

FINAL PROGRESS REPORT

Care at the End of Life: A Public/Private Partnership

Presented by

The Maine Consortium for Palliative Care and Hospice

Grant ID#: 36223

Covering Grant Dates January, 1999 through June, 2002

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1. *What were the project's objectives and to what extent has the project met these objectives?*
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Introduction: The Maine Consortium for Palliative Care and Hospice (MCPCH) through the Robert Wood Johnson Community State Partnership Initiative has just completed a \$450,000 three-year initiative to encourage community groups, organizations, and individuals in Maine to reshape public policy affecting end-of-life care. The original fourteen consortium partners contributed an additional \$201,000 to supplement the RWJ grant.

This narrative has each partner's original goals, objectives and outcomes. Note, some of the efforts are collaborative partner activities and are so noted in the text.

MAINE HOSPICE COUNCIL (MHC)

Goal: Increase awareness and education regarding Hospice and Palliative Care in Maine.

Objectives: 1) Administer the grant. 2) Develop a central repository for information regarding end-of-life care working in collaboration with the Maine Hospital Association. 3) Develop and publish a Statewide Resource Directory in collaboration with the Coalition for Dialogue on Death and Dying and the Maine Council of Churches; 4) Design and implement a Hospice and Palliative Care curriculum for medical students at the University of New England (UNE) in collaboration with UNE and the Maine Osteopathic Association. 5) Produce interim reports to the legislature. 6) Engage, print, and broadcast media in the partnership effort. 7) Schedule public hearings on end-of-life care throughout the state. 8) Increase Medicare Hospice referrals from 6% to 10% over a three-year period in collaboration with the Home Care Alliance and other appropriate organizations.

Outcomes:

1. The Maine Hospice Council (3 co-directors and administrative assistant) fulfilled its responsibilities for the technical aspects of grant administration. Writing contracts; sending invoices; producing monthly reports; managing/revising the budget; holding Steering Committee meetings; following up with grant partners – all key elements necessary for the successful completion of the project's objectives.
2. Development of the Central Repository for End-of-Life Care information has been implemented and we continue to catalogue print, audio, video, and electronic material. Through use of surveys, health care institutions throughout the state identified institutions with resource material and data appropriate for the repository and a willingness to participate in the repository program. This project work will now come under the new Maine Center for End of Life Care which is housed within the Maine Hospice Council office. The Central Repository has been able to avail itself of the following technology in its operations:

- 1) Discount computer software from “Gift in Kind” and “Compumentor” including Microsoft Office Professional, Frontpage, Adobe PageMaker, Adobe Acrobat, and Norton Antivirus.
- 2) Discount computer hardware from various vendors including computers, scanners, printers, digital camera, and LCD and overhead projectors.
- 3) Discount web hosting and internet services from XWave New England, Susquehanna Communications, and MaineHosting.Com
3. A State-Wide End-of-Life Resource Directory has been compiled with the assistance of the Coalitions and the Maine Council of Churches. The directory will be available in print and electronic form.
4. Successfully implemented an End-of-Life Curriculum (see University of New England report below) in cooperation with the Maine Osteopathic Association and advisement from the Council (MHC).
5. Produced three annual reports on the status of end-of-life care in Maine for the Health and Human Services Committee. These were also delivered to the general legislature and other interested stakeholders.
6. The web sites have been successfully implemented. The following indicates the detailed and comprehensive information available:
 - 1) www.mcpch.org – Organizational information, contacts, members, reports, surveys, discussion groups, links, calendar, legislative updates.
 - 2) www.mcpch.org/community_state/ Executive summary, contacts, partners, projects, goals, objectives, reports, calendar.
 - 3) www.mainecenterforendoflifeinfo.org This site is being developed to include all the relevant information from the MCPCH sites (above) as well as new material developed for the Maine Center for End of Life Care.

