

State Initiatives

in End-of-Life Care

Issue 19, June 2003

Focus: Community-State Partnerships

Championing End-of-Life Care Policy Change



Drew Edmondson, (left) Oklahoma Attorney General and president of the National Association of Attorneys General (NAAG), consults with key state coalition leaders about protection of seriously ill consumers at the NAAG Conference on End-of-Life Care in Baltimore, May 15–16, 2003.

Also pictured are (from left) Judi Lund Person, vice president for policy at the National Hospice and Palliative Care Organization (NHPCO) and former leader of the North Carolina coalition of the Community-State Partnerships to Improve End-of-Life Care (CSP) Program; Gwynn Sullivan RN, MSN, director of North Carolina Community Outreach, the Carolinas Center for Hospice and End-of-Life Care; and William M. Polk, director, Victims and Citizens Services Section, North Carolina Department of Justice—Attorney General's Office.

Edmondson is just one of a growing number of high-level state policy leaders who for the past four years have formed partnerships with CSP coalitions to improve state policy affecting end-of-life care. This issue of State Initiatives explores these partnerships and the policy-related achievements of the CSP program.

INSIDE

- **Community-State Partnerships: Origins and Legacies**
PAGE 2
- **Powerful Change Agents: The Coalitions' Influence on Public Policy**
PAGE 3
- **Nine Activities of Policy Entrepreneurship**
PAGE 4
- **Mapping Coalition Policy Successes**
PAGE 5
- **The Partnerships as Policy Entrepreneurs**
PAGE 6
- **Contact Information for CSP Coalitions**
PAGE 8

Community-State Partnerships: Origins and Legacies

Among West Virginia’s citizens is a large group of former coal miners, now aging and suffering from an array of chronic, progressive illnesses: black lung, emphysema, cancer, and the like. The state has one of the highest rates of in-hospital deaths—where aggressive life-saving intervention is often performed, but to no avail—coupled with one of the lowest rates of nursing home deaths. So when a request for proposals was issued in 1998 to fund state coalitions working to improve end-of-life care, those already engaged in this issue in West Virginia ran for the brass ring, formally establishing one of 21 Community-State Partnerships (CSP) to Improve End-of-Life Care.

Four years later, evidence of West Virginia’s policy successes abounds: a comprehensive Health-Care Decisions Act was passed; hospitals were seeded with interdisciplinary palliative-care teams; the state’s four professional licensing boards issued a joint policy on pain management; a public engagement campaign involved the governor in promoting advance care planning; a Physician Orders for Scope of Treatment, an advance care planning form, was incorporated into existing law; the legislature mandated continuing education in end-of-life care for health care professionals; and the crown jewel, a palliative care resource center, was established and financed with funds committed by a state well known as one of the country’s poorest.

What was the foundation of the policy successes of this and the other CSP coalitions, all of which saw outstanding achievements? According to an independent evaluation, it was their “policy entrepreneurship.”



“Policy entrepreneurship’ describes the coalitions’ activity: they worked collectively to bring together ideas, expertise, and time, all of which legislators didn’t have, in the hopes of a return—improved public policy for end-of-life care.”

Melanie Merriman, president,
Touchstone Consulting

“Policy entrepreneurship’ describes the coalitions’ activity: they worked collectively to bring together ideas, expertise, and time, all of which legislators didn’t have, in the hopes of a return—improved public policy for end-of-life care,” notes Melanie Merriman, president of Touchstone Consulting, which conducted an independent review of the CSP coalitions. “The way the policy entrepreneurs differ from business entrepreneurs is that policy entrepreneurs such as the CSP coalitions are motivated by altruism and focused on the public good.”

