Community-State Partnerships to Improve End-of-Life Care
An RWJF national program

SUMMARY

From 1997 to 2003, the Robert Wood Johnson Foundation (RWJF) funded a national program called Community-State Partnerships to Improve End-of-Life Care. The program supports the work of state-based commissions and task forces to identify and implement changes in policy and practice to improve care for terminally ill patients and their families.

Groups that received funding formed state and local coalitions with other organizations interested in working on end-of-life care policies, and secured matching funding equal to one-third of their RWJF grant. A total of 24 applicants received grants.

RWJF’s Board of Trustees authorized up to $11.25 million in funding for the program in 1997. The Midwest Bioethics Center of Kansas City, Mo., served as the national program office.

Key Results

In furthering statewide projects, site staffs:

- Worked with hospitals and nursing homes to improve the care of dying patients.
  - Seven sites (California, Hawaii, Kansas, Kentucky, Michigan, North Carolina and Rhode Island) provided some form of training for hospital staffs and administrators in addressing the needs of dying patients and improving the quality of their treatment.
  - Sites in Rhode Island, California and North Carolina similarly educated administrators and staff at nursing homes.
  - In 2000, the Rhode Island project, Improving Quality of Care for Our Most Vulnerable Population, convinced 21 nursing homes to form continuous quality-improvement teams. Findings from a pre- and post-intervention study of the Rhode Island work showed a nearly tenfold increase in the rate of comprehensive assessment of pain among these nursing homes during the
project's three-year span. Each nursing home developed pain policies and procedures, which included medication management and the use of non-drug interventions.

- Worked with project partners to provide or improve education about palliative care to professionals in training and practice. The audiences for this professional education fell into two groups: the academic community including students and faculty; and the practicing professional community who require continuing education.
  - Fourteen sites sponsored training for physicians, nurses and pharmacists using a nationally recognized end-of-life care curriculum. These professionals in turn trained their colleagues.
  - Beginning in 2001, the DC Partnership to Improve End-of-Life Care facilitated the training of 16 physicians in the American Medical Association's Educating Physicians on End-of-Life Care (EPEC) project. The EPEC project, though it does not confer continuing education credits, is designed to educate physicians on clinical competencies required to provide quality end-of-life care.

- Worked with project partners to increase demand for and access to quality end-of-life care. Staff held community meetings, focus groups and developed materials for health professionals and the general public to educate and excite them about the need for better care at the end of people's lives, such as palliative care and advance care planning.
  - The Oklahoma Alliance for Better Care of the Dying spurred interest in its work by creating a Palliative Care Week each April that grew to include 70 communities between 1999 and 2002.
  - In six states, legislatures enacted laws requiring new or increased reimbursement for hospice care under Medicaid (Florida, Hawaii, Maine, Nevada, New Jersey and West Virginia).
  - In two states, lawmakers passed legislation that required that all insurers to cover hospice (Maine and New York).

- Held activities to improve advance care planning. Project partners distributed educational materials (which sometimes included advance directives such as living wills and medical power of attorney forms) to patients and others, and helped in efforts to simplify state law regarding advance care planning. Project directors realized that not only the general public but also health care professionals are often confused about the purpose of and process for advance care planning. As a consequence:
  - About a dozen statewide projects led education efforts in the need for advance care planning and provided advance directive forms (to be included in medical records) and assistance to patients in filling them out.
— At least six statewide projects also provided information that helped legislators as they developed policy changes designed to simplify and remove conflicting provisions from legislation and regulations governing advance directive completion.

- Aided those in public policy to encourage physicians to prescribe needed pain medication. Participants in statewide projects helped educate legislators about the importance of requiring professional education on pain control.

**THE PROBLEM**

RWJF funded a study of 9,000 critically ill patients at five major medical centers in the United States. The 1995 findings of the $28-million project—Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT)—confirmed that most Americans die in hospitals, often alone and in pain.

See the RWJF Anthology, *To Improve Health and Health Care* for a full description of the study.

**CONTEXT**

Because the SUPPORT study showed how poorly Americans are cared for at the end of life, soon after its release RWJF staff began meeting with experts in end-of-life care and members of interested medical organizations such as the American Medical Association and the American Nurses Association to plan how to address the issues raised by the study.

Based on this work, RWJF staff in 1996 articulated a three-pronged strategy to improve end-of-life care, intended to inform its grantmaking in this area:

1. To improve the knowledge and capacity of health care professionals and others to care for the dying.
2. To improve the institutional environment in health care institutions and in public policies and regulatory apparatus to enable better care of the dying.
3. To engage the public and professionals in efforts to improve end-of-life care.

**RWJF Funds Other Efforts to Bolster End-of-Life Care**

But even before deciding on its overall strategy, RWJF made its first foray into programming to address the concerns and issues raised by the SUPPORT study in 1995 with the funding of *Last Acts®,* a coalition of professional and consumer organizations dedicated to making the public more aware of end-of-life issues and finding better ways to care for the dying.
Then, in 1997, RWJF created the national program *Promoting Excellence in End-of-Life Care* (for more information see *Program Results Report*). This program funded efforts at a number of clinical and community sites to encourage clinicians to introduce palliative care earlier in patients' diagnoses. Sites also worked to change the culture of medical institutions, which often focus exclusively on cure.

Both *Last Acts* and *Promoting Excellence in End-of-Life Care* sought to overcome educational deficiencies and institutional barriers to adequate end-of-life care. Among those barriers are:

- Physicians, patients and families are reluctant to refer dying patients to hospice because they see hospice care as a sign of giving up.
- Physicians are educated to cure patients and many continue aggressive, cure-oriented treatment into the last stages of disease.
- Physicians are sometimes reluctant to prescribe adequate pain medication because they fear that they will run afoul of the practices and standards of their state medical boards.
- Medical and nursing schools, which train the next generation of health professionals, provide little education about palliative care and advance care planning.
- The Medicare hospice benefit, which requires that patients eligible for hospice have six months or less to live, limits the number of people who can benefit from palliative care.

In addition to public education and clinical improvements, could there be other means to achieving better end-of-life care that RWJF might try?

**States at Center of Decision Making**

Vicki Weisfeld, senior communications officer for RWJF, noted in 2003 that experts in end-of-life care had long recognized the crucial role states and communities play in policy affecting end-of-life care. "These policies need to change in order for lasting improvements to be made," she said.

State policies, for example, affect the delivery of palliative care to people with terminal illness, particularly the amount and quality of pain control. The policy is transmitted mainly through regulations. But sometimes there is a lack of clear guidelines about how often prescriptions for pain medications, which are controlled substances, can be refilled.

While hospice and palliative care insurance benefits vary widely from state to state (and not all states include hospice as a Medicaid benefit), state legislatures have the power to issue laws mandating insurance coverage of hospice and other end-of-life care.
States also establish standards and regulations for nursing homes and other health care facilities—where dying patients sometimes receive less palliative care than they require.