From their implementation and through the active period of the grant project, these sites were frequently visited by grant partners, state agencies, and other organizations and individuals interested in end-of-life care. The sites averaged over 3,000 hits per month.

7. Over the project period, a major series of collaborative ventures and initiatives were undertaken:
 - 1) Educational outreach regarding the PBS Bill Moyers series;
 - 2) Bureau of Health Palliation Work-group for the Maine Cancer Consortium’s Strategic Cancer Plan;
 - 3) Meetings with nursing faculty to discuss end-of-life content in nursing curriculum (nursing curriculum audit presently in progress);
 - 4) Task Force regarding Medicaid Hospice Benefit (see below);
 - 5) Continued interest within the Dept. of Corrections and the Maine State Prison system to pursue a strategic planning process with the Maine Hospice Council for quality end-of-life care. A retreat was held at the Maine State Prison on November 8th with participants from Maine State Prison, Volunteers of America and Maine Hospice Council to outline the plan and assign tasks, including grant writing and a preliminary budget. A statewide conference, hosted by the Maine Hospice Council, for law enforcement and corrections was held in June 2001 to bring awareness to this issue. To date, education programs for prison staff, memorial services within the prison and grief support groups have been implemented and are ongoing;

- 6) Support of Medic Alert document banking for Advance Directives; and the 15 week Knight-Ridder series.
- 7) A study regarding grief and bereavement in the workplace was initiated by our late co-director, Larry Harcourt, and funded by the Gertrude Ford Foundation. Initial findings were reported at a symposium in December 2001 and are included in the bibliography.
8. Major series of presentations regarding the RWJ program and other end-of-life issues at locations through the state.
9. The MHC offered consultation to a bipartisan legislative process which culminated in the passage of comprehensive end-of-life legislation by convening an initial meeting to discuss barriers, addressing questions, providing historical data and relevant background information and contributing appropriate data.
10. The Maine Center for End of Life Care was awarded to the Maine Hospice Council by the Department of Human Services, Bureau of Health. The focus of the Center will be education, research, and advocacy. The center will maintain a registry, undertake a study of end-of-life and palliative care, pain management, and barriers to establishment of inpatient hospice programs in the State. The Center will also make recommendations for overcoming those barriers and develop a strategic plan for providing end-of-life and palliative care state-wide.
11. In light of community dialogues, congregational dialogues, responses to both the Moyer program and the Knight-Ridder series, the need for developing an approach to Advance Directives became very apparent. As a result, two professionals were sent by the CSP to be certified at the Advance Directives program in LaCross, Wisconsin. They have commenced providing advance care education throughout the state.
12. The Council convened nine public hearings throughout the State (see Bibliography for Executive Summary).

COALITION FOR DIALOGUE ON DEATH AND DYING (CDDD)

Goal: Engage the local community to assume responsibilities toward end-of-life care by replicating an existing coalition model in 5 regions of the state.

Objectives: 1) Understand each of the area's diverse cultures of dying and bereavement. 2) Identify and assess the current system of care. 3) Evaluate end-of-life care delivery systems. 4) Adopt an action plan addressing end-of-life care systems change in each area. 5) Increase knowledge about end-of-life issues and resources available.

Outcomes

1. As noted in previous years because of specific area difficulties in geography, service patterns and feelings of "community", the number of coalitions was fluid (some merged as well). Androscoggin County, York County, Kennebec-Somerset Counties, and Franklin County Coalitions all moved rapidly, implemented community dialogues and focus groups, built a cadre of facilitators, enlarged their memberships, utilized a new instrument for organizational analyses of relevant end-of-life organizations. The MidCoast Coalition resurrected itself into an active, vital organization. Other groupings (Cumberland, Penobscot, and northern counties) did not officially form on-going coalitions but did engage in involving core groups, and engaged in cooperative data-gathering activities. Over the project period, over 200 dialogues and 130 focus groups were conducted. Individual findings were utilized in dealing with local and state institutions and the legislature (see bibliography). The individual

coalitions held a minimum total of 75 local workshop/program forums regarding end-of-life issues