In addition to public policy reforms, CSP initiatives undertook a host of other reform efforts. These 21 initiatives implemented projects to empower and educate patients, families, and communities to advocate for better end-of-life care; build clinical capacity among physicians, nurses, social workers, pharmacists, clergy, and other professionals; and establish mechanisms for quality improvement at the institutional level in hospitals and long-term care facilities. Funded by The Robert Wood Johnson Foundation, the \$11.25 million CSP program enabled coalitions of providers, academic institutions, insurers, policymakers, and consumer organizations to work together toward several ends:

- removing barriers to good care
- developing policies and implementing practices to promote excellent care
- creating public understanding about end-of-life care choices
- monitoring their efforts’ impact

This issue of *State Initiatives in End-of-Life Care* explores the program’s primary policy accomplishments, as well as the nontraditional activities and processes that enabled the coalitions to engage their publics and to change policy and culture in their communities and states. ■

Powerful Change Agents: The Coalitions' Influence on Public Policy

The Anatomy of a Successful Coalition

Statewide coalitions play a vital role in health policy reform. With the right leadership and modest resources, state coalitions can bring together organizations with diverse and perhaps even competing interests, harness their resources and talents, and focus them on a shared vision and goals.

Key structural features enabled the coalitions to achieve policy success. The coalitions counted many diverse kinds of organizations in their membership: governmental agencies, professional licensing boards, consumer advocacy groups, academic institutions, medical providers, and media organizations, as well as individuals from across the states. Far from just participating on a conference call per month, coalitions were active at the grassroots level on leadership teams, steering committees, and task forces, and many leaders volunteered time to coalitions on top of full-time jobs. Some of the state coalitions were made up of existing local coalitions, which allowed them to make use of networks and relationships already in place:

- The North Carolina coalition not only used an existing coalition structure, they tripled its membership.
- In Florida, state hospice service areas morphed into local coalitions that carried out much of the work on the CSP agenda.
- The Kansas coalition made innovative, exemplary use of the state extension agency.
- The D.C. coalition included several national associations in its membership, as well as local, grassroots groups, making up a rich mix of stakeholders that has been able to achieve success on a wide range of issues.

The evaluation concluded that the coalitions are “powerful change agents” in their states. “The partnerships are focal points for statewide [end-of-life] care initiatives and an important link in the expanding network of end-of-life care activists,” Merriman wrote.

Coalitions influenced policy change in five broad areas, as indicated in the following discussion and the table on page 5.

Expanding Reimbursement Mechanisms

Coalitions helped increase access to end-of-life care through policy changes requiring Medicaid and private insurers to pay for hospice and other palliative care services. In Maine, for example, after a referendum on assisted suicide was defeated, the coalition began to educate legislators about the need for better reimbursement for hospice. Working with the coalition, the legislature enacted “the ideal hospice package,” says Kandyce Powell, RN, MSN, co-director of the Maine Center for End-of-Life Care and the Maine Hospice Council.



“The CSP coalitions had a profoundly positive impact on their communities in terms of public education. They held public forums on advance care planning—that was a huge undertaking and a major success. Also, they held dialogues around the Moyers series, raising consciousness so that the public could take charge of their own experiences of the end of life.”

Sylvia McSkimming, executive director,
Supportive Care of the Dying: A Coalition for
Compassionate Care

In their efforts to educate policymakers about the need for better reimbursement for palliative care therapies and medications, some coalitions paid special attention to their Medicaid programs, since Medicaid is the primary reimbursement mechanism for prescription medication therapy. In Oklahoma in early 2003, for example, coalition leaders teamed with the Assistant Attorney General to advise the Oklahoma Medicaid program that a change requiring Medicaid HMO physicians to obtain prior authorization for prescribing more than 60 tablets of an opioid medication was not in the best interest of patients.

Some coalitions were able to secure state sponsorship for centers devoted to fostering better end-of-life care. Despite the worst state budget crisis ever, four CSP coalitions—Kentucky, Maine, Nevada, and West Virginia—have received financial and other support from their legislatures for permanent resource centers in end-of-life care.