Finally, states and communities have some power to affect the attitudes of new physicians and nurses through influencing what is taught in their publicly funded local medical and nursing schools. In the past, many medical and nursing schools provided little or inadequate education on palliative care and advance care planning.

**Physician-Assisted Suicide**

States are also a primary arena for the debate over a number of end-of-life issues. In the late 1990s, the existence of physician-assisted suicide made headlines when Jack Kevorkian, M.D., admitted that he had assisted in more than 40 patient suicides in Michigan and elsewhere.

The U.S. Supreme Court in 1997 wrote a decision on physician-assisted suicide that left the issue for states to decide. Rosemary Gibson, senior program officer at RWJF, notes that by this time, close to half the states had legislation introduced on physician-assisted suicide.

In 1996–97, RWJF started receiving proposals from states that wanted to build statewide coalitions or commissions on end-of-life care, in part to address issues raised by proponents of physician-assisted suicide and avoid a vote on the divisive issue.

In 1997, RWJF provided a planning grant to support such a project in Maryland (see Program Results Report on ID# 031630) and in 1996 and 1997 provided funding for other convening efforts in Florida and Colorado (see Program Results on ID# 029110 and on ID# 030689).

"We did not want to fund more of these ad hoc efforts," Weisfeld said. "We preferred to do a national program and let people share their ideas and get direction from a national program office, which could bring some coherence to the effort.

"Why have each state reinvent the wheel? On the other hand, some states like Arizona, Alabama and New York had had commissions examining end-of-life care issues for quite a while."

In fact, state-based projects to improve end-of-life care through public policy were already underway in more than 20 states toward the end of the 1990s. But this work was new, people carried it out in isolation from similarly concerned people in other states, and some of the key players lacked background in end-of-life care.
PROGRAM DESIGN

Trying to provide a coherence and framework for state activities, in 1997, RWJF authorized *Community-State Partnerships to Improve End-of-Life Care*.

Under this national program, RWJF was to award up to $11.25 million to fund as many as 25 projects, each with a statewide scope, whose purpose was to promote policies and practices that support high-quality end-of-life care for terminally ill people and their families.

"Our strategy was a combination of state and community interventions. RWJF doesn't usually do that," said Gibson. "It has a lot of state programs but they are not linked with the community."

RWJF asked each statewide project to focus on three goals:

- Build clinical capacity to deliver quality end-of-life care.
- Empower individuals, families and communities to advocate for quality end-of-life care.
- Help reform public policies to support quality end-of-life care.

Educationally, according to Weisfeld, the program intended to work in two ways:

- Statewide project staffs and partners were to gather information from community citizens about their needs and problems in obtaining end-of-life care. Project sites would hold focus groups and town meetings, and help form local coalitions and other partnerships.
- Project participants were to use the information they gathered to help educate policymakers, Medicaid directors and legislators about end-of-life issues. The idea was that the process of providing well-researched information might encourage policy change.

RWJF also expected each program site—or statewide project—to articulate an overall strategy for improving end-of-life care in the state, then monitor the impact of its implementation over a range of areas, such as:

- Promoting a community dialogue about choices at the end of life and the value of meaningful advance care planning.
- Ensuring that academic health centers train future professionals adequately in end-of-life care.
- Encouraging physicians and nurses already in practice to improve their knowledge and skills to care for the dying and their families.
- Asking state medical, nursing and pharmacy boards to develop and improve their knowledge and skills concerning care for the dying and their families.
• Examining the adequacy of public and private health insurance benefits for hospice and palliative care and the feasibility of making these benefits available to the uninsured.

• Making sure that health care providers that practice excellent palliative care are adequately reimbursed.

• Reviewing nursing home regulations for their impact on near-death transfers to hospitals and good pain and symptom management.

• Establishing or revising emergency medical protocols so that patient and family wishes regarding resuscitation are honored—whether the emergency occurs at home, during transport, in a nursing home, in the hospital or elsewhere.

• Collecting data so public policy officials and advocates can evaluate the accessibility and quality of end-of-life care.

Grants were to average $450,000. Applicants who needed to undertake a planning process would be eligible for a $75,000 planning grant and could subsequently apply for an implementation grant of $375,000. RWJF required grantee organizations to secure a matching grant or grants equal to one-third of their RWJF grant.

RWJF staff did not wish the program to result in large new infrastructures that needed to be sustained after funding ended.

Rather, staff hoped that the program would galvanize existing organizations—such as state hospital associations, medical societies, hospice organizations, AARP, councils of churches, medical and nursing schools and other groups—to work together to implement and institutionalize reform that would continue after RWJF funding ended.

THE PROGRAM

The National Program Office

The Midwest Bioethics Center in Kansas City, Mo., served as the national program office. Myra Christopher, president of the center, served as the national program director, and Erika Blacksher served as deputy director.

In 1991, Christopher had been instrumental in designing the Patient Self-Determination Act introduced by U.S. Senator John Danforth. The act requires that health care facilities ask patients if they have chosen a person to make health care decisions for them if they are later unable to do so themselves. An author and frequent speaker on bioethical issues, Christopher has consulted on health policy for health care delivery corporations, regulators, accrediting organizations and national and state legislators. She has also worked with health care organizations seeking to develop internal mechanisms for dealing with ethically complex clinical cases.
Midwest Bioethics Center is a nonprofit, unaffiliated organization that works at the local, regional and national levels to find solutions to ethical problems in health and health care.

**Technical Assistance and Direction**

The national program office provided technical assistance and direction to statewide projects through a variety of means. National program office staff:

- Hosted annual meetings that allowed project staff to network with each other and to hear speakers addressing relevant issues.
- Convened leadership meetings for project managers addressing their specific needs and issues.
- Conducted site visits.
- Monitored bimonthly project reports.
- Encouraged the sharing of best practices among projects through on-site workshops and conference calls.

The national program office distributed technical resources to project staff, including an 85-page *Community Engagement Guide* and a *Media Tactics* newsletter series.

In addition, the program evaluator, Melanie Merriman of Touchstone Consulting, North Bay Village, Fla., provided consulting assistance on evaluation to project staff.

**National Advisory Committee**

Thirteen experts in end-of-life care and public policy comprised the program's national advisory committee. Members of the committee assisted in reviewing grant proposals, participated in site visits and helped monitor the program's operations (see Appendix 1 for a list of members).

**Site Selection and Awards**

RWJF program staff, the national program office staff and the National Advisory Committee together selected the projects that participated in the program. They gave priority to grant applicants with a lead organization able to provide sustained leadership in end-of-life care when RWJF funding ended.

They also sought applicants that gave evidence of a true partnership among statewide leaders representing a variety of stakeholders: physicians, nurses, clergy, ethicists, health care institutions, payers, public officials, consumer organizations and others committed to change end-of-life care.
The applicant pool included state agencies, universities, professional associations, ethics institutes and other bodies that could bring a broad constituency together effectively. Since RWJF funded only one application per state, it encouraged separate organizations to work together on their proposals.