2. Despite initial conflict, the consortium of local coalitions program took a major leadership role/involvement in the PBS program “On Our Own Terms: Moyers on Dying” Each implemented of follow-up community dialogues around the State including; discussion instruments, facilitator/recruitment and training, consumer education, and information materials. Over 30 community dialogues were held in the initial one-month period. An additional 35 community dialogues relating to all or individual PBS program units have been held. Local coalitions are now utilizing tapes of the program as a stimulant to additional dialogues and focus groups as well as outreach and capacity building.
3. Development and implementation of a State-wide Outcome survey “What Does Maine Want.” An initial distribution of 500 plus placement on the website was effected. The survey is now being utilized with dialogue and focus groups activities and initial findings are being analyzed.
4. A very successful statewide PBS televised program was held as a follow-up to the Moyers series with Laurel Coleman, MD, Kandyce Powell, MSN, and Michael Murphy, PhD (latter two, co-directors of the CSP grant).
5. The coalitions were successfully involved in the 15-week Knight-Ridder series by holding dialogues relevant to each article, and some coalitions wrote accompanying articles that supplemented the series.
6. The findings from the dialogues, focus groups and organization materials were actively shared with state and local organizations and effected opportunities for community collaboration with local institutions (i.e. serving on hospital palliative care committees, etc.).
7. The lack of knowledge of services, by both providers and the general public, became readily apparent and this stimulated local coalitions to develop local information and referral pieces that are folded into the state-wide directory. Further, it focused attention on specific local and state issues and needs that were addressed through subject-specific workshops (i.e. advance directives).
8. The coalitions have now come together to share information, develop joint programs and collaborative action. In the new Maine Center for End of Life care, a special coalitions section is being formed to institutionalize and increase this activity.
9. Produced and disseminated (see question #5 and bibliography) a number of publications: Manual for Building Successful Coalitions, Facilitator’s Handbook, What Does Maine Want, etc.

MAINE COUNCIL OF CHURCHES (MCC)

Goal: To engage the local faith communities to assume responsibilities for improving end-of-life care.

Objectives: 1) Establish multi-faith congregational dialogues. 2) Develop Clergy and Pastoral Care surveys. 3) Develop an anthology/manual; 4) Prepare report for congregations in Maine. 5) Develop a resource guide for end-of-life services in the Greater Portland area.

Outcomes

1. Congregational Dialogues were, as a pilot, developed in congregations in the Greater Portland area as a prelude to more activity throughout the state. While initially successful, congregations had difficulty in sustaining interest in the project. As a result, a program to

develop leadership along lines of Compassionate Sabbath (re. Midwest Bioethics experience) was implemented with more success.

2. Conducted a series of interfaith dialogues.
3. Conducted EPEC-like training, in cooperation with the Maine Medical Association.
4. Conducted surveys to over 800 clergy statewide which addressed clergy's perception of being very comfortable and capable of dealing with end-of-life issues, except for dealing with children and death.
5. Developed survey for use by congregations to assess their own human resources, volunteers, etc. Material included for use in congregational manual.
6. Held two successful Annual Interfaith End-of-life symposiums. A third major interfaith (2-day) symposium postponed due to death of co-director, Larry Harcourt.
7. Completed a manual for developing and sustaining dialogues and activities in congregations. The manual includes a bibliography of recommended readings and films on end-of-life issues; an explanation of the training needed for dialogue facilitation along with a training resource kit and referral to trainers; the curriculum for monthly sessions including topic, titles, and recommended questions to stimulate conversations as well as suggested presentation to introduce each topic; a model for developing and growing a nucleus of leadership regarding end-of-life in the congregation.

MAINE MEDICAL ASSOCIATION (MMA)

Goal: To provide more physician education in end-of-life care.