Continues on page 4

**Powerful Change Agents:
The Coalitions' Influence on Public Policy**
Continued

Improving Pain and Symptom Management

The professional licensing boards in Kansas, North Carolina, and West Virginia, working with CSP coalitions, issued joint policy statements on the use of controlled substances in the treatment of pain at the end of life, sending clear messages to physicians that it's acceptable to use opioids to treat pain without fear of investigation. West Virginia is the only state to include all four boards, while Kansas's statement addresses the pain treatment in chronic, acute, and terminal situations.

Another way CSP coalitions worked to improve pain management was to encourage providers to assess pain as a vital sign. In 2001 the Joint Commission on the Accreditation of Health Care Organizations (JCAHO) began to require accredited health care facilities to assess pain as the fifth vital sign. At that time, CSP coalitions reached out to help local hospitals as well as nursing homes implement the new standards.

Raising the Bar on Educational Requirements

The coalitions helped legislators interested in requiring professionals to obtain training in end-of-life care. The coalitions also helped increase capacity to deliver end-of-life care through education of licensed health care professionals (including not just doctors but also nurses and social workers) and changes in medical school curricula. "We're one of only about three or four states that require continuing education for recertification," says Alvin Moss, MD, director of the West Virginia University Center for Health Ethics and Law, and a leader of the West Virginia coalition. "Every licensing period,

Nine Activities of Policy Entrepreneurship

Coalitions are "policy entrepreneurs" because they...	Policymakers benefit because...
...neutralize special interests and defuse contentious policy issues	...they can enter safe waters, focusing on a public health issue that affects everyone
...orchestrate reform efforts, coordinating and connecting the dots	...they can be free to focus on the big picture of improving end-of-life care
...leverage resources—including not only money but also time and influence—by building private-public partnerships	...they appreciate the wise use of resources
...engage the public to create informed and mobilized constituents	...their work is made easier: they can access these publics and trust that their values and views have been sought out, listened to, and acted on
...build consensus around a social, public good	...they can focus on the issues around which there is public support and a political mandate
...provide access to credible sources	...they can tap directly into a fund of bipartisan, objective knowledge and research
...produce servant leaders, grounded in the collective good rather than their own personal advancement	...they trust and relate to leaders who have the public's best interest at heart, can implement policy in creative ways, and can be called on to function as "SWAT teams" when necessary
...collect data about the issues and make it available to the public	...they have access to ready and reliable data that illustrate the issues and help clarify the best policy options
...engage the news media	...the news media is attuned to end-of-life data, stories, and experts

doctors have to get two hours in end-of-life care and pain management. This has been wonderful. . . . Doctors go in saying, 'I resent the legislature telling me what I need to know.' They come out saying, 'Boy, I didn't know this stuff—this has been really helpful.'

Simplifying Advance Care Planning

From 2002 to 2003, three state legislatures—Maine, Michigan, and West Virginia—passed important policy packages that removed barriers to good advance care planning and palliative care. Coalitions in these states

educated policymakers about the need for living wills, do-not-resuscitate orders that are filed and followed by emergency medical personnel, and surrogate decisionmakers who may make medical care choices for patients who can no longer do so. In addition, the coalitions established public engagement workgroups that trained 400 community facilitators to educate the public. "We recruited and trained community facilitators to shift the focus from complying with regulations to engaging people in the advance care planning process," says Shawn LaFrance, MS, MPH, director of the New Hampshire coalition.