*Community-State Partnerships* staff reviewed 51 applications and awarded 12 planning grants and 23 implementation grants. Two grantees received only planning grants (Indiana and Texas); 10 received both planning and implementation grants. The other 13 projects started with implementation grants; one implementation grant project closed early (New York).

Groups that received RWJF funding secured matching funds equal to one-third of their RWJF grants. In all projects, partners contributed their own resources. Some partners applied membership dues to project work; others donated space, part-time staff or release time allowing their employees to work on project activities; others secured outside grants and donations.

While some projects functioned as partnerships (with formal organization and resource sharing), others were coalitions of organizations working separately toward common goals. Project memberships varied in size, from as few as 16 individuals and organizations to well over 100.

The types of partnering organizations that were involved differed from project to project but included:

- Health care providers
- Hospice organizations
- Community coalitions
- State medical associations
- Advocacy organizations
- Professional associations
- Health professional schools
- State licensing boards and state agencies
- Research organizations
- Religious organizations
- Insurers.

Project staff and partners in Texas used the grant-funded planning as an impetus to continue their ongoing work even though the project did not receive implementation funding under this program.

Implementation grantees received an average of $440,000. Between January 1999 and June 2003, applicants received RWJF funding totaling $9,834,509. For a list of grant recipients, see Appendix 2. For links to Program Results reports on the work of four program grantees, go to the Project List.
CHALLENGES

RWJF established *Community-State Partnerships to Improve End-of-Life Care* at a time when state officials, advocates and citizens were grappling with the issue of legalizing physician-assisted suicide. Much of the program's work—done through local coalitions or partnerships—sought to improve care for the dying so that physician-assisted suicide would not be necessary.

However, these statewide projects ran into several challenges externally and internally, some raised by this broader political context, as well as other factors.

**Substance Abuse Scares**

For example, project staff and partners in Maine found themselves in the midst of a contentious referendum vote on the issue of physician-assisted suicide in November 2000, which threatened to overshadow their work on improving palliative care. The program's work also competed with substance abuse headlines.

Oxycontin is an effective opium-related medication for treating the often severe pain of dying patients. However, in this same period it became a popular drug with substance abusers, an increasing numbers of whom began taking it for temporary pain relief and became addicted or died from an overdose.

This resulted in a proliferation of media stories that also caused difficulty for program sites in Kentucky, Florida and West Virginia—as well as for thousands of physicians throughout the United States who wanted to increase its use, most specifically to fight cancer pain where it is an important and appropriate drug.

Efforts by the some in the federal Drug Enforcement Agency to stem its abuse at this time led many physicians to express legitimate fear of criminal prosecutions for prescribing this underutilized drug, according to NPO staff.

These issues were not the only challenges faced by state programs. During the program's operation, many states faced severe budget deficits, which made it difficult for them to focus on any issues that required additional funding, including initiatives to improve end-of-life care.

**Inclusivity and Diversity Difficulties**

Project directors and investigators faced internal, or structural, difficulties as well. One, as described by RWJF Senior Program Officer Gibson, was that "the program perhaps erred on the side of being too inclusive. The projects got everyone at the table, with the result that it became difficult to focus on two or three strategic moves. Perhaps there were too many interests, too many people in the process. The attitude was 'let's get everyone on board.'"
A second issue was that, while statewide projects in the form of coalitions strived to be inclusive, they were not always successful in recruiting minority members to their work.

According to Erika Blacksher, the deputy director, "Program Director Christopher and I were committed to making sure that the coalitions did not interpret the program goal of 'public engagement' to mean just upper-middle-class white people, but people from diverse backgrounds.

"While some statewide projects did a brilliant job, Alabama being the exemplar, other states struggled. It is difficult to engage minority and marginalized communities around end-of-life issues.

"These communities have more pressing priorities, like access to basic health care. Having nice end-of-life care is like having an ambulance at the bottom of the cliff. Also, difficulties encountered by projects in some states may have had something to do with approaches used by the projects, not the other priorities of minority communities."

The North Carolina End-of-life Care Coalition may be a case study in a project's inability to foster sufficient leadership on end-of-life care in minority communities.

Looking back, staff concluded that their initial attempts to recruit minority leadership lacked a clear understanding of the cultural issues surrounding end-of-life care for minority communities. In retrospect, they realized that such cultural issues are complex, and one cannot simply translate a successful approach used elsewhere out of its original cultural context.

**Staff Turnover**

Burnout and administrative turnover in the projects slowed progress. About a third of directors at statewide projects left their positions during the first 18 months, causing significant disruption.

In response, the national program office convened leadership meetings to address directors' needs and issues. Following those meetings, project leadership became more stable. The statewide projects also faced difficulties in getting their work done due to limited staff, including administrative support.

**Resistance to Change**

Some statewide projects reported that their target audiences exhibited resistance to change, lack of interest or serious time constraints, which impeded progress, according to evaluator Merriman.

These target audiences included health care professionals, provider institutions, clergy and the community at large. "Clergy proved to be a very difficult group to engage,"
according to Merriman. "They had little time for new endeavors and did not initially perceive end-of-life care to be an area where they needed to devote time. At the same time, clergy endorsement and support were critical to engaging congregations." Several sites had difficulties engaging physicians as well.

As a result of these challenges, and based on their experience in the early stage of their projects, nearly all of the statewide projects implemented mid-course corrections. In general, staffs tended to scale down the focus and size of their efforts after discovering that their original plans were too inclusive, given their resources and the length of the funding period.

**The Moyers Effect**

During this national program, RWJF funded a four-part public television series by journalist Bill Moyers on end-of-life care called *On Our Own Terms: Moyers on Dying* (see Program Results Report on ID#s 034625, 035477, 038858, 041076 and 042520).

An outreach component of the Moyers project helped organize and activate local coalitions to take action in their communities to improve care at the end of life. Work by the *Community-State Partnership* projects became a key force in developing these local coalitions.

About two-thirds of the more than 300 community coalitions developed because of the Moyers special were spawned by *Community-State Partnership* projects, according to Christopher. In Iowa alone, 42 local coalitions came together.

While the Moyers series stimulated the creation of new local coalitions that the statewide projects of *Community-State Partnerships* could later draw on, many projects in the program struggled to respond to a flood of requests for speakers and resources following the television series.

**EVALUATION**

In 2000, RWJF hired Melanie Merriman of Touchstone Consulting, North Bay Village, Fla., to carry out an evaluation of the program. RWJF staff envisioned the evaluation as a two-phase project. However, RWJF decided against funding the second phase of the evaluation because of programmatic changes at the foundation.

Under Phase 1, the evaluation focused on four goals:

- To analyze the grantee partnership structures, functions and leadership to identify common elements and differences across grantees.
- To describe common strategies being used by grantees to make change.
- To identify common challenges, strengths and opportunities that grantees found in their communities.

- To gather baseline information on certain indicators of end-of-life care quality and access that would be useful in assessing the measurable impact of the Community-State Partnership projects.