Objectives: 1) Send five to ten physicians to train with the AMA's EPEC project. 2) Establish forums to implement the EPEC Program statewide.

Outcomes

1. Increased EPEC faculty from five physicians to fourteen.
2. Over 40 EPEC presentations were given to providers (physicians and other clinicians), plus 3 two-day conferences held in Portland, Lewiston, and Bangor; and selected EPEC faculty participated in two clergy conferences.
3. Designated MMA staff time to coordinate EPEC faculty and EPEC presentations.
4. Authored parts of and promoted the new legislation.
5. Worked with Federal and State law enforcement officials and others to examine ways to reduce prescription drug abuse without impinging on legitimate prescribing for adequate pain control.
6. Developing a CME course on pain management for primary care physicians.
7. Developed presentations of CME course on Advanced Directives.

MAINE HEALTH CARE ASSOCIATION (MHCA)

Goal: Develop base-line data in long-term care settings.

Objectives: 1) Design an assessment tool. 2) Collect information on LTC residents who are transferred to acute care facilities to die; the existence of pain management protocols in the LTC facilities; and the percent of patients with advance directives.

Outcomes

1. The MHCA worked with its nursing council and designed an assessment tool to survey MHCA members. A low response rate rendered the data unusable. Resignation of MHCA during the grant period also contributed lower than anticipated outcomes for this project. The Maine Hospice Council is in discussion with the new executive vice-president regarding

continued partnership efforts with MHCA to improve the quality of end-of-life care in LTC settings, perhaps under the auspices of the Maine Center for End of Life Care.

2. Worked in cooperation with Home Care Alliance and Maine Hospice Council in a series of educational programs, including “A Partnership for End-of-Life Care” which brought providers from nursing homes and hospice programs together to address end-of-life care in institutional settings.

MAINE MEDICAL ASSESSMENT FOUNDATION (MMAF)

Goal: Collect epidemiological data on pain and symptom management across several practice settings in two communities in Maine.

Objectives: 1) To begin the process of meeting the need for basic epidemiological data regarding symptoms in terminally ill patients, from the patients’ vantage. 2) Contribute to development of a state-wide, community-based data collection system for establishing benchmarks related to end-of-life care and to track performance over time.

Outcomes

1. Data collection proved to be inordinately difficult in 3 pilot sites. Interest was strong at site administration level but did not necessarily filter down to first-line, overburdened caregivers and lack of family participation.
2. Have effected a survey form, designed and programmed, ready for use in future efforts.
3. Learned some lessons in order to achieve future results: cultural barriers regarding discussing how terminally ill patients experience their symptoms must be broken down; develop approach that is effective in improving patient/family participation in quality improvement efforts; develop understanding of issues facing provider staff who are asked to assist in research activities.

ANTHEM BLUE CROSS AND BLUE SHIELD OF MAINE

Goal: Develop a “model” hospice benefit that is interdisciplinary, community-centered, and evidence based.

Objective: 1) Develop a working group of relevant parties. 2) Develop an ideal hospice service package. 3) Look at potential implementation.

Outcomes

1. Working group activity (HMO’s, providers, care managers, Consortium, E.S. Muskie School, Medicaid).
2. Finalized ideal hospice service package and presented to HMO Council.
3. Series of external and internal changes affected this project: Tufts Health Plan withdrew from Maine marketplace in 2000; Anthem absorbed Blue Cross – Blue Shield; end-of-life legislation passed that included mandated hospice benefit provisions for insurers and HMOs.
4. NPO offered to sponsor a visit by Dan Tobin, M.D. (who has developed advanced illness/end of life for Veteran’s Administration).

HOME CARE ALLIANCE OF MAINE (HCA)

Goal: Work collaboratively with other grant partners to shape public policy.

Objectives: 1) Provide legislative oversight information and action related to home care and hospice services. 2) Provide on-going education to families, individuals, legislators, members, and medical providers.