Continues on page 6

Mapping Coalition Policy Successes

Policy Areas	Alabama	California	Connecticut	District of Columbia	Florida	Hawaii	Iowa	Kansas	Kentucky	Maine	Michigan	Minnesota	Nevada	New Hampshire	New Jersey	North Carolina	North Dakota	Oklahoma	Rhode Island	Utah	West Virginia
Finance/Reimbursement																					
Make progress in expanding Medicaid/Medicare EOLC* reimbursement policy	•				•	•				•	•			•						•	•
Sponsor palliative care resource centers	•		•	•		•		•	•	•	•		•			•					•
Broaden private insurers' EOLC* coverage						•			•	•		•									
Make progress in removing barriers to hospice access/eligibility		•			•	•		•	•	•	•			•					•	•	•
Pain & Symptom Management																					
Bring pain policy in line with current medical practice		•	•		•				•		•		•		•	•			•	•	•
Require professional education	•	•			•		•			•			•		•	•	•	•	•		•
Support consumer education about pain control	•		•		•	•	•	•	•	•	•	•	•	•	•					•	
Support the issuance of pain policy statements by licensing boards		•			•			•	•	•	•		•		•	•				•	•
Inform the adoption of model guidelines by medical board					•			•	•	•	•		•			•				•	•
Address balance in diversion policy	•	•	•		•	•		•		•	•										•
Educational Requirements																					
Require continuing ed/recertification in EOLC*		•		•									•		•				•		•
Expand EOLC* curricula in state-supported schools	•	•	•	•	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•	•
Require EOLC* competency for licensing													•						•		
Advance Care Planning																					
Support model legislation or Uniform Acts	•	•				•				•							•			•	•
Support laws to mandate honoring of patients' EOLC* treatment choices			•	•	•		•			•	•				•			•		•	•
Support state forms including guardianship and surrogacy policies	•	•	•	•	•	•		•			•		•	•			•		•	•	•
Win policy leader support for public information campaign					•	•		•			•		•	•		•		•		•	•
Quality of Care																					
Require EOLC* training for surveyors		•			•					•									•		
Establish quality indicators	•	•	•			•			•	•	•			•					•		•
Educate regulators about quality indicators		•	•				•			•	•	•							•		•
Work with medical examiners on unattended death				•							•	•								•	

*End-of-Life Care

**Powerful Change Agents:
The Coalitions' Influence on Public Policy**
Continued

Improving Quality of Care

The coalitions helped nursing homes establish quality indicators for pain management and palliative care and to report their performance to the public. This work on quality indicators may have more general benefits: there is growing consensus that improving end-of-life care within nursing homes leads to improved care for all patients. In addition, coalitions held meetings with directors of nursing homes, state regulators, and surveyors to resolve misunderstandings about the role of hospice care in nursing homes and other regulatory topics.

The Rhode Island and California coalitions undertook particularly extensive quality improvement projects. The California coalition trained nursing home administrators, physicians, and nurses in how to have effective end-of-life discussions with patients and families; state surveyors also received training. The Rhode Island coalition's project with 21 nursing homes resulted in a tenfold improvement in assessing pain for all residents—not just those at the end of life—with more than half of the facilities showing significant improvement. “It’s exciting to take research findings and apply them in a practical way on a population level,” says Joan Teno, MD, MS, associate professor of Community Health and Medicine at Brown University’s Center for Gerontology and Health Care Research and project director for the Rhode Island coalition. “We’re not going to change the quality of end-of-life care until we work on this as a public health intervention.” ■

The Partnerships as Policy Entrepreneurs

One reason coalitions were able to have such a timely and enduring impact was that they were engaged in creative, entrepreneurial activities and processes that laid the groundwork for policy change. These activities, according to the evaluation, demonstrate the ways in which the coalitions are “policy entrepreneurs” (see table, p. 4).

Producing Servant Leaders

The quality that differentiated the coalitions as policy entrepreneurs from entrepreneurial businesses was that they were headed by “servant leaders”—“who make serving employees, customers and the community their number one priority,” Merriman wrote in Touchstone’s evaluation. Servant leaders, she added, are humble and reflective; flexible, open-minded, collaborative, and patient. They inspire others to work toward a clear vision, and they possess and use their reputation, influence, and powers of persuasion to bring the required players to the table.



“The coalitions have a philosophy of inclusiveness and dialogue. They were stubbornly persistent—they kept calling the meetings, and people came... Policymakers at the health systems level looked at the coalitions and said, ‘These are people with energy who are going to help us do something we want to do anyway.’ The coalitions’ goals were in natural alignment with those of health care systems.”