At the end of Phase 1, in a 2002 report to RWJF, Merriman provided baseline data gathered from surveys her firm commissioned in 28 states, as well as end-of-life care indicators derived from existing U.S. databases. See Overall Results of the Program (The Baseline Indicators).

During Phase 1, Merriman and a number of hired consultants with expertise in evaluation and/or end-of-life care also worked with individual project staffs. For the most part, these consultants helped staffs write plans to evaluate their projects, including selection of the type of evaluation method appropriate to their strategies.

The approach, modeled after that of another RWJF national program, Promoting Excellence in End-of-Life Care, called for a team of evaluation consultants at both the sites and the national program office.

According to Seth Emont, former RWJF evaluation officer, "We learned from Promoting Excellence that project staffs need a lot of assistance in evaluating their work because these staffs generally don't have the appropriate tools to do evaluation." Merriman and her consultants also provided case studies of sites to RWJF.

Only seven grantees (Hawaii, Iowa, Kansas, California, West Virginia, Rhode Island, and North Carolina) could show evaluation plans that were completed or in development when RWJF funding for the evaluation ended in January 2002.

The decision by RWJF to stop the evaluation was a source of frustration to some project directors, who felt that they were just learning how to do an evaluation when assistance under the evaluation funding ended.

Although it was truncated, the program evaluation revealed a consistent finding about insufficient focus at many statewide projects. Evaluator Merriman wrote:

*The goal of the first part of the evaluation was to understand the structure of the grantee coalitions or partnerships. How they were putting themselves together, what kind of leadership they had and objectives they settled on. The most important finding was that the grantees did not spend enough time clarifying specific objectives and the methods that would get them there.*
Many grantees had broad objectives and were really planning to work on anything and everything that affected end-of-life care in their state. We were constantly trying to get them to clarify their objectives and be thoughtful about whether their interventions would get them to those objectives. What we did in the first part of the evaluation was reveal that they needed more planning time.

Communications

The national program office communicated with its two-dozen project staffs and other audiences through a variety of publications it created. These included:

- *Media Tactics*, a series of nine newsletters that provided media relations tips on end-of-life care.
- *CSP Update*, twice-yearly inserts to the *Last Acts* coalition newsletter, which described the work and lessons of individual projects.
- *Lightning Rods of Change*, a 60-page program overview.
- *Media Campaign Toolkit* developed in 2000 by consultants. It included television and radio public service announcements, newspaper print ads, posters, brochures and template press releases. These focused on several messages:
  - Encouraging people to have a conversation about end-of-life care
  - Pain management
  - Caring for someone ill
  - Palliative care
  - Putting one's wishes about end-of-life care into writing

Statewide projects used the *Toolkit* materials at their discretion.

In 2000, the national program office contracted with Barksdale Ballard, a communications firm in Tysons Corner, Va., to create television, radio and print advertising materials intended to educate the public and medical caregivers about advance care planning, pain management and palliative care. The national program office distributed these ad messages to program sites.

In 2000, the national program office engaged Wirthlin Worldwide, a communications firm in New York City (ID# 040266) to field test the use of ads in two states, North Carolina and Kansas.
Their post-ad interviews found no indication that the advertising campaign mounted in these two markets was successful in raising awareness of issues of end-of-life care. However, both caregivers and non-caregivers when interviewed responded positively to the messages contained in the ads.

At the end of the program, the NPO expected to publish a special section of the *Journal of Palliative Medicine* that would describe the work of the program and highlight specific statewide projects.

**OVERALL PROGRAM RESULTS**

Program results are drawn from two sources: the program evaluator's 2002 report to RWJF and reports to RWJF by the national program office.

Evaluator Merriman drew several caveats to her findings. At the time of her report, only nine statewide projects had completed their work. It was also difficult to attribute cause and effect to site activities because of other end-of-life care projects operating nationwide.

The evaluator pointed out that the objectives of the sites encompassed comprehensive, long-term change in cultural or social norms and in professional standards and behavior. Even where statewide projects appeared to have met their goals, the full influence of their work might not be discernible for several more years.

The program evaluator and the NPO staff consider the following to be the key results:

- **Project staffs worked with nursing homes and hospitals to improve the care of dying patients.** Seven program sites (California, Hawaii, Kansas, Kentucky, Michigan, North Carolina and Rhode Island) gave training for nursing home and hospital staffs and administrators in how to address the needs of dying patients and improve the quality of their treatment. Among the efforts:
  - Rhode Island, California and North Carolina project staffs educated staff and administrators at nursing homes. For example:
    - The **Rhode Island** project, *Improving Quality of Care for Our Most Vulnerable Population* (ID#s 036178 and 038225), recruited individuals on staff at 21 nursing homes to form continuous quality-improvement teams. Each of these nursing homes also received a toolkit with information on pain management, national pain guidelines and ways to apply continuous quality improvement to strengthen efforts at pain management.
    - Nursing homes’ staff members attended six workshops during 2000 and received instruction from a nurse with both nursing home and quality-improvement experience. As a result of this project work, each nursing home developed pain
policies and procedures, which included medication management and the use of non-drug interventions.

Findings from a pre- and post-intervention study showed a nearly tenfold increase in the rate of comprehensive assessment of pain among these 21 nursing homes.

— Staff at the West Virginia Initiative to Improve End-of-Life Care (see Program Results Report on ID#s 035923 and 038456) in 1999 established palliative care teams at four hospitals and a hospice to:
  
  ● Help terminally ill patients receive comfort care at the end of their lives.
  
  ● Educate health professionals about hospice care.

Teams headed by a nurse worked with dying patients, their families and physicians to provide pain and symptom management, advance care planning and support for the patient and family.

According to the project director, these consultations reduced hospital costs by $2,000 per consult. The cost reductions resulted from patients' shorter lengths of stays and fewer laboratory tests, radiological examinations and days in the intensive care unit.

● Project staffs and partners worked to provide and/or improve education about palliative care to professionals in training and practice. The audiences for this effort at professional education fell into two groups:

  — The academic community including both students and faculty.
  
  — The practicing professional community who require continuing education.

Staffs at several project sites trained physicians and nurses using "Education on Palliative and End-of-Life Care" (EPEC), a nationally recognized end-of-life care curriculum developed with support from RWJF (see Program Results Report in Targeted End-of-Life Projects Initiative on ID#s 030204, 036767, 039301, 039847, 040507). These individuals in turn trained their colleagues.

— The District of Columbia Partnership to Improve End-of-Life Care (grant ID#s 036322 and 038203) in 2001 and 2002 facilitated training of 16 physicians through the Education on Palliative and End-of-Life Care (EPEC) project funded by RWJF through its Targeted End-of-Life Projects Initiative. See Program Results Report on ID# 040507, etc. on the EPEC project.