Outcomes

1. Over 3 years, worked with members of the Home Care Alliance and the Maine Hospice Council to draft legislation specifically designed for hospice care. The 119th legislature passed LD 2454 (see bibliography) “An Act to Create a Medicaid Hospice Benefit”. However, the Appropriations Committee did not allocate necessary funds.
2. Collaborated with providers, MHA, MMA, MHCA, MHC, Maine Long Term Care Ombudsman, Mainers for Death with Dignity, Alpha One, and Roman Catholic Diocese regarding proposed rules for a Medicaid hospice benefit. LD 1641 “An Act to Increase Reimbursement for Medicaid Hospice Services” resulted from that collaboration. This legislation increased the Medicaid reimbursement to the Medicare rate plus 23%. This legislation, along with LD 802 was passed by the 120th legislature.
3. Sponsored educational programs including “A Partnership for End-of-Life Care” (see MHCA Outcome #2)
4. Involvement in development of an ideal services package designed to be of use by Maine’s health plans.

MAINE HOSPITAL ASSOCIATION (MHA)

Goal: Examine the role of health care institutions regarding end-of-life care.

Objectives: 1) Implement a state-wide effort to improve care at the end-of-life. 2) Institute Palliative Care Compact. 3) Conduct MHA Educational Conference for Hospital improvements teams. 4) Work closely with Maine Medical Association (MMA) on joint EPEP program.

Outcomes

1. Instituted the Palliative Care Compact within major member facilities; conducted a series of successful educational and information-sharing sessions after the Institute for Health Care Improvement Collaborative with interdisciplinary teams across the state.
2. Assisted hospitals in developing palliative care initiatives in their organizations and developed/implemented the palliative care initiatives.
3. Recruited, in cooperation with MMA, EPEC trained physicians within Maine to support and participate (40 sessions) in the educational program.
4. Developed a standardized chart assessment instrument to assist teams in identifying potential areas for improvement.
5. Published a directory of hospital improvement projects and their outcomes.

MAINE OSTEOPATHIC ASSOCIATION (MOA)

Goal: Implement a Hospice rotation for medical students at UNE in collaboration with UNE and MHC.

Objectives: 1) Plan and implement program.

Outcomes

1. Curriculum successfully implemented (see UNE Outcomes)

E.S. MUSKIE SCHOOL OF PUBLIC SERVICE at University Of Southern Maine

Goal: Support other projects within the initiative by providing analysis and consultation.

Objectives: 1) Provide background research and assistance to Anthem HMO project. 2) Assist in the RWJ Grant Evaluation Committee.

Outcomes

1. Worked with the HMO Council regarding ideal hospice benefit, especially regarding implementation issues and strategies.
2. Led the RWJ Grant Evaluation Committee and provided technical assistance to the project partners.
3. Conducted a qualitative analysis of seven public forums held through the state in late 1999. Findings and conclusions (see bibliography) are being used by provider organizations. Findings were presented at the 6th National Conference on Cancer Nursing Research (Oncology Nursing Society) February 2001.

ORGANIZATION OF MAINE NURSE EXECUTIVES (OMNE)

Goal: Communicate partnership activities and information regarding end-of-life care to health care organizations, health facilities, and patients in the State.

Objectives: 1) Serve as conduit of information about end-of-life, the RWJ project through OMNE membership. 2) Assist in sharing public policy.

Outcomes

1. Distributed resource materials state-wide.
2. Provided on-going education to legislators regarding Medicaid hospice benefit.
3. Conducted forums on EPEC program, specifically the EPEC Nursing Curriculum.
4. Worked with a series of organizations on the legislation for Medicaid hospice benefit reimbursement (LD 1641 and LD 802)
5. Prepared report on “How current Medicaid reimbursement can be applied to a Medicaid Hospice Benefit without requiring more dollars.”

UNIVERSITY OF NEW ENGLAND

Goal: Implement a Hospice rotation for medical students.