Michael Garland, DScRel, emeritus professor of Public Health and Preventive Medicine, Oregon Health & Science University (OHSU), and associate director, OHSU Center for Ethics

Neutralizing Special Interests and Defusing Contention

Servant leadership along with representation from so many sectors of the health care industry and the public gave the coalitions the ability to help find middle ground and therefore keep policy discussions from moving toward the extremes. Best illustrating this capacity, perhaps, are the ways in which coalitions responded to proposals to legalize assisted suicide. The Maine coalition conducted focus groups to determine the public's opinion, then educated citizens about how improved end-of-life care could dispel their desires for assisted suicide. After the referendum failed, the coalition further built consensus by inviting as many groups to the table as possible, including vocal supporters of assisted suicide and right-to-life groups.

Powell attributes her coalition's successes to its focus on "galvanizing the grassroots to look at themselves as change agents in the policy arena," she says. "The 'real' legislators need to hear from the talking heads, but they also need to hear from the constituents. I really believe that it's only when the silent majority speaks up that things change."

Orchestrating Reform Efforts

The coalitions' diverse, inclusive memberships also enabled them to establish productive relationships with other stakeholders in their states. Coalitions in two states—Rhode Island and North Carolina—illustrate how such relationships enabled the coalitions to achieve reforms.

Through its nursing home quality-improvement project, the Rhode Island coalition orchestrated reform by helping long-term care facilities develop continuous quality improvement policies and procedures and by



"When you work in a coalition, you have to give up part of your own individual identity to work toward a common good. You need a critical mass of people who understand that. It takes a lot of trust. Such people are far more likely to succeed than those who are accustomed to working only within their own organization."

Marge Ginsburg, MPH, executive director,
Sacramento Healthcare Decisions

encouraging physicians to treat pain more assertively. They also added a systems-level part to the symphony by educating legislators who were revising a law to allow doctors to fax prescriptions to nursing homes rather than having to provide original copies. The coalition knew that the institutional-level reforms would not stick without the policy reform to support them. "Really early on, we focused on making it easier for people to do the right thing," says Rhode Island's Teno.

In North Carolina, the name and mission of the lead agency, formerly called Hospice for the Carolinas, changed from a focus on a special interest—hospice—to a coalition of organizations serving a public good—end-of-life care. Now called The Carolinas Center for Hospice and End-of-Life Care, the coalition's shift in name and mission illustrates its movement toward orchestrating reform efforts on multiple fronts. The coalition came to be seen as a group that generated collaborations and provided information. "We were viewed as a collaborative force, the place that had the information," says Judi Lund Person, formerly the project director of the coalition, now a vice president at the National Hospice and Palliative Care Organization. "People said about us, 'We know that the Carolinas Center has lots of information from different sources, or if they don't, they can point us somewhere.'"

Person says that relationships—bringing diverse stakeholders to the table—

were behind each of the coalitions' successes. "I can almost hear detractors saying, 'Yeah, yeah, so you brought people together, so what?'" she says. "But bringing people together is so critical. I've said this a thousand times—it's all about relationship."

Building Consensus around a Public Good

Fostering relationships and their altruistic motivations enabled the coalitions to build consensus around the public good of end-of-life care. One of the best examples of how the coalitions built consensus among diverse groups occurred in Alabama, where the coalition spent most of its time trying to establish credibility among residents whose access to and quality of health care was below standard. "We knew that in focusing on African-American populations, we were going to have a credibility problem," says John L. Shuster, Jr., MD, director of the University of Alabama-Birmingham Center for Palliative Care and leader of the Alabama coalition. "Our coalition was composed mostly of people who were white, from larger cities, and based in universities." So coalition leaders decided to spend their time building consensus around the social good of end-of-life care. Rather than "sitting in some conference room somewhere" and drafting a list of barriers to end-of-life care, Shuster says, the coalition reached out through faith communities and held public hearings "to make sure we really heard what they were saying." As a result, the Alabama

The Partnerships as Policy Entrepreneurs
Continued from page 7

coalition counts more than 3,000 residents and organizations as active members, and it has received funding from the National Cancer Institute (NCI) to study racial and economic disparities in access to hospice care.

