUSE CONFERENCE ON AGING SEPTEMBER 19, 1984

# WELCOMING REMARKS

# Margaret Russell, Chair Maine Committee on Aging

I AM MARGARET RUSSELL, CHAIR, OF THE MAINE COMMITTEE ON AGING FROM AUGUSTA, MAINE. I AM PLEASED TO SHARE THE CHAIR RESPONSIBILITIES WITH TRISH RILFY, DIRECTOR OF THE BUREAU OF MAINE'S ELDERLY. ON OUR JOINT BEHALF, I WELCOME YOU ALL TO THE 9TH BLAINE HOUSE CONFERENCE ON AGING. THE MAINE COMMITTEE ON AGING IS PLEASED TO WELCOME NEW DELEGATES TO THE BLAINE HOUSE CONFERENCE ON AGING AND DELIGHTED TO SEE RETURNING DELEGATES. WE ARE PLEASED TO HAVE I NURSING AND 4 BOARDING HOME RESIDENTS IN ATTENDANCE THIS YEAR, AS WELL AS ELDERLY WHO RECEIVE LONG TERM CARE SERVICES IN THEIR HOMES. WE WOULD LIKE TO RECOGNIZE GEORGE CATTERSON AND RUBY YOUNG FROM WALRIC ESTATES BOARDING HOME, IRBY DAVENPORT AND MARGARET BLACK FROM GILBERTS BOARDING HOME AND JIM BUCHAN FROM WILLIAMS MURSING HOME.

This year's Blaine House Conference on Aging will have a total of seven (7) workshops which will deal with a wide variety of topics.

You all have received a summary of the workshops in your package. I would like to expand on that information at this time.

THE FIRST WORKSHOP WILL ADDRESS THE "EFFECTS OF DRG'S (DIAGNOSTIC RELATED GROUPS) ON THE QUALITY OF HEALTH CARE."

LAST YEAR CONGRESS APPROVED A MAJOR CHANGE IN MEDICARE BY CHANGING THE METHOD OF PAYMENT TO HOSPITALS. THE EFFECT THAT THIS NEW HOSPITAL PAYMENT SYSTEM WILL HAVE ON THE QUALITY OF HEALTH CARE FOR THE ELDERLY WILL BE EXAMINED.

Medicare supplemental insurance is confusing to the elderly consumer as well as being unsatisfactory in providing needed health coverage. Abusive sales practices continue to adversely affect Maine's elderly citizens with the result being duplicate and unnecessary coverage being bought by numerous elderly consumers. A workshop entitled "Medicare Supplemental Insurance:

Too much or Too Little?" will focus on ways to deal with this consumer problem.

In many instances elderly people who are receiving Medicald are not allowed admission to nursing homes simply because they receive Medicaid. A workshop to address "Access to Nursing Home Care for Medicaid Eligible Consumers" will explore ways that access to needed nursing home care can be assured.

The fourth workshop, "Increasing Employment Opportunities

FOR OLDER Workers" WILL FOCUS ON THE ROLE OF GOVERNMENT, EMPLOYERS,

EMPLOYEES AND UNIONS IN INCREASING THE KIND AND NUMBER OF WORK

OPPORTUNITIES FOR OLDER WORKERS.

A VERY COMPLICATED AND PROBABLY CONTROVERSIAL WORKSHOP WILL BE DEALING WITH "RIGHT TO MEDICAL TREATMENT/RIGHT TO REFUSE MEDICAL TREATMENT," A DIFFICULT YET VITAL ISSUE FOR OUR DISCUSSION. Some of the QUESTIONS THAT ARE BEING POSED TO THIS WORKSHOP INCLUDE: WHO WILL RECEIVE HEALTH CARE? WHEN SHOULD LIFE SUPPORT SYSTEMS BE USED AND/OR WITHDRAWN? WHO SHOULD DE-

CIDE WHEN ARTIFICIAL LIFE SUPPORTS CAN BE STOPPED? THE PURPOSE OF THIS WORKSHOP IS NOT NECESSARILY TO ANSWER THESE COMPLEX QUESTIONS DEFINITIVELY BUT TO BEGIN THE DIALOGUE THAT MUST TAKE PLACE IN MAINE ON THESE DIFFICULT QUESTIONS.

THE "IMPROVING HOUSING AND HOME CARE OPTIONS" WORKSHOP
WILL DEAL WITH FOUR ISSUES RELATING TO HOUSING AND HOME CARE
INCLUDING (1) PROTECTION IN SALE/LEASE-BACK TRANSACTIONS
(2) NEED FOR A HOME CARE BILL OF RIGHTS (3) STATUS OF EATING
AND LODGING ESTABLISHMENTS AND (4) STATE FUNDED RENTAL ASSISTANCE.

The seventh and final workshop will examine "Guardianship:

Protecting the Elderly or Taking Away Their Legal Rights."

Guardianship is the legal term for a situation where an individual can have rights taken away if they are determined to be incapable of handling their own affairs. The seriousness of the loss of rights, the abuse that can occur if an inappropriate guardian is named, and the need for protection that a guardianship can afford will be debated.

THESE ARE IMPORTANT ISSUES AND WE HOPE WE HAVE PROVIDED YOU WITH STARTING POINTS AND INFORMATION FOR YOUR DISCUSSIONS TODAY IN THE WORKSHOP PAPERS WHICH WERE FORWARDED TO YOU ALL.