Objective: Educate a new generation of medical professionals.

Outcomes

1. Successfully planned and implemented, in cooperation with MOA and MHC, a Hospice/End-of-Life curriculum into the Experiences in Doctoring course; developed Hospice Opportunities in Physician Education (HOPE); implemented a hospice curriculum with a pilot project in 1999-2000, and a mandatory hospice IDT for all second-year medical students (2000-2001); enhanced the existing didactic curriculum (including physician’s role in transitioning from curative to palliative care; team approach in hospice care, philosophy and skills basic to hospice; and identification of community support, social support, etc.
2. Worked with WCSH, Channel 6, on programs on the curriculum, and presentations in various professional conferences.
3. Worked with Cumberland County Jail administrators and staff regarding end-of-life education and training of jail staff.

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2. *What internal challenges were encountered during this year that are related to the project’s design, collaborations, staffing, operations, or other project factors?*
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This was a major comprehensive and complex project with multiple objectives and multiple partners. A major challenge was to keep the partners on task, communicating and reporting in a timely manner. The project design was sound, but demanded time and partner nurturing. Obligatory quarterly meetings improved the process, along with obligatory monthly “bullet” reports and full use of increased electronic dialogue. Partnership changes occurred as

well, somewhat expected (see question 3): downsizing in the Maine Funeral Directors' Association, Maine Osteopathic Association, new directors at the UNE Medical School, and changes in the MMAF leadership served to affect the timing of yearly objective completions. While these factors caused delays, they did not prevent meeting project goals.

A major setback, of course, was the death of Larry Harcourt, MD, co-director of the project. A loss of both substance, style, leadership, and support. To voice once again previous years' commentaries, NPO was very supportive with apt suggestions, especially on inter-partnership relationships. Further, the NPO was helpful in our Council of Churches program, specifically related to Compassionate Sabbath. The major lesson for NPO activities is to expect and plan for the delays, be proactive, build a strong adaptable communication process with effective feedback mechanisms and nurture.

3. *What challenges or successes were caused by factors external to the project?*

For the most part, the external environment, in many ways, was conducive to the project's success. There is a rapidly increasing public interest in end-of-life care and the quality of life. That said, the project did face a number of external challenges. The referendum vote on physician assisted suicide in November 2000 was a long drawn-out, bitter period of time in the state. The PAS referendum was defeated in a close vote. As noted in previous reports, the Consortium stuck to its non-profit, non-lobbying stance and maintained a neutral stance. Members were active through their own organizations, but not in Consortium activities, especially true in area coalition and faith group RWJ activities. The referendum did, however, pre-occupy Consortium members, naturally, and seemingly may have delayed some grant activities. The positive premise was that the Consortium and the coalitions would be able to bring the dissident groups together, after the vote, to work for improved end-of-life care in the state. This turned out to be a most positive factor. The opposing groups were able to resume or begin cooperative activities in such areas as consortium activities, the Knight-Ridder series, the work of area coalitions, the passage of the Medicaid Benefit legislation, etc.

The scope of the PAS issue did negatively affect initial cooperative activity with Maine Public Broadcasting and the Consortium regarding the Moyers series. MPB acted prematurely to close down relationships because of mistaken presuppositions of the Consortium's role in the referendum. Arduous renegotiations managed to clear up the issues and the Consortium took a major leadership role in the successful program.

Other external changes, as noted in Section 2 above, affected the timing of some of the project's activities: Anthem acquired Blue Cross- Blue Shield of Main affecting the model benefits program activity; resignation in top leadership at the Maine Medical Assessment Foundation placed overload strain on MMAF staff; down-sizing in the Maine Osteopathic Association and, importantly, the financial staffing and legislative pressures affecting home health agencies and hospices as well as the nursing home industry. This certainly affected activities in the Northern and Eastern part of the state where organizations were completely focused on survival.