The D.C. coalition used similar methods to build consensus around professional education. “The reason the partnership has been so effective is because we’re all able to come together on neutral ground—all the partners have been at the table since day one,” says Joan Lewis, project director of the D.C. coalition. “No individual, no discipline is given preferential treatment. Our partnership represents hospitals, hospices, community organizations, professions not related to health care—we have lots of attorneys, for example—and just interested individuals. It’s very neutral, which creates a safe environment to share ideas.”

Leveraging Resources

The coalitions used relationship-building and servant leadership to leverage other resources. “Leveraging resources is not only raising money, it’s also leveraging someone’s power and ability to draw attention—their influence,” says the Maine coalition’s Powell. The Maine coalition leveraged the visibility of a clerk emeritus of the State House who during the project was diagnosed with Lou Gehrig’s disease. “He told me he wanted to do everything he could do [for the coalition] for as long as he could do it,” Powell says. He used his story to illuminate for his former colleagues in the legislature the need for improved palliative care.

Continues on page 9

Contact Information for CSP Coalitions

The following is a list of coalitions participating in the CSP program. For more comprehensive information about each individual coalition, please refer to a forthcoming issue of the *Journal of Palliative Medicine*, which will be dedicated to the CSP program, as well as *Lightning Rods of Reform*, available from the Midwest Bioethics Center offices (see page 10 for contact information).

Alabamians for Better Care at Life’s End

Phone (205) 975-9815
www.abcle.org

California Coalition for Compassionate Care

Phone (916) 552-7573
www.finalchoices.calhealth.org

Connecticut Coalition to Improve End-of-Life Care—Better Endings

Phone (203) 237-4556
www.canpfa.org/endoflife/index.htm

District of Columbia Partnership to Improve End-of-Life Care

Phone (202) 682-1581
www.dcha.org/EOL/eol.htm

Florida Partnership for End-of-Life Care

Phone (850) 878-2632
www.floridapartnership.org

Hawaii: Kokua Mau

Phone (808) 586-7285
www.kokuamau.org

Improving End-of-Life Care in Iowa

Phone (319) 335-8708
www.public-health.uiowa.edu/EndOfLife

Kansas: Living Initiatives for End-of-Life Care (LIFE)