WE LOOK TO YOU FOR YOUR IDEAS, YOUR IMPRESSIONS AND MOST IMPORTANT, YOUR COMMITTMENT TO THE DEVELOPMENT OF CREATIVE RESOLUTIONS TO THE PROBLEMS THAT FACE MAINE'S OLDER PEOPLE. LET US REMEMBER THAT WE ARE NOT HERE FOR OURSELVES BUT TO REPRESENT AS BEST WE CAN THE INTERESTS OF THOSE UNABLE TO BE HERE.

AT THIS TIME, I WOULD LIKE TO ASK MRS. GEORGIA TRUSLOW TO COME TO THE PODIUM.

As many of you know, Dr. John B. Truslow of Biddeford, Maine, served as Chairman of the Maine Committee on Aging from 1980 to 1983, a position that he held at the time of his death. Dr. Truslow was chairman and member of the Southern Maine Senior Citizens Advisory Council from 1978 to 1980, and was a founding member of the Cumberland-York Task Force on Aging and Later Southern Maine Senior Citizens, Inc. Dr. Truslow was an active member of the Maine Committee on Aging, serving on our Technical Review Committee until his appointment in 1980 as chairman of the Maine Committee on Aging.

He served as chairman of the Maine Committee on Aging During some very active legislative years, leading the Committee in our efforts to get passage of a home based care bill to serve those elderly who desire long term care in their own homes. His knowledge of health care issues was invaluable; his commitment to the needs of Maine's elderly was unyielding; his dedication to advocate for those elderly who cannot advocate for themselves was a goal he instilled in us all.

In appreciation of Dr. John Truslow's years of dedicated service to Maine's elderly, for his inspiring leadership and advocacy as chairman of the Maine Committee on Aging, and for his heartfelt concern for and committment to those elderly in greatest need, the Maine Committee on Aging dedicates the 1984 Blaine House Conference on Aging to his memory.

NOW I SHALL TURN THE MEETING OVER TO TRISH RILEY, DIRECTOR OF THE BUREAU OF MAINE'S ELDERLY, WHO WILL TELL YOU ABOUT OUR KEYNOTE SPEAKER TODAY, THE FEDERAL COMMITTEE ON AGING MEETING

THIS EVENING AND EXPLAIN SOME OF THE RULES AND PROCEDURES FOR THIS YEAR'S BLAINE HOUSE CONFERENCE ON AGING.

AGAIN, THANK YOU ALL FOR COMING. I LOOK FORWARD TO A VERY PRODUCTIVE TWO DAYS. Now, AS Dr. Truslow would say - "Carry on:"

# BLAINE HOUSE CONFERENCE ON AGING September 19, 1984

#### KEYNOTE ADDRESS

Elias S. Cohen, Director, Division of Policy and Information
Dissemination, Temple University,
Mid-Atlantic Long Term Care Gerongoloty
Center, Philadelphia, Pennsylvania

The <u>Wall Street Journal</u> of July 30, 1984 carried a frontpage article on the aging population with a headline that read,
together with its subheadlines, "The Oldest Old - Ever more Americans
living into 80's and 90's, causing <u>big problems</u> - The strain on
social services and relatives will rise; Should care be
rationed?" Following the four introductory paragraphs, the first
bold-faced headline reads, "The Problem Group." The article goes
on to say, "Is is these 'oldest old' - often mentally or physically impaired, alone, depressed - who pose the <u>major problems</u>
for the oncoming decades." The language of the paragraph is
all essentially negative - "It is they who will <u>strain</u> the families
with <u>demands</u> for personal care and financial support. It is
they who will require the extra hospital and nursing home beds that
will further burden federal and state budgets." (emphasis supplied)

The article goes on to raise the questions of rationing health care, "'Can we afford the very old?' is becoming a favorite conference topic for doctors, bio-ethicists, and other specialists."

And the article ends with similar negative expressions,

talking about "Sharpened intergenerational conflict ahead as low fertility rates provide fewer working age taxpayers to meet the growing needs of the elderly," or a reiteration of the discussion of "rationing health care to the very old: no kidney dialysis or liver transplants after 55, for example."

The Wall Street Journal is not entirely alone by any means.

There is scarcely a week that goes by that one cannot read in USA Today, The New York Times, The Washington Post or for that matter the Johnstown Tribune Democrat or the Harrisburg Patriot, articles headlined, "The old folks at home - economizers talk about keeping them there" or \$85 billion by 2000 - Costs to zoom for 'oldest old,'" or simply, "What's ahead for the elderly."

What is important about these articles in the context of these remarks is not that we are arriving at some general understanding of the implications of demographic changes for service configurations, public budgets or training needs, but rather that they signal changes in perceptiins about the elderly.

My major thesis is that the rights of any group are a function of how that group is perceived by the majority. Perception of a minority is multi-dimensional, taking into account perceptions of power, of competition, of threat to or support for cherished values or a stable order, as well as perceptions of the utility or disutility of the group to the rest of society.

Perceptions are also a function of the ongoing dialectic that continually redefines human relationships, rights, duties and

obligations. It is the ongoing dialectic that leads to redefinition of the ethical underpinnings that always precede the definition of the rights and benefits conferred through both public and private decision making.

When black people were perceived as property, they had few enforceable rights. Even following the enactment of the 13th, 14th and 15th amendments to the Constitution, the perceptions of blacks as somehow legally different affected their rights.