EPEC is designed to educate physicians on clinical competencies required for quality end-of-life care. In this period, project staff also held an annual conference for nurse educators on end-of-life care and encouraged nursing schools to include end-of-life care in their curricula.
At Howard University, all medical students must be EPEC trained to graduate. The Georgetown University School of Nursing and Health Sciences instituted a master's-level course in end-of-life care for a short period of time.

— Staff at the **Nevada Center for Ethics and Health Policy** (ID# 036180) trained 12 rural end-of-life care teams consisting of physicians, nurses and pharmacists during 1999–2002. The care teams educated local consumers and providers about pain, palliative care and other end-of-life care issues, and assisted providers and others in developing health policy regarding these subjects.

— The **Oklahoma Alliance for Better Care of the Dying** (ID#s 036196 and 037636) spurred interest in its work by celebrating a Palliative Care Week each April. Staff created the event in 1999 to highlight Oklahoma University School of Medicine's new Palliative Care Program. The week included lectures and other activities for health care professionals and students.

Project staff later expanded this effort to include more than 70 communities across the state. A news conference at which the governor of Oklahoma officially declared a Palliative Care Week and kicked off activities by signing his own advance directive aided their work.

- **Project staffs and partners worked to engage and empower individuals and communities to increase demand for better care at the end of life.** The partnerships conducted community assessments to learn about the issues of concern with respect to end-of-life care.

They also conducted widespread public education via speaker's bureaus and train-the-trainer efforts that built "lay" capacity for advance care planning assistance within the community. In several cases, the partnerships built grassroots support for change efforts through the development of local coalitions.

— Staff at **Alabamians for Better Care at Life's End** (ID# 038454) sponsored more than 30 meetings throughout the state between 2000 and 2002—most of them in African-American communities—to learn about community needs for end-of-life care.

Project staff also surveyed clergy and physicians and reviewed state policies on end-of-life care, as well as curricula in Alabama's health professional schools. The process culminated in a 2001 statewide public consensus meeting to develop a strategy to address end-of-life care needs in Alabama.

Nearly 100 individuals attended the two-day retreat, including physicians, nurses, public health professionals, state policy-makers, and members of vulnerable communities (according to the project's director "vulnerable" refers to populations that could experience a diminished access to care because of disparities due to race, geography or socioeconomic status).
— The California Coalition for Compassionate Care (ID#s 036287 and 037784) in 1999 created a *Community Education Kit* to promote the message that individuals and families need to consider end-of-life care well in advance of a medical crisis. Staff tailored the materials to reach diverse groups, including Chinese- and Spanish-speaking audiences.

Approximately 25 local coalitions throughout California used the kit—which included one guide for making end-of-life care decisions and another for group discussion—as their core activity in reaching community members.

— Staff and project partners at the North Carolina End-of-life Care Coalition (see Program Results Report on ID#s 036258 and 038474) carried out a public education campaign in 2000–2002 that included the training of health care professionals and others in advance care planning.

Those trained in turn trained their colleagues and people in their local communities. The project supplemented this training with educational materials to help people talk about their wishes at the end of life and to increase their use of forms, such as *advance directives*, making those wishes known.

- **Several projects focused on providing information to legislators concerning issues with access to end-of-life care in their state.** Between 2000 and 2002 six state legislatures enacted laws requiring new or increased reimbursement for hospice care under Medicaid:
  
  — Florida  
  — Hawaii  
  — Maine  
  — Nevada  
  — New Jersey  
  — West Virginia

The laws were at least in part due to the education efforts of this program’s statewide projects, according to the NPO and evaluator. Lawmakers in Maine and New York enacted legislation that required insurers to cover hospice.

— The Maine Consortium for Palliative Care and Hospice (see Program Results Report on ID# 036223) worked with a range of groups formed after a divisive 2000 referendum that narrowly defeated legalized physician-assisted suicide in the state. Members of the consortium contributed funds from membership dues to the project.

The Maine legislature charged the consortium with submitting annual reports on access and accountability in end-of-life care. This information helped the legislature craft new legislation to improve end-of-life care. The legislation increased the state's Medicaid hospice reimbursement rate, funded Maine hospice volunteer programs and mandated that private insurers in Maine pay for hospice care.
• Project staffs held activities to improve advance care planning, including the provision of information to legislators about the need for new laws. "At the beginning of this program, every state in the U.S. had living will legislation and durable power of attorney," said Program Director Christopher. "Some of these laws were old, and pretty antiquated with clumsy features. Some of the requirements that were burdensome have been removed."

Individual project directors also realized that health care professionals and the general public were confused about the purpose and process for advance care planning. Thus, many statewide projects led efforts to educate people about the need for advance care planning.

Project staff provided advance directives and medical powers of attorney and assistance in filling them out. Staffs also directed some education efforts at state associations of physicians, nurses, nursing homes and hospitals. Among the work by statewide projects:

— Staff at Kokua Mau (see Program Results Report on ID# 036297), the Hawaii project, took advantage of a change in the state's driver's license requirements to make it possible for people to designate on their licenses that they have an advance directive. Hawaiian citizens can also submit those directives to a database that is available to hospitals and other health care facilities.

— Staff from at least six statewide projects worked with groups that were separately funded, providing them with information needed to simplify and remove conflicting provisions from legislation and regulations governing advance directive completion:
  • California
  • Washington
  • The District of Columbia
  • North Dakota
  • Rhode Island
  • Hawaii
  • Rhode Island
  • West Virginia

— Staff and project partners at the West Virginia Initiative to Improve End-of-Life Care (see Program Results Report on ID#s 035923 and 038456) focused on ways to make it easier for patients to communicate their wishes about end-of-life care and to assure that health professionals follow their wishes.

Staff undertook data gathering, providing information to the state legislature when asked. Their work helped establish a convincing case for legislative change (including the establishment of the West Virginia Center for End-of-Life Care, a state-funded public education resource center).
Staff also disseminated the "Physician Orders for Scope of Treatment" (POST) form, a standardized document that incorporates a patient's advance directive and is signed by a physician.

Subsequent physicians treating the patient would be required to follow the orders on the form. The document would also provide legal protection to health care professionals, hospices and nursing homes as they follow patient's preferences about life-sustaining measures. In 2002, West Virginia's legislature incorporated the POST form into state law.

- **Project staffs educated legislators and members of state licensing boards about the importance of requiring professional education on pain control.** Staff in at least five projects provided information to state boards as they worked to craft new standards for pain management:
  - California
  - Florida
  - Kansas
  - North Carolina
  - West Virginia

According to Program Director Christopher, health care professionals are far more compelled to alter their practice when the entities that license them encourage this, than when a law is passed. Among the changes that took place at state licensing boards:

- **In Florida,** the state's pharmacist licensing board implemented a new pain management certification that requires pharmacists to undertake regular, continuing education to maintain certification.

- **In West Virginia** (see Program Results Report on ID#s 035923 and 038456), the state boards of medicine, nursing, pharmacy and osteopathy developed a joint policy statement with the goal of promoting better pain management at the end of life, which the legislature subsequently enacted in 2002.