Phone (316) 263-6380
www.lifeproject.org

Kentucky: Journey’s End

Phone (502) 592-4551
www.journeysendky.org

Maine Center for End-of-Life Care

Phone (207) 626-0651
www.mcpch.org

Michigan Partnership for the Advancement of End-of-Life Care

Phone (517) 886-6667

Minnesota Partnership to Improve End-of-Life Care

Phone (651) 917-4626

Nevada Center for Ethics and Health Policy

Phone (775) 327-2309
www.unr.edu/nehcp

New Hampshire Partnership for End-of-Life Care

Phone (603) 225-0900
www.healthynh.com

New Jersey Comfort Care Coalition

Phone (973) 857-5552
www.njcomfortcare.org

North Carolina: The Carolinas Center for Hospice and End-of-Life Care

Phone (919) 677-4100
www.carolinasendoflifecare.org

Matters of Life and Death Project—North Dakota

Phone (701) 223-9475
www.ndmed.com

Oklahoma Alliance for Better Care of the Dying

Phone (405) 236-2280
www.okabcd.org

Rhode Island: Improving Quality of Care for Our Most Vulnerable Population

Phone (401) 863-9630
www.chcr.brown.edu/commstate/homepagewithframes.htm

Partnership to Improve End-of-Life Care in Utah

Phone (801) 892-6626
www.carefordying.org

The West Virginia Initiative to Improve End-of-Life Care

Phone (304) 293-0662
www.wvinitiative.org

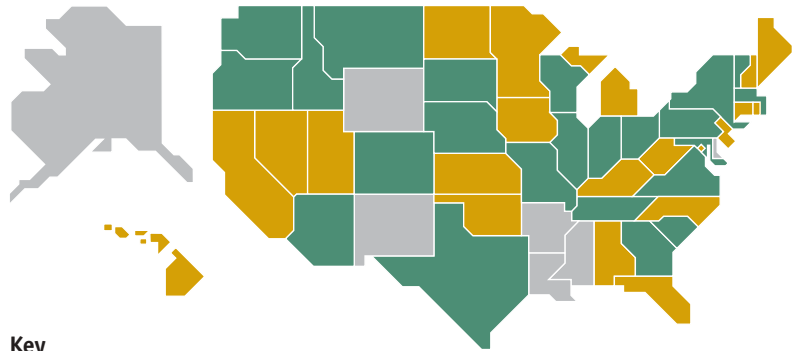
The Partnerships as Policy Entrepreneurs
Continued from page 8

Leveraging resources also meant building partnerships between the public agencies and private organizations. By the end of the Rhode Island coalition’s nursing home quality project, the coalition had found a permanent home in the attorney general’s office. “We didn’t just give them presentations—we *partnered* with them,” emphasizes Teno. “This gave us legitimacy and gave the project a life beyond the original grant. People were no longer saying, ‘This is something Brown University is doing.’ It became, ‘This is something *our state government* is doing.’”

Informing the Public

By helping policymakers access and mobilize the public, the coalitions made policymakers’ work easier. Policymakers could trust that the public’s needs and views had been sought out and listened to. The Iowa coalition, for example, activated key leaders in 54 communities, and the Kansas coalition worked in more than 30 “caring communities” around the state. These leaders coordinated community engagement activities—holding town hall meetings, conducting focus groups, and training facilitators to educate the public about advance care planning and other issues. They also joined with leaders in other communities across the state to increase public awareness and listen to citizens’ concerns about end-of-life care. Without changing any statute or law, pain management can improve because the public’s expectation for better pain management and palliative care “has been ratcheted up,” says Donna Bales, director of the Kansas coalition. “To me, that’s

Statewide End-of-Life Care Initiatives



Key

- Community-State Partnerships States
- State End-of-Life Care Coalitions

improving public policy—it’s giving information and education to consumers and public policy leaders alike.”

Engaging the Media

Coalitions also used print and broadcast media to engage the public. To maximize editorial sensitivity to end-of-life care events and issues, coalition leaders got media representatives involved both as participants in coalition activities and as coalition members. Kansas, for example, counted the state press and broadcast associations as members; so when Knight-Ridder newspapers offered a 15-week series of stories about end-of-life care in 2001, the newspaper in Lawrence, a university community, not only ran the series but also created stories with local angles to pair with each installment. In addition, the paper’s editor held training sessions for coalition members about how to persuade other Kansas newspapers to buy into the series. Community libraries kept laminated copies of the series on their bulletin boards.

Providing Access to Credible Sources and Expertise

The coalitions integrated and built on existing, interprofessional “issue networks.” For example, one network might connect academic researchers in the state who study pain management, cancer treatment, and medical ethics. Another might connect providers who care for terminal patients—hospice, nursing homes, and hospitals. Policymakers benefited from this activity because it gave them access to bipartisan, objective knowledge and research—people who understand the subtleties of the policy issues. “What enabled us to build consensus was that we were able to bring together a core group of folks who had clinical expertise and credibility,” says Marge Ginsburg, MPH, executive director of Sacramento Healthcare Decisions and codirector of the California coalition. The coalition provided access to clinical experts in pain management and palliative care for state legislators who wished to sponsor bills to promote better end-of-life care.

As one result, California law now requires all medical schools to include end-of-life care in their curricula and all health care facilities to assess pain as a vital sign.

Gathering and Releasing Data

Another way the coalitions engaged the public and policymakers was to collect and disseminate data about public needs and values.