"Separate, but equal" reflected a perception of a legal difference between blacks and whites - a difference which was to persist until Brown v. Board of Education enunciated a new rule both reflecting and laying the groundwork for new perceptions. It was a beginning of a new perception, and the beginning of a range of new effective rights.

At a time when women were perceived as legally different from men, American society sought to "protect" women from work at night, work in bars, "heavy work," men's work, excess overtime, and other situations. This did not change with the enactment of the 19th amendment to the U.S. Constitution granting women the vote. And the perception of women has not yet changed to the point where the U.S. Supreme Court is prepared to say that classifications based upon sex are as suspect as those based upon race, color, or national origin.

But there is no doubt that perceptions of minorities and women <a href="have">have</a> changed. The changes in access to public and private benefits which have accrued to racial minorities and women are, in my opinion, a function of the changes in the perception of

those racial minorities and women by majority groups. For the most part, the changes in perception have been those which have affected issues of equity, fairness, justice and compassion.

If this is so for women and racial minorities, I believe that the principles are the same for the elderly. And indeed there have been enormous changes in the space of a half century reflecting changes in perception. Since the passage of the Social Security Act almost 50 years ago, we have seen a veritable revolution in not only the <u>nature and substance</u> of benefits for the elderly, but also, and perhaps at least as important, what those benefits reflect. In an earlier time, the elderly, particularly the poor and infirm, were given benefits in the poorhouse along with idiots, lunatics, cripples and other sub-categories not so much as <u>human</u> beings as living beings.

The list of benefits now available includes such things as cash assistance for the poor - as opposed to in-kind or voucher assistance; unrestricted cash grants as opposed to restricted cash grants only good for those items some state or local bureaucrat declared were okay for older people to purchase; the elimination of indoor relief - the poor house - as the dominant mode of income relief; a retirement income program; medical case; a wide array of social services; housing assistance in a variety of forms; new sets of mental health services; surplus commodities distribution and subsequently food stamps; transportation assistance; educational and recreational services. Indeed the array is so broad that it defies coordination, "one-stop service centers," effective case management, and rational funding arrangements.

I should add parenthetically that that's not a bad problem to have to confront. These changes could not have occurred without changed perceptions.

The changes in the perceptions of the eldery fall roughly into three periods.

The first period comprises the first 160 years of our history as a nation. The pre-1935 perception of the elderly was an inheritance from colonial times, and persisted through the agricultural development and industrial revolution - a trend that lasted so long as we had a frontier, and 40 years beyond.

Like orphans, victims of Indian massacres, famine, drought, as well as visitations by the deity which left some deformed, deranged, or deficient, the elderly were perceived as objects of charity - particularly if they were ill, alone, poor and feeble.

Between 1935 and 1960 a new perception was born. In some ways this was a transitional perception which mixed the notions of charity with the notions of equity as well as notions of economics. It was the Social Security Act which made monumental conceptual leaps - the first of which was that poor people were people like other folks, except that they had less money. People, it was reasoned, didn't lose their brains when they lost their money. They could make spending decisions on their own. This resulted in the unrestricted cash grant. The Social Security Act said that old people who were poor could and should live in their own homes in their own communities making their own decisions rather than being herded into almshouses, work houses or poor houses, where they, together with other flotsam and jetsam of society, would be

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fed, watered, and bedded down. This was a transitional period in which some rights to services for health care began to be articulated and where the intellectual foundations for the right to health services were beginning to be laid.

It was in the 1960's, however, that what I might call the ethical age begins. For it was in the 1960's that the Congress enacted, in response to enormous political and moral pressures, medical assistance for the aged - the precursor to Medicaid and Medicare; and Congress enacted the Older Americans Act, significant extension in the National Housing Act, and the Social Service Amendments to the Social Security Act - which in their earliest iteration were remarkable for the breadth of the population on whom they conferred benefits. Imagine, an open-end appropriation to pay for social services to help those who had been recipients of public assistance, those who were currently recipients of public assistance, and those likely to become recipients of public assistance. Furthermore, recognizing the precarious financial circumstances of the majority of America's elderly, the elderly were be definition brought within the ambit of social services designed to ameliorate the worst impacts of poverty, ill health, family disruption, or other social change adversely affecting older people.

Between the mid-60's and the present time, perceptions of older people have changed substantially.

They are not perceived as objects of charity.

They are not perceived as useless.

They are not perceived as being without economic power or an

effective voice in the marketplace.

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They are not perceived as being uniformly without vigor, energy or capability.

This is cue in no small part to the work that State Units and Area Agencies and their precedessors have accomplished over the last 20 years. It is reflected in some of the first tentative beginnings around eliminating age discrimination - something that would have been utterly unthinkable 50 years ago - or for that matter, 25 years ago.

And that brings me to my second premise: Rights and their exercise are a function at any given point in time of how a system operates, rather than what the official declarations are relative to those rights.

It was insufficient to adopt the 13th, 14th, 15th and 19th amendments to guarantee racial minorities and women basic legal rights. The social system didn't operate in accord with those fine Constitutional declarations. Society was building slowly to a new mode - a new mode that found articulation in the visions and force of John Kennedy, Martin Luther King, Adam Clayton Powell, Hubert Humphrey, and others, erupting in the adoption of the Civil Rights Act of 1964 and a new set of operating rules and procedures which quickly became the norm.