According to project staff, the West Virginia law now:

- Gives health care professionals clear guidance on the type of prescribing practices that are acceptable to control pain in dying patients.

- Provides protection to health care professionals who practice according to this policy statement.

- Encourages adequate pain relief for dying patients.

**The Baseline Indicators**

Beginning in 1999, program evaluator Merriman (ID# 038540) assembled data and trend information on indicators of end-of-life quality and access.
She employed data from commissioned surveys administered in 28 states, including all states with projects under the program, and data gathered yearly or semi-yearly by U.S. health care organizations and other sources, including:

- The American Board of Hospice and Palliative Medicine
- The Hospice and Palliative Nurses Association
- The American Medical Association
- The American Hospital Association
- A number of state legislative websites

In 2002, Merriman reported the following to RWJF:

- Nationally, the number of physicians and nurses certified in palliative care increased between 1999 and 2001, but there are still considerably more professionals certified in oncology than in palliative care. In every state with a Community-State Partnership project, the number of health care professionals trained and certified in palliative care increased between 1999 and 2001.

In several states, according to Merriman, these increases seem attributable to project strategies to increase the number of EPEC trainers in the state, and to offer preparation for certification exams to nurses. In 28 states, including states with a Community-State Partnership project, more survey respondents reported being a member of palliative care team than are certified in palliative medicine or palliative nursing home care.

- Less than 20 percent of nearly 6,000 hospitals responding to a 2001 American Hospital Association survey (1200 hospitals) provided any kind of specific end-of-life services; however, this was a huge increase over the number of hospitals (50) in 1995. Nursing homes in the evaluator's survey reported somewhat higher levels of palliative care services. There was no difference between nursing homes in program states and those in non-program states.
  - A greater percentage of survey respondents reported being a member of a palliative care team than are certified in palliative medicine or palliative nursing care.

- The number of health care professionals trained and certified in palliative care increased in every state with a project in Community-State Partnerships between 1999 and 2001.

- Approximately 50 percent of nurses and physicians surveyed in 2001 did not know about opportunities to obtain continuing education on end-of-life topics. A majority reported that they were likely to participate in end-of-life care continuing education, but did not know where to find such training.
• Less than 50 percent of nurses and physicians surveyed in 2001 reported feeling comfortable or very confident with certain tasks and skills of palliative care. These included discussing treatment preferences with patients and their families, identifying psychosocial and spiritual needs, and breaking bad news.

• In a 2001 survey of state associations representing physicians, nurses, nursing homes and hospitals in 28 states (including all program sites' states), more than 50 percent of state associations reported no committees or task forces addressing end-of-life care issues.

• Data from the American Medical Association in 2001 show that 86 percent of U.S. medical schools include some end-of-life care content in their curriculum. According to Merriman however, the program's 23 projects identified several schools during the grant period (1999–2002) where the content was absent or inadequate.

LESSONS LEARNED

In a 2002 report of interim findings to RWJF, the evaluator noted some lessons common to the statewide projects that achieved all or most of their goals. The deputy director added additional lessons:

1. **Statewide project coalitions or partnerships of people who had worked together on the program's issues before RWJF grant funding seemed to begin their work more quickly and have more success early on.** Partnerships that came together specifically for a statewide project had to spend considerable time for different staffs to get to know one another and to become a cohesive group. (Evaluator)

2. **The development of local coalitions, whether part of the original plan or not, contributed significantly to the growth of statewide projects both in terms of their geographical presence and level of influence within the state.** In North Carolina and Florida, the projects used existing connections with hospices to develop local coalitions early on in their project work.

   In all states, the outreach project of the Moyers PBS series *On Our Own Terms*, a four-part public television series on the cultural medical, ethical and spiritual aspects of death and dying in America (see Program Results Report on ID#s 034625, 035477, 038858, 041076 and 042520) became a catalyst to increase the number and cohesion of local groups. (Evaluator)

3. **It appears that the work of statewide projects is sustained longer when the project's objectives and strategy are incorporated into the fabric of the lead or coordinating agency.** According to the program evaluator, successful incorporation of goals tends to continue program efforts beyond the period of RWJF support, a critical transition.

   Illustrating this idea, the Hospice for the Carolinas changed its name to the Hospice for the Carolinas and End-of-Life Care (see Program Results Report on ID#s
036258 and 038474) to reflect—like the statewide project it led—a clearer focus on palliative care and end-of-life care issues. (Evaluator)

4. **Organizations that started small but planned effectively and "fanned the flames" of their efforts still attracted the interest of funders and health care providers.**

The **Florida Partnership for End-of-Life Care** (ID#s 037917 and 038540) sought to prepare pharmacists to advice physicians about appropriate use of opium-related analgesics that fell within state regulations. Project staff offered only a single training session and set an initial limit on the number of participants in order to gauge the level of interest among pharmacists.

The session was oversold by a factor of two, and this response attracted additional support from the Health System Pharmacists Associations.

The **West Virginia Initiative to Improve End-of-Life Care** (see Program Results Report on ID#s 035923 and 038456) asked for RWJF funding for just a few palliative care teams but gathered data to demonstrate convincingly that the teams could support themselves. Later, other funders and hospitals asked them to expand the program and to develop a palliative care team network. (Evaluator)

5. **Statewide projects that achieved policy changes focused on linking public policy to the concerns of private lives.** An examination of projects in Minnesota (ID# 037635), Maine (see Program Results Report on ID# 036223) and Hawaii (see Program Results Report on ID# 036297) showed that the site directors and partners in these states secured change by focusing on finding common ground with citizens' interests.

Further, these partnerships realized that stakeholders in those interests are more likely to implement policy that they have helped to shape. Each project framed end-of-life policy issues as public health concerns, emphasizing the ways that care of the dying affects everyone in the community, including the most vulnerable. (Evaluator)

6. **A strong visionary leader is essential to a project or coalition with statewide reach.** These leaders were the glue that held successful projects together. Project staffs experienced little turnover in these positions and the leaders were seen as credible, unbiased and capable of bringing the necessary partners and resources to the work.

It appears that partnership members need to spend time finding and cultivating project directors who can provide this sort of leadership. Unfortunately, in some cases, partnerships hired people who did not have experience, which resulted in problems. (Evaluator and NPO/Blacksher)

7. **Statewide projects that underwent an explicit vision and mission planning process, framed in terms of shared values, worked better together and stayed better focused over the course of the project.** (NPO/Blacksher)
8. Focusing on a few carefully crafted strategies for which partners have committed resources was a better course for a statewide project than putting effort into many different areas to see which ones take root. (Evaluator)

9. To reach significant numbers of health care professionals, it is better to offer continuing education for them in small doses and at venues already attended by target audiences, than to try and hold separate meetings devoted only to end-of-life care issues. Examples of such existing venues are local and state professional meetings, institutionally based training, and institutional grand rounds. (Evaluator)

10. The educational efforts of project staffs, particularly those aimed at a community audience, should be targeted to those who are "primed" to receive it. In most cases, "primed" audiences were older individuals and current and future caregivers (mostly women aged 40 and over). (Evaluator)

11. Taking a system-wide approach is essential in making any long-lasting change. Most health care reform is not just about the health care system, but touches on many aspects of the community and other sectors of society.