The Maine coalition conducted focus groups with residents about their opinions on assisted suicide and used that data to inform an educational campaign during the debate surrounding a referendum on that issue. And in Rhode Island, coalition members surveyed bereaved family members, examined state mortality files (which showed the increasing role of nursing homes in care of dying patients), and documented high rates of persistent severe pain among nursing home residents. The coalition made its findings public through newspaper stories, a conference sponsored by the Office of the Attorney General, and in the *Rhode Island Medical Journal*. These data informed revisions in the state intractable pain law and amendments to the pain assessment act, which now requires all licensed health care facilities to conduct and document pain as a vital sign. “We were able to take the data, engage our state government with it, and work with a large coalition to implement what had been legislated,” says Rhode Island’s Teno.

A Well-Oiled National Network

In addition to hundreds of individual state policy success stories, the CSP program also has a bigger story to tell, according to Myra Christopher, president and CEO of Midwest Bioethics Center and director of the national program. “We’ve created a vibrant national infrastructure that can respond quickly and effectively to important health issues,” says Christopher. “It’s a well-oiled network that enables us to do more together than we could do alone.” This network helps coalition leaders learn from one another’s mistakes and respond collectively to crisis issues, such as illegal diversion of pain medication.

Sustainability is always an issue, notes Christopher, but more than half of the coalitions have found some ongoing funding for staff while others continue to convene stakeholders and tackle important issues on a volunteer basis. “These are passionate and dedicated servant leaders,” she says. “No matter what their funding status, they will continue their extraordinary work and make a real difference in the lives of seriously ill and dying persons and their loved ones.” ■

Information about the Series

“Community-State Partnerships—Championing End-of-Life Care Policy Change” is the nineteenth in a series of briefs profiling promising new policies and practices in end-of-life care.

Executive Editor:

Myra Christopher

President and CEO, Midwest Bioethics Center

Director, Community-State Partnerships National Program Office

Researcher and Writer:

Jennifer Matesa

Associate, Spann Publications Consulting, LLC, Pittsburgh, PA

Designer:

Rob Henning

Rob Henning Design for Spann Publications Consulting, LLC

State Initiatives in End-of-Life Care is a publication of Midwest Bioethics Center (MBC) in cooperation with Last Acts. MBC directed the Community-State Partnerships national program office (1998-2003), a program supported by The Robert Wood Johnson Foundation. MBC continues to provide resources and education about ethical issues in health and health care to advocates, policymakers, professionals and consumers.

To Order Publications

To order copies of this publication, phone, write, or fax Midwest Bioethics Center at the following address and reference **Issue #19** in your request.

Previous issues of this series are also available. Midwest Bioethics Center will provide a list of available back issues upon request. Only Issue #3 is out of print.

Midwest Bioethics Center

1021-1025 Jefferson Street
Kansas City, MO 64105-1329

Telephone (816) 221-1100

Fax (816) 221-2002

E-mail partners@midbio.org

Web site www.midbio.org



To Order Audio Programs

To order Parts I, II, III, or IV of the new *State Initiatives* audio series, *Heart-to-Heart: Improving Care for the Dying through Public Policy*, visit www.partnershipforcaring.org/statepolicy/audioseries/ or call **1 (800) 989-9455**.



Last acts.

A national coalition to improve care and caring at the end of life

Last Acts is a coalition of more than 1,100 national and local organizations dedicated to improving end-of-life care. For more information about the Last Acts campaign, contact

Partnership for Caring

1620 Eye Street—Suite 202
Washington, DC 20006-4017

Telephone (202) 296-8071

Fax (202) 296-8352

E-mail lastacts@aol.com

Web site www.lastacts.org

(go to “Activities” and click on “Publications” for the series in PDF format)

All State Initiatives Audio Programs Now Available

For information about *Heart-to-Heart* audio programs on pain, policy heroes, children, and cultural diversity, call **1 (800) 989-9455** or visit <http://www.partnershipforcaring.org/statepolicy/audioseries/>