The post-1935 era and the era from the 60's to the present have been periods of enormous progress. The next quarter century may not continue that progress. Indeed, if there is, in fact, a change in perception of the elderly, that may portend a radical change in the perception of the rights of older people

and how those rights are realized. If, as the <u>Wall Street Journal</u> article suggests, older people are perceived as a <u>problem</u>, then ethical considerations dealing with autonomy, distributive justice, beneficence and nonmaleficence, fairness and justice will fade in the face of what are articulated as pragmatic utilitarian imperatives.

Already, we have Governor Lamm declaring publicly what many believed - that old people should get out of the way for young people. What is scariest is not that this is going to be shoved down the throats of old people, but rather that old people will buy into it in a new elderly mystique and that they will march to the ice floes on their own accord, not driven or forced by others.

In 1963, Betty Friedan stirred America with her remarkable analysis of the American Woman. She argued that in the forties, women withdrew from opportunities for self-realization and full participation in society - opportunities that had been hard won - privileges to vote, participate politically, work at a wide variety of occupations - they withdrew and viewed themselves in terms of more traditional, sexual, child-brering, housewifely functions, and they subordinated their lives to family, home, consumption, glamour and sex, abandoning the quest for fuller identity and self-realization. But contentment and happiness did not ensue from the buy-in to this insidious mystique.

The perception of the elderly as a problem, and the adoption of that perception by the elderly in an elderly mystique can only lad to the abandonment of the quest for full participation, growth and continued self-realization throughout the lifespan.

In 1965, Rosalie Rosenfelt wrote about the consequences of belief in the elderly mystique as follows:

As with the feminine mystique, acceptance of so limited and limiting a view ends by not only blinding its holders to the full range of possibilities available to them, but also by deforming them in conformity with its warped image that they become as restricted as the mystique would have them. A vicious circle is set in motion. There is no hope in old age, and those who grow old are quite hopeless. That, in essence, is the elderly mystique.

The position articulated by Governor Lamm is not outrageous for its literal meaning - although it is surely obscene. It is outrageous and dangerous because it may find supporters among the elderly. It is the elderly mystique taken to its ultimate logic.

I am no doctrinaire right-to-lifer. Nonetheless, I am dismayed by the increasing willingness of judges, lawyers, legal scholars and others who are ready to find ways for third parties to make life and death decisions about prolonging or ending life under this or that circumstance, or for that matter, of justifying murder when it is a "mercy killing." If war is too important to be left to the generals, then for heaven sake, the rights of the elderly are certainly too important to be left to the lawyers and judges.

The perception of the very old as a <u>problem</u> is perhaps the first step in the dehuamnization of one set of the older people.

And it is dehumanization which can and will strip older people of not only fundamental rights, but also of those most newly won rights which recognize our human qualities as opposed to those which regard us simply as living organisms.

I want to devote the remainder of my time to an exploration with you of a conceptualization of the rights of the elderly and finally the broad tasks that lie before us in assuring the opportunity for the elderly to exercise these rights.

First, let me m ke clear that when I talk about rights,
I am talking about thoseentitlements which can be guaranteed
through the use of legal sanctions available through the justice
system. That is not to say that all of these rights are currently
available or capable of being vindicated in every jurisdiction.
It is to say, however, that these are matters which lie within our
grasp, within our theory, and within the range of sensibility.
It is one thing to assert that an older person has an enforceable
right to mental health services that will ameliorate his psychic
distress, but it is quite another thing to assert that an older
person has an enforceable right to a happy family life, kind
friends and a successful marriage.

All the rights of the elderly can be subsumed under two major rights: First is the right of all older persons to flourish - to grow - to become.

- The Right to Flourish presumes the right to an adequate income to sustain life, to give comfort, to make choices freely.
- The Right to Flourish presumes the right to an education not only to the age of 16 or 21, but at any age that brings a

stand what one's rights, duties and obligations are - an education that enables one to consume wisely and behave in reasonable ways within very, very broad limits. It presumes an education such that one can make rational choices from among the wide array of choices that are laid before us. And it presumes an education that permits one to participate fully in the labor market during working years.

- The Right to Flourish presumes the right to quality health care that is, health care provided at the right place, at the right time and in the right amount. Of necessity, this means good diagnosis and the capacity to distinguish between and among those pathologies which are biological, those which are psychological, those which are social and those which are economic, and to secure the remedy of choice not merely the remedy of convenience.
- The Right to Flourish means the right to be free from poor quality health care and social services.
- The Right to Flourish means the right to <u>access</u> to services, benefits and the opportunities for growth. Access may imply economic capability, removal of architectural barriers, the availability of interpreters or interlocutors to assist people with overcoming language or speech barriers, as well as other help in overcoming barriers, physical or otherwise.
- The Right to Flourish, especially for the elderly, requires

  the right to a clean environment an environment in which those

  with respiratory problems are not excessively disadvantaged,

  an environment which does not produce in disproportionate

amounts the horrible and painful cancers that afflict the elderly, an environment in which the human body can flourish and grow through its entire lifespan.