Despite these external changes, a positive side emerged through the years. The Consortium, through its project activity, took advantage of the increased public interest spurred by the PAS, Moyers series, and the Knight-Ridder series. Concerted activity dramatized the need for better service delivery, general public and provider education, advance directives, and the need to be involved at the local level, through coalitions, faith groups, professional associations, as well as at the state level.

The Consortium is grateful to the NPO for serving as a sounding board regarding the PAS and MPB. Further, the information provided regarding changes and happenings at the national level has been invaluable. The “Early word” provided to the Consortium enabled it to plan more strategically and act more effectively.

4. *If you are working in collaboration with other organizations, or depend on other organizations or institutions to meet the objectives of this project, how are those relationships working?*

This was a varied, comprehensive, complex project with multi-partners and was predicated upon a positive collaboration with many groupings. As noted in previous years, these “quid-pro-quo” complementary relationships are necessary to the effort. The Consortium often plays a leadership role with such organizations as Maine Consortium for Comprehensive Cancer Control; Maine Cancer Pain Initiative; Zero Acceptance of Pain Protocol (ZAP); Maine Bioethics Network; Maine Funeral Directors’ Association; and the Jason Program (Pediatric Hospice); various church groupings; the state legislature, the Maine State administration, the national congressional and senate delegation, the Maine Alzheimer’s Association; Task Force on Medicaid Benefit; Maine State Prison System; and Maine Public Broadcasting.

In sum, these collaborations worked very well to the benefit of the EOL initiative. One major insight, pure common sense, was to agree on joint activity that would benefit the greatest number, be deemed as worthwhile activity to devote resources and time, be mutually supportive, keep in constant communication (formal and informal), and mutually nurture and celebrate success!

5. *With a perspective on the entire project, what have been its key dissemination activities?*

The Consortium has produced a range of publications, utilized a series of survey and research instruments, sponsored conferences, meeting and workshops (including nine public hearings, invited testimony to the legislature – all testimony before legislative bodies, on behalf of the Consortium, were by invitation – meetings with Senator Collins), series of presentations, produced a web page and press releases, and approximately 60 print coverage articles. With the advent of the new Strategic Communications Plan, an aggressive impetus utilized print and electronic media.

The Consortium collaborated with PBS on the Bill Moyers program and especially on the “On Our Own” Outreach Program tying the Leadership Training Seminar Video-conference with the Consortium’s Congregational and Coalition building activities. The Coalitions were leaders in the Knight-Ridder series, holding over 30 dialogues and producing over 40 complementary articles tuned to the local level. By December 2001, over 200 community dialogues and 130 focus groups were held by local coalitions.

A “Facilitator’s Handbook” (see bibliography) was disseminated to each Coalition’s facilitators, the “Manual for Building Successful Coalitions” was disseminated to the Coalitions, as well as the Congregations Manual to the congregations. Additionally, over 20,000 area-wide end-of-life resource guides were disseminated. The Outcome Survey “What Does Maine Want” was also disseminated in consortium activities.

The Consortium, through the newly-formed Maine Center for End of Life Care, fully expects to continue and increase collaborative conferences, workshops, educational programs, website information, capacity and multi-media activities.

6. *What are the project's other sources of support? Was total support more or less than expected?*

Program	Cash Match	In-Kind Match	Total Match
Bingham Program	\$30,000		\$30,000
Blue Cross/Blue Shield	\$35,500		\$35,500
Maine Council of Churches	\$15,000	\$700	\$22,700
Home Care Alliance		\$2,400	\$2,400
Maine Health Care Association		\$3,000	\$3,000
Maine Hospice Council	\$8,127	\$55,400	\$63,527
Maine Hospital Association		\$18,000	\$18,000
Maine Medical Association	\$3,000	\$9,000	\$12,000
Organization of Maine Nurse Executives		\$3,300	\$3,300
University of New England		\$13,800	\$13,800

For the most part, the partners all came through with promised cash match. All partners exceeded expectations with in-kind match (donated time, supplies, postage, etc.). Disappointing was the state and national Funeral Director Association's promised financial support. The loss of these monies did not significantly affect project work.