A multi-faceted "ecological” approach that engages a community, develops awareness and does it in cooperation with civic groups, state and local leaders and professionals appears essential to any health care reform. (NPO/Blacksher)

AFTERWARD

Statewide projects in Maine (ID# 036223) and West Virginia (ID#s 035923 and 038456) have evolved into state-sponsored centers to address issues in end-of-life care.

Of the remaining projects funded under this program, the national program director believes that as many as half will continue to function in the absence of RWJF funding. Several projects have received funding from RWJF's Rallying Points initiative (ID#s 042520 and 042603), a $12-million effort that encouraged community coalitions to: advocate for health system changes and develop projects to support dying people and their families.

Prepared by: Susan G. Parker
Reviewed by: James Wood and Molly McKaughan
Program Officers: Victoria D. Weisfeld and Rosemary Gibson
## APPENDIX 1

### National Advisory Committee

*(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)*

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Paul W. Armstrong, M.A., J.D., L.L.M.</strong></td>
<td>Judge, Superior Court of New Jersey, Family Division, Somerville, N.J.</td>
</tr>
<tr>
<td><strong>Lenore B. Duensing, M.Ed.</strong></td>
<td>Public Relations and Media Specialist, Tuxedo, N.Y.</td>
</tr>
<tr>
<td><strong>Bernice Harper, M.S., M.P.H.</strong></td>
<td>Medical Care Advisor, U.S. Department of Health and Human Services, Rockville, Md.</td>
</tr>
<tr>
<td><strong>Gema Hernandez, D.P.A.</strong></td>
<td>Former Secretary, Florida Department of Elder Affairs, Tallahassee, Fla.</td>
</tr>
<tr>
<td><strong>Susan Goldwater</strong></td>
<td>Executive Director, Hospice of the Valley, Phoenix, Ariz.</td>
</tr>
<tr>
<td><strong>David E. Joranson, M.S.S.W.</strong></td>
<td>Director, Pain and Policy Studies Group, Madison, Wis.</td>
</tr>
<tr>
<td><strong>Debbie Rubenstein</strong></td>
<td>Public Affairs Television, Inc., New York, N.Y.</td>
</tr>
<tr>
<td><strong>Charles P. Sabatino, J.D.</strong></td>
<td>Assistant Director, Commission on Legal Problems of the Elderly, American Bar Association, Washington, D.C.</td>
</tr>
<tr>
<td><strong>Jack Schwartz, J.D.</strong></td>
<td>Chief Counsel, Opinions and Advice, Maryland Attorney General's Office, Baltimore, Md.</td>
</tr>
<tr>
<td><strong>Marian Gray Secundy, M.S.S., Ph.D.</strong></td>
<td>(deceased) Professor Emeritus, Howard University, Washington, D.C.</td>
</tr>
<tr>
<td><strong>Susan Tolle, M.D.</strong></td>
<td>Director, Center for Ethics in Health Care, Oregon Health Sciences University, Portland, Ore.</td>
</tr>
<tr>
<td><strong>Steven C. Zweig, M.D., M.S.P.H.</strong></td>
<td>Professor and Coordinator of Geriatric Activities, University of Missouri-Columbia School of Medicine, Columbia, Mo.</td>
</tr>
</tbody>
</table>
APPENDIX 2

Sites and Site Grantees

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

Alabamians for Better Care at Life's End
University of Alabama at Birmingham (Birmingham, Ala.)
$449,038 (January 2000 to September 2003) ID# 038454
  John Lee Shuster, M.D.
  (205) 975-8197
  shuster@uab.edu
  Website: www.palliative.uab.edu

California Coalition for Compassionate Care
California Health Foundation and Trust (Sacramento, Calif.)
$340,000 (January 2000 to July 2002) ID# 037784
  Judith J. Citko, J.D.
  (916) 552-7573
  jcitko@calhealth.org
  Website: www.finalchoices.calhealth.org

Connecticut Coalition to Improve End-of-Life Care—Better Endings
Sage Services of Connecticut (New Haven, Conn.)
$75,000 (January 1999 to December 1999) ID# 035924
  Louis Zaccaro
  (203) 777-7401
  sageservices@snet.net
  $375,000 (January 2000 to December 2001) ID# 038453
  James Duff, M.D.
  (860) 545-2629
  jduffy@harthosp.org
  Website: www.canpfa.org

District of Columbia Partnership to Improve End-of-Life Care
DCHA Program Services Company (Washington, D.C.)
$75,000 (February 1999 to December 1999) ID# 036322
$374,708 (March 2000 to December 2003) ID# 038203
Joan Panke  
(202) 289-4923  
jpanke@dcha.org

**Florida Partnership for End-of-Life Care**
Florida Hospices and Palliative Care (Tallahassee, Fla.)
$449,960 (October 1999 to October 2002) ID# 037917  
Samira K. Beckwith  
(941) 489-9140  
samibeck@aol.com

**Kokua Mau Project**
State of Hawaii (Honolulu, Hawaii)
$450,000 (January 1999 to August 2003) ID# 036297  
Marilyn R. Seely  
(808) 586-0100  
msreely@mail.health.state.hi.us  
Website: [www.kokuamau.org](http://www.kokuamau.org)

**Iowa Partnership for Quality Care in Dying with Dignity**
University of Iowa (Iowa City, Iowa)
$74,999 (January 1999 to December 1999) ID# 036251  
$375,037 (January 2000 to June 2003) ID# 038458  
Douglas S. Wakefield, Ph.D.  
(319) 335-9822  
douglas-wakefield@uiowa.edu

**Kansas LIFE Project: Living Initiatives for End-of-Life Care**
Life Project Foundation (Wichita, Kan.)
$74,829 (January 1999 to December 1999) ID# 035931  
$375,000 (January 2000 to December 2002) ID# 037599  
Donna Bales  
(316) 263-6380  
donna@lifeproject.org  
Website: [www.lifeproject.org](http://www.lifeproject.org)

**Journey's End: A Kentucky Partnership for Quality End-of-Life Care**
Kentucky Hospital Research and Education Foundation (Louisville, Ky.)
$73,880 (January 1999 to June 2000) ID# 036262
$376,093 (January 2000 to December 2002) ID# 038202
Cynthia A. Keeney
(502) 426-6220
ckeen@kyha.com

Maine Consortium for Palliative Care and Hospice
Maine Hospice Council (Manchester, Maine)
$450,000 (January 1999 to December 2002) ID# 036223
Kandyce Powell
(207) 626-0651
kpowell@mainehospicecouncil.org
Website: www.mainehospicecouncil.org

Michigan Partnership for the Advancement of End-of-Life Care
Michigan Hospice Organization (Lansing, Mich.)
$449,984 (January 2000 to December 2002) ID# 038452
Penny Murphy
(517) 886-6667
chateaux24@aol.com