- The Right to Flourish must include, especially for the old, the rights to exercise the special relationships which come with grandparenthood. If this seems odd, it is included here because of the extraordinary prevalence of divorce and the potential threat that brings to the grandparent/grandchild relationship, and because it is through that relationship that children probably enjoy their most important interactions with those two generations away, and hence, "old," Of course, one should note that an increasing number of children have the potential for having as many as eight grandparents, assuming one divorce and remarriage of each of the parents. It is from the grandparent relationship, I believe, that young people get their most important influence on their own selfimage in old age. And, thus it is, in my opinion, an important element which deserves attention in law, because it is important to the constant improvement of a stable society which an increasing number of older people.

But the Right to Flourish is not enough. There are a set of companion rights - sometimes difficult to separate out from those listed above.

These are the rights that I group under a general rubric of the right to autonomy, to dominion, to the exercise of mastery. With but few exceptions, these are rights less likely to be articulated in statute than they are in the common law. These

are the rights associated with equity, fairness, the ethical principles noted above.

- The right to autonomy and mastery includes that set of rights having to do with the range of choices involved in continuing or terminating life, the choice of lifestyle, and the freedom to choose even when living, for example, in a total institution.
- The right to autonomy, of necessity incorporates the doctrine of the least restrictive alternative.
- The right to autonomy is the right to be free from coercive environments in which such matters as informed consent may be impossible, and in which free choice is precluded. For example, imagine the hip fracture patient who has come down to the last of the permissable hospital days under the particular DRG classification. The hospital wants the patient removed because of the adverse financial affect she may have on the hospital. The patient is confronted with going to a nursing home. If there is no mechanism to fashion a program of home health services, homemaker services, transportation services, and similar services, the patient is truly in a coercive environment in which she has no choice and no way of vindicating her right to a less restrictive alternative or the affirmative right to good case management which will yield the right care in the right place at the right time.

- The right to autonomy includes the right to be free from the subtle coercions of the white-coated physician, the white-coated social worker, and the professional nurse all of whom proclaim, "We're doing what is best for you and we're trying so hard, so why don't you recognize that a nursing home is the best possible thing."
- The right to autonomy and mastery includes, of course, that most precious right of all - the right to folly, the right to a foolish decision. For some, the exercise of that right may be no more than smoking to excess, eating oneself into obesity, going out in the weather inappropriately dressed, or drinking too much. For others, however, the right to folly may represent spending one's money "foolishly", becoming involved in foolish romantic relationships, remaining in what some might regard as a dangerous or unhealthful environment, or otherwise making choices that a prudent person might not make. It is the right to folly, the right to be different - the right to be frivolous or arbitrary which is the right that sets the limits of our right to autonomy and mastery. The right to mastery that is defined only by wise decision-making is virtually no right at all.
- The rights associated with autonomy include the right to that whole range of protective services which involves changed legal relationships between and among individuals whether brought about voluntarily or compulsorily by judicial action. Thus, the right of autonomy includes the

right to designate agents, trustees, joint owners of bank accounts, or joint tenants as well as those rights associated with adequate protections against the inappropriate imposition of conservatorships, guardianships, or findings of incompetency. The foregoing is the menu.

It is the vindication of those rights associated with the right to flourish and those rights associated with autonomy with which we must be concerned. And to the extent that society's perceptions of the elderly change, our tasks will change. There, fore, those of us who toil in the vineyard of services for older people, have the task of producing an impact not only on the immediate population of the elderly, their families, friends and caregivers, but also on the society at large.

This is more than a public relations effort. The tasks associated with this require our involvement, yea, our leadership across the range of public services, and public understanding. It involves our concern with fundamental, ethical, values that are widely held, or which ought to be widely held.

It requires that we pay attention not only to the operation of the small systems, and procedures, and methods which are defined by the immediate statutes and ordinances we administer and which consume us almost beyond belief and which we dare not ignore, but also that we regard the larger society, the larger systems of economic distribution and transfers, of environmental quality, of education from elementary schools through professional training, of the justice system, and beyond.

Assuring the exercise of the rights outlined above requires four things.

First, we are obliged to participate in creating a society in which the right to flourish is understood and incorporated into the social psyche. It partakes of Jesse Jackson's call to minority youth to declare, "I am somebody." It partakes of the Holocaust survivors' call that says firmly, "Never again." It partakes of Betty Friedan's call to an understanding of the viciousness of the feminine mystique and what it imposed upon the women of the world.

Our first call, then, is to insist that old people have the right to flourish, to grow: That indeed they can and will even in the face of some biological and psychological decrement-that old age is not a period of unvarnished 'diminution, but rather that human beings flourish and grow until the end of life.

Second, we must lay down the conditions precedent to the securing of individual rights. That means the creation of a society with a powerful infrastructure that not only assures the survival, maintenance, and growth of the society as a whole, but that also undergirds every individual's ability to flourish.

What this means is that everyone should have the right to come to old age able to read, write, add, substract and manage in his or her community and be capable of addressing the world of claims and asserting one's rights.

Everyone should have the right to come to old age, having had the benefits of decent nutrition in early childhood.

Everyone should come to old age having had the benefits of decent housing, decent neighborhoods, garbage collection and a clean environment throughout the lifetime.

Everyone should come to old age without ever having had to go through the searing experience of long-term unemployment, "skidding", defeat at the hands of the marketplace with its horrendous impact on the family.

Everyone should come to old age without ever having had the experience of war.