7. *What was the significance of what was accomplished by the project?*

The Community State Partnership initiative brought considerably more attention to barriers impeding quality end-of-life care in Maine, especially during the second year of the grant when Maine was embroiled in a referendum on physician assisted suicide.

The 14 CSP partners underscored the importance of involvement from both the public and private sectors and also highlighted the process of social change and how it takes place.

The partnership proved to be a valuable resource to policy makers during a bipartisan effort to pass comprehensive end-of-life legislation. As a result of this legislation, the Department of Human Services designated the Maine Hospice Council as the host for the Maine Center for End-of-Life Care. It is the intention that the work of the Maine Consortium for Palliative Care and Hospice and the work of the CSP Initiative will continue under the Center. The focus will be on research, education, and advocacy.

8. *What lessons did you, as project co-director of a project in a National Program, learn from under taking this project?*

This has been a very complex but rewarding project. We believe a number of lessons were either learned or reinforced from this project

1. A major lesson for the other NPO activities is: expect and plan for delays in completing large-number activities, build in a process of communication that is adaptable, and find ways to nurture the relationships. NPO has been supportive regarding these challenges, provided suggestions on inter-partner communications.
2. The value of inclusivity as opposed to exclusivity in the project. Everyone can play a role in such a comprehensive project.
3. The need to involve a mix of public and private organizations, health care and non-health care organizations, inclusion of the general public, patients and families.

4. Recognition of the value of the community in the process of change – local coalitions and local congregations.
5. The value of early and continual involvement, informing, educating relevant policy decision-makers such as local, state legislators, and administrators as well as the federal senate and congressional leaders.
6. The need to build upon the capacity of the partner’s work in the past and to recognize and build upon their capacity to engage their constituencies and or clients.
7. Recognition of the over-riding need to constantly work on communication, nurturing relationships, making friends with the media, planning and revising plans, and gaining acceptance of the plan. Expect any change efforts to encounter resistance, so plan for that as well.
8. The value of diversity in the disciplines of the co-directors (in this case, an MD, and MNS, and PhD in Social Policy). This brought a breadth of perspective, knowledge and style to the project.

Finally, for good teamwork, remember “Life is a Quid Pro Quo” and humor is a necessity for survival!

9. *What are the post-grant plans for the project if it does not conclude with the grant?*

In all likelihood, the work of the CSP and the Consortium for Palliative Care and Hospice will come under the Maine Center for End of Life Care, which is a new committee of the Maine Hospice Council. The MCEoL Care was conceived by legislation in 2001 and formally offered to the MHC by the Bureau of Health in the same year. (refer to the organizational chart)

The MCEoL Care will involve many partners, both project and financial. We are in the process of developing a strategic financial plan for the Center, as it came with no fiscal appropriation.

10. *How do you assess the Foundation’s role and the NPO’s role? Have the Foundation’s policies or operations helped or hindered the project in any way? Are their changes to our programmatic oversight, our financial monitoring, or our dissemination activities that might have facilitated or improved the project?*

We can only reiterate that the NPO and the Foundation were extremely supportive and, in fact, proactive in working with the Consortium. Excellent consultation and nurturing was especially helpful during the period of the PAS as well as with the Maine Public Broadcasting problem. We appreciate the provision of increased opportunities for networking, national and regional issues, ideas and the like. The annual conferences were extremely beneficial in these regards, as were opportunities afforded the Consortium regarding communication planning and “heads-up” on what was happening at the national level. Sometimes the “turn-around” on NPO’s assistance was quite short, but this improved as the project progressed.

The major advantage to being part of a national program with multiple grantees was the exchange of information, support, gathering of new ideas and problem solving amongst the grantees. No disadvantage was apparent in this program.