Minnesota Partnership to Improve End-of-Life Care
Metropolitan Area Agency on Aging (St. Paul, Minn.)
$445,080 (October 1999 to February 2002) ID# 037635
Edward R. Ratner, M.D.
(651) 641-8618
eratner@tcaging.org

Nevada Center for Ethics and Health Policy
University of Nevada (Reno, Nev.)
$440,310 (January 1999 to June 2002) ID# 036180
Barbara Thornton
(775) 784-4041 x 249
thornton@unr.edu
Lawrence J. Weiss
(775) 784-4774
weisslj@unr.edu
New Hampshire Partnership for End-of-Life Care
Foundation for Healthy Communities (Concord, N.H.)
$449,747 (November 1999 to December 2002) ID# 037881
   Shawn V. LaFrance
   (603) 225-0900
   slafrance@nhha.org
   Website: www.healthy nh.com/index-fhc.php

Establishment of a Statewide Program to Improve End-of-Life Care
New Jersey Health Decisions (Verona, N.J.)
$450,000 (December 1999 to November 2002) ID# 038219
   Gary L. Stein
   (973) 857-5552
   healthdec@aol.com

Carolinas Center for Hospice and End of Life Care
Carolin as Center for Hospice and End-of-life Care (Cary, N.C.)
$75,000 (January 1999 to December 1999) ID# 036258
$375,000 (January 2000 to December 2002) ID# 038474
   Gwynn Sullivan
   (919) 677-4117
   gsullivan@carolin asendoflifecare.org
   Website: www.carolin asendoflifecare.org

Matters of Life and Death Project
North Dakota Medical Research Foundation (Bismarck, N.D.)
$75,000 (February 1999 to November 1999) ID# 036224
   Catherine Rydell
   (701) 223-9475
$371,593 (January 2000 to December 2002) ID# 038457
   Bruce T. Levi, J.D.
   (701) 223-9475
   blev i@ndmed.com
   Website: www.ndmed.com

Oklahoma Alliance for Better Care of the Dying
Oklahoma Association for Healthcare Ethics, Inc. (Oklahoma City, Okla.)
$373,683 (October 1999 to July 2002) ID# 037636
Laura Cross, J.D., R.N.
(405) 239-4300
lauracross@okhealthlawyer.com

**Improving Quality of Care for Our Most Vulnerable Population**
Brown University (Providence, R.I.)
$69,839 (January 1999 to August 1999) ID# 036178
$380,161 (February 2000 to January 2003) ID# 038225
Joan M. Teno, M.D.
(401) 863-1606
joan_teno@brown.edu

**Partnership to Improve End-of-Life Care in Utah**
HealthInsight (Salt Lake City, Utah)
$74,404 (January 1999 to December 1999) ID# 036179
$374,964 (January 2000 to December 2003) ID# 038455
Jay A. Jacobson, M.D.
(801) 408-1135
ldjacob@ihc.com

**West Virginia Initiative to Improve End-of-Life Care**
West Virginia University Foundation (Morgantown, W.Va.)
$75,000 (January 1999 to December 1999) ID# 035923
$375,000 (January 2000 to December 2002) ID# 038456
Alvin H. Moss, M.D.
(304) 293-7618
amoss@hsc.wvu.edu
Website: [www.hsc.wvu.edu/chel/wvi](http://www.hsc.wvu.edu/chel/wvi)

**Project closed early**
Health Research (Albany, N.Y.)
$268,903 (January 1999 to February 2001) ID# 036292
Ernestine S. Pantel, Dr.P.H.
(212) 305-7354
esp4@columbia.edu
Planning grants only
Indiana University (Bloomington, Ind.)
$63,833 (January 2000 to December 2000) ID# 037819
   David H. Smith, Ph.D.
   (812) 855-0261
University of Texas Medical Branch at Galveston (Galveston, Texas)
$74,709 (January 1999 to December 1999) ID# 036296
   Ronald A. Carson, Ph.D.
   (409) 772-2376

APPENDIX 3

Glossary

Advance care planning—Advance care planning involves talking about one's wishes for future medical care in the event one is unable to make one's own decisions about care. Those discussions typically include a doctor and people who will act as health proxies if patients are no longer able to speak for themselves.

Advance directives—An advance directive is a living will and medical power of attorney that spells out an individual's wishes for care if they can no longer speak for themselves.

Palliative care—Palliative care is an approach to care that addresses the patient's physical, emotional, social and spiritual needs and seeks to improve quality of life not only for the ill person, but also for his or her family. It is usually provided by interdisciplinary teams, often including physicians, nurses, social workers, chaplains or spiritual counselors and other health care professionals. Palliative care is similar to hospice care in that it emphasizes providing comfort care to a patient including pain relief, but it can begin earlier than hospice care—the latter typically starting only when a physician certifies that a patient probably has six months or less to live. Palliative care also includes treating depression and anxiety, and helping dying patients and their families discuss their wishes at the end of life. See also advance care planning and advance directives.
BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Articles


Reports


Radtke J. *Citizen Engagement Toolkit.* Kansas City, MO: *Community-State Partnerships to Improve End-of-Life Care.*


**Audio-Visuels and Computer Software**


**Survey Instruments**


**Grantee Websites**


**Sponsored Conferences**

"First Annual Meeting," March 24–26, 1999, Virginia Beach, VA. Attended by 82 people, including the principal investigators and project directors of each of the 15 projects, RWJF end-of-life care workgroup members and NPO staff.

"Second Annual Meeting," March 29–31, 2000, Chicago. Attended by 105 people, including the principal investigators and project directors of each of the 23 coalitions, leadership from five non-funded end-of-life coalitions (Massachusetts, Ohio, Georgia,
Wisconsin and Vermont), speakers, RWJF end-of-life care workgroup members and program office staff.


"Third Annual Meeting," May 16–18, 2001, Kansas City, MO. Attended by approximately 85 participants, including principal investigators and project directors from each of the 21 coalitions and an unfunded coalition from Massachusetts.


**Evaluation Bibliography**

**Reports**


Merriman MP and Norris K. *Evaluation of the Community-State Partnerships to Improve End-of-Life Care: Not a Randomized Controlled Trial*. Unpublished.

**Survey Instruments**


PROJECT LIST

Reports on the projects managed under this National Program are listed below. Click on a project's title to see the complete report, which typically includes a summary, description of the project's objectives, its results or findings, post grant activities and a list of key products.

- **Divisive Debate Drives Maine to Improve End-of-Life Care** (Grant ID# 36223, October 2004)
- **Hawaii Overcomes Cultural Barriers to End-of-Life Care** (Grant ID# 36297, September 2006)
- **North Carolina Spreads the Word About End-of-Life Care Rights** (Grant ID# 38474, etc., October 2004)
- **West Virginia Clarifies End-of-Life Care Laws** (Grant ID# 38456, etc., June 2008)