Third, for those who do come into old age and may look to government for an array of benefits, there are system requirements which must do the following:

- 1) We must have systems that produce centralized problem assessment. We cannot expect old people to florish if they must work their way through a virtually inpenetrable maze of government or private offices each assessing this or that little segment of his life.
- 2) A centralized problem assessment scheme, or something close to it, must be accompanied by case management and individual advocacy.
- 3) Problem assessment and case management will come out to very little unless there is a rational system in which services and benefits can be requistioned, monitored and accounted for.
- 4) These will do little unless we have a service delivery system that permits - indeed requires respect for maximum autonomy - a system that will tolerate and

respect the right of folly. And yet, a system that understands that even the richest, most bountiful and most beneficent society in the world has limited resources.

And Fourth, we must create mechanisms to secure rights of the elderly, and affect the large and small systems whether those mechanisms consist of legal services for the elderly, friend/advocates for the elderly, better education about self-help, or some other as yet not understood method for asserting, claiming, and securing those rights associated with the right to flourish and the right to autonomy and mastery.

We seek nothing less than Justice. And in the words of the prophet, "Justice, Justice, shall you pursue."

#### INTRODUCTION OF GOVERNOR JOSEPH BRENNAN

by Margaret Russell, Chair Maine Committee on Aging

It is my pleasure to introduce a man who is well known to Maine's elderly and who has supported programs on behalf of older citizens since his early days in the Maine State There he was instrumental in the passage of the Senate. Priority Social Services Program which created funding for homemakers, meals and other critical programs. He is a strong advocate for assuring that older people are guaranteed the full and equal opportunity for employment. He was a strong supporter of Maine's efforts to abolish mandatory retirement and at the invitation of Claude Pepper, spoke before the United States House of Representatives Select Committee on Aging during a hearing regarding the abolition of forced retirement at the federal level. He supports his strong words on behalf of the elderly with policy and program decisions and is responsible for giving the Bureau of Maine's Elderly and the Area Agencies on Aging leadership for older worker programs through the Senior Community Service Employment Program and the Job Training and Partnership Act.

He has a deep and personal commitment to many of the State's older people, whom he has long considered friends. He is responsible for creating the Congregate Housing Program based on a Blaine House Conference on Aging resolution and continues

to be a strong supporter of home based care. The Governor is responsible for appointing the members of the Maine Committee on Aging, and we have always found him to be willing to meet with us and responsive to our concerns. We are pleased that the Blaine House Conference on Aging recommendations are carefully considered by him and his office. We look forward to sharing the results of the recommendations from this Conference with him and to hearing him today. It is my pleasure to ask you to join me in welcoming the Governor of the State of Maine, Joseph E. Brennan.

#### ADDRESS

#### The Honorable Joseph E. Brennan Governor

Once again I am privileged to join you at this all important conference.

I have had the distinct honor and pleasure to address you on several occasions.

What has become apparent to me as Governor is that your role as leaders in shaping public policy is critical.

Over the past six years, we have combined forces to develop a long term care policy governed by two major considerations.

First, a strong belief in the principle that wherever and whenever possible, programs and services should be provided at home or in the community.

Second, a policy and a deep personal belief, one shared by you, that views the elderly as individuals and not as a segment of the population presenting a collective problem.

This long term care policy continues to evolve, recognizing the dignity and value of the individual.

I am proud of our record in the area of Home Based Care Services.

At this time, my Administration is working to get the federal government to loosen some regulations so that more money will be available for home based services, thereby making it possible for more of our senior citizens to continue to live

in their own homes, as I know they prefer to do.

Another area in which we have worked together is congregate housing.

To date there are 8 publicly funded congregate sites throughout Maine and others being mandated by the private sector.

These new programs allow frail elderly to stay out of nursing homes and live in facilities where they receive health and social services as well as a noontime meal.

But at the same time living independently in their own homes.

You at a previous conference provided the spark for these new programs.

Finally, I want to thank you for your support for the passage of Maine's law to control hospital costs.

Medicare costs and who pays the bill will be a major social issue during the rest of this century.

It will be a profound challenge for all of us - beneficiaries, providers, and public policymakers.

This year our nation will spend 360 billion dollars on health care.

We do not need to ask the vast majority of elderly to sacrifice more of their modest incomes for health care.

Instead we need strong action by the Congress to redirect our nations' health budget toward more appropriate and efficient care, such as home based services and strongest controls to prohibit unnecessary growth of costly medical facilities.

As medical costs rise, Medicare benefit levels have not kept pace.

Today Medicare covers only about 44 percent of the total health care costs of the elderly.

The elderly spend about as much out of pocket as a percent of their income as they were spending before Medicare was enacted in 1965.

Since the average elderly household income in Maine is only six thousand dollars a year, and many have incomes much smaller than this, it is neither realistic nor just to ask our elderly citizens to pay more from their meager income for health care.

Finally, we are honored to have a special guest from the great State of Minnesota, a state that provided so many great leaders for this nation.

#### VI CONFERENCE PROGRAM

#### AGENDA



#### BLAINE HOUSE CONFERENCE ON AGING

September 19, 1984

8:00 - REGISTRATION - Outside Main Auditorium Coffee and Doughnuts

9:00 - CALL TO ORDER
WELCOMING REMARKS - Margaret Russell, Chair
Maine Committee on Aging

9:15 - OVERVIEW OF WORKSHOP RULES AND PROCEDURES
INTRODUCTION OF WORKSHOP CHAIRS AND CO-CHAIRS Trish Riley, Director
Bureau of Maine's Elderly
Department of Human Services

9:30 - CONCURRENT WORKSHOPS

Room

Effect of DRG's

Main Auditorium

Medigap Insurance

Androscoggin/Aroostook/Cumberland Rooms

Access to Long Term Care Penobscot Auditorium

Employment

Kennebec Auditorium

Medical Treatment

Cushnoc Auditorium

Housing and Home Care

Lincoln/Oxford Rooms

Guardianship

York Room

12:00 - LUNCH - Main Auditorium - KEYNOTE ADDRESS

Eli Cohen, Director Div. of Policy and Information Dissemination Temple University Mid-Atlantic Long Term Care Gerontology Center Philadelphia, Pennsylvania

- 1:30 WORKSHOPS CONTINUE
- 4:00 Showing of Film "GRACE" Cushnoc Auditorium
- 5:00 DINNER (On your own)
- 6:30 DESSERT AND COFFEE RECEPTION Blaine House Conference Delegates and Federal Council on Aging - Main Auditorium
- 7:00 FEDERAL COUNCIL ON AGING HEARING Main Auditorium
  "Aging in Place: Implications for Long Term Care"
  Chaired by Trish Riley, Director
  Bureau of Maine's Elderly

#### AGENDA



#### BLAINE HOUSE CONFERENCE ON AGING

September 20, 1984

9:00 - CALL TO ORDER - Trish Riley, Director
Bureau of Maine's Elderly
Department of Human Services

WELCOMING REMARKS - Margaret Russell, Chair Maine Committee on Aging

INVOCATION - Fr. Valmont Gilbert

#### Presentation of Workshop Resolutions

- 9:30 EFFECT OF DRG'S Stuart Fergusson, Chair
- 10:00 MEDICARE SUPPLEMENTAL INSURANCE David Brenerman, Chair
- 10:30 ACCESS TO LONG TERM CARE Wil Pombriant, Chair
- 11:00 EMPLOYMENT
  William Cunningham, Chair
- 11:30 MEDICAL TREATMENT John Joyce, Chair
- 11:55 INTRODUCTION OF THE GOVERNOR Margaret Russell
- 12:00 ADDRESS The Hon. Joseph E. Brennan, Governor
- 12:15 LUNCH

#### Presentation of Remaining Workshop Resolutions

- 1:15 HOUSING AND HOME CARE Fr. Valmont Gilbert, Chair
- 1:45 GUARDIANSHIP
  Norman Hall, Chair
- 2:15 RESOLUTIONS FROM THE FLOOR
- 3:00 ADOPTION OF CONFERENCE RESOLUTIONS
  ADJOURNMENT

VII
SELECTED PRESS REVIEWS

## **Editorials Elderly a problem?**

Too many of Maine's elderly residents find "the golden years", so-called, something far less than that as illness intrudes on lives which are troubled enough by the difficulty of managing with meager incomes and by loneliness which is often more debilitating than illness.

This is no exaggeration, where most of our senior citizens are concerned. Some lucky ones, of course, manage nicely and enjoy reasonably good health and are fortunate to have families which have not forgotten them, but they are not in the majority.

Too many of the younger ones among us prefer not to be troubled by the problems of the aged, forgetting, perhaps, that they, too, may one day be in the same situation.

Some deserve it. An example is Colorado Gov. Richard Lamm, who earlier this year said without shame that the terminally ill have a "duty to die and to get out of the way" of the young and the healthy.

At the Blaine House Conference on Aging this week, the Lamm proposal was termed obscene, outrageous and dangerous, and it is surely all of those. That a public official in any state of the union could be so callous, so unfeeling and so wrong, is almost beyond belief.

The view that our elderly are "a problem" for society is true. The problem is not the elderly, however, but how to make their final years more liveable.

They have made their contributions, big and small, to our nation and our state, and it is time for reward, not punishment, for the responsible lives that most of them have experienced.

Lewiston Daily Sun 9/21/84

### Dying with dignity

A Blaine House Conference on Aging last week raised the issue anew: The need for a Maine law to allow "living wills"—legal documents allowing a person to specify under which conditions the use of life-support systems should be withheld or discontinued.

In essence, living wills do nothing more than recognize that individuals have a fundamental right to determine the extent of the medical care they wish to receive.

The presence of living wills, documents in which the living

to the use of life-sustaining procedures in the event they become terminally ill, give the patient the power of decision.

Even without living wills some patients are able to make pacts with their doctors asking that they be allowed to die with dignity. But other patients may not be able to communicate their desires. That leaves the decision to others. And for survivors, the agonies of making the decision can be traumatic and leave emotional scars.

Back in 1977 the Legislature had the opportunity to make Maine the second state in the union to legalize living wills. Unhappily, the measure failed for lack of support.

In Maine, that responsibility often rests not with the patient but with the doctor or a relative. Living wills spare the need of a relative making the agonizing decision on behalf of

a parent or loved one who is kept alive only by artificial means.

That's not the case in 22 other states where, in one form or another, living wills have legal validity.

Artificial life-support systems and other medical techniques may sustain life but they will not cure. Once terminally ill, the question is not one of life or death, but rather when death will occur.

In those instances, it is the individual directly involved whose wishes should be honored. A living will law in Maine would provide a humanitarian vehicle to permit prospective or actual terminally ill patients to make the decision as to the extent of medical care they wish to receive.

Maine Sunday Telegram

9/23/84

## Aging The right-to-die issue

By M. KATHLEEN WAGNER Staff Writer

Elderly patients and others may encounter interference no matter which way they turn — whether they seek to obtain advanced medical care, or die without it.

As medical costs soar, America may one day be unable to provide

#### Schedule, Page 7

advanced technological treatment to all those who need it.

Conversely, the parents of the comatose Karen Ann Quinlan and the handicapped "Baby Jane Doe" have run up against the state, doctors, lawyers and hospitals in seeking to forego such care.

One of seven workshops at this week's Blaine House Conference on the Aging will address the right-to-live/die debate, which has focused on the elderly with Colorado's Gov. Richard Lamm's reported "duty to die" speech last spring and a story in the New England Journal of Medicine ethically excusing doctors from

force-feeding severely demented elderly people who have stopped eating.

"If you're not going to do everything possible to save the lives of the ill, you might as well hit them over the head with a sledgehammer," steamed Florida congressman Claude Pepper. in response to the latter report.

"Emotions run high both ways," and the Blaine House workshop may rightly spur debate but no answers, says Virginia Norman, acting staff director of the Bureau of Maine's Elderly, conference co-sponsor.

A workshop paper, prepared by a six-member panel of doctors, law-yers and hospital administrators, sets the stage: "Our society stands at the threshold of being forced to make some critical decisions about health care for our citizens. Questions demanding answers are: Who will receive health care? ... How much should we pay for health care? ... When should life support sys-

See: AGING Back page this section



## Aging

(Continued from page 1)

tems be used and/or withdrawn? Who should decide when artificial life support systems can be terminated?... Must a patient consent to orders not to resuscitate?"

Warren C. Kessler, president of the Kennebec Valley Medical Center, says the Augusta-Gardiner hospital's only policy in this category requires that brain death be established by the Harvard Medical School definition before a plug is pulled on life-sustaining machines.

How aggressively to treat illness—whether a machine is plugged in, in the first place—usually is decided by the patient, family, and doctor, Kessler says.

An KVMC ethics panel of physicians, lawyers and clergy formed last spring is debating and advising doctors on ethics — "the vexing things we spend time on in the next 20 years," Kessler predicts.

Great Britain, which spends about 5 percent of its gross national product on health care compared to America's 11 percent, already rations dialysis and intensive coronary care based on patient age.

Kennebec Journal 9/17/84

# Conference on Aging expected to draw 400 elderly delegates

By M. KATHLEEN WAGNER Staff Writer

An estimated 400 elderly delegates from across Maine are expected to attend the ninth annual Blaine House Conference on the Aging, Wednesday and Thursday at the Augusta Civic Center, to vote on issues from Medicare to employment of the elderly.

Virgina Norman, acting staff director of the Bureau of Maine's Elderly, says the conference in the past has led to legislation which abolished mandatory retirement, required reporting of elderly abuse, and increased financing for care of

the elderly at home.

Eli Cohen, director of the Division of Policy and Information Dissemination for the Temple University Mid-Atlantic Long Term Care Gerontology Center, will discuss the elderly's right to obtain and refuse medical care in this year's keynote address, scheduled for Wednesday at noon in the Civic Center's main auditorium.

Philip Abrams, under-secretary of Housing and Urban Development, is scheduled to outline HUD's policies on elderly housing at a hearing Wednesday at 7 p.m. before the Federal Council on Aging, which is advi-

sory to President Reagan.

Kathleen A. Boland, director of Maine State Housing Authority, and Margaret Russell, chairman of the Maine Committee on Aging, will respond with Maine's viewpoint.

Both the council hearing and Cohen's speech are open to the

public.

Each of the 400 delegates, named by the bureau, the Committee on Aging and five agencies around Maine, will participate in one of seven workshops each on a different tonic.

Each workshop will be chaired by at least one member of the Committee on Aging, a group of 15 people named by the governor to advise the executive and legislative branches on elderly issues. Papers prepared by experts on the seven topics are given the delegates in advance.

The workshop groups will present three resolutions each to the total assembly for adoption. The Committee on Aging later will pick 10 to 15 of the accepted resolutions to act upon, pursuing legislative action as needed, Ms. Norman said.

The workshop topics are:

How changes in the Medicare payment structure will affect health care for the elderly.

✓ Supplemental Medicare insurance — are the elderly paying for unnecessary duplicate coverage?

How to ensure long-term nursing home care, irregardless of whether the patient is a Medicaid recipient.

How the government, employers and employees can increase job opportunities for the elderly.

An elderly person's right to obtain and refuse medical treatment.

✓ Improving housing and and

home care for the elderly.

✓ Guardianship — the loss of an elderly person's rights weighed against the need for a guardian's assistance and protection.

The conference is scheduled to open Wednesday with registration at 8 a.m., and call-to-order at 9 a.m. Rules and procedures will be outlined and the workshops then will run concurrently from 9:30 a.m. to

Lunch with Cohen's keynote speech is set for noon, followed by resumption of the workshops from 1:30 to 4 p.m.

The 7 p.m. council hearing will occupy the evening time slot.

On Thursday, workshop leaders and speakers from the floor are to present resolutions from 9:30 a.m. to 11:55 p.m., and 1:15 to 3 p.m.

Gov. Joseph E. Brennan is scheduled to give the luncheon address at noon, between the morning and afternoon sessions.

Voting on the resolutions is set to begin at 3 p.m., followed by adjournment.

Kennebec Journal

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