Hawaii Overcomes Cultural Barriers to End-of-Life Care

Establishment of a statewide collaborative program to improve end-of-life care

SUMMARY

Between 1999 and 2002, Kokua Mau—a statewide project in Hawaii—took advantage of several legislative and policy changes in the state to educate its public about advance care planning.

Advance care planning involves communicating about one's wishes for future medical care in the event one is unable to communicate them.

The project was part of the Robert Wood Johnson Foundation's (RWJF) national program Community-State Partnerships to Improve End-of-Life Care.

Key Results

- Kokua Mau members developed a public awareness campaign to increase the use of advance directives.

- Project staff encouraged residents of Hawaii to add an advance directive designation to their driver's license or civil identification card.

- Project staff helped Hawaii's network on aging bring end-of-life care information and resources to its constituency—primarily people 65 and older.

Key Findings

Data reported in 2001 by the University of Hawaii Center on Aging, a member of Kokua Mau, revealed progress on several measures important to this project:

- The number of residents of Hawaii over 65 years old completing advance directives\(^1\) increased 10 percent from 1998 to 2000, as measured by the statewide Behavioral Risk Factor Surveillance Survey.

\(^1\) 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.
• Some 21 percent of all renewed Hawaiian drivers' licenses in 2002 carried the AHCD, or advanced health care directive, designator.

• Statewide hospice admissions increased 20 percent from 1999 to 2001, and referrals at the state's largest hospice increased 48 percent during 2002.

**Funding**

RWJF funded the project with a grant of $450,000 between January 1999 and August 2003.

**THE PROBLEM**

Health care professionals in Hawaii faced some cultural barriers in improving end-of-life care. "There are traditional beliefs that make it taboo to talk about death and dying," said Jeanette Koijane, project manager at the state's Executive Office on Aging. "If you talk about dying, you will bring it on."

In late 1996, Hawaii's Governor Benjamin J. Cayetano appointed representatives from the fields of medicine, nursing and law, and from churches and temples, foundations, government and the media to serve on the state's Blue Ribbon Panel on Living and Dying with Dignity. Cayetano's father had Alzheimer's disease and he was caring for him; his father would wander off and get lost and the governor would be on television looking for him. As a result, he understood better than most the set of issues facing people in the last chapter of life.

The panel published four recommendations for improving end-of-life care. In 1997 and 1998, as an offshoot of its subcommittee meetings, a group of about 25 people representing organizations with interests in improving end-of-life care began to meet to facilitate the implementation of these recommendations.

**THE PROJECT**

In 1999, the group received a grant from RWJF supporting implementation efforts, which fell primarily into areas of public and professional education, policy adjustment and systems analysis. At that time, the group named itself Kokua Mau, which means continuous care. In its first year of existence, its partners matched RWJF funding.

Kokua Mau's leadership team represented four organizations or constituencies with four approaches to implementation:

• Hawaii's Executive Office on Aging served as the lead agency and provided policy analysis and information to policy-makers and health care regulatory boards.
• The Hawaiian Islands Hospice Organization (the state's hospice organization) took responsibility for increased public awareness of end-of-life issues.

• The St. Francis International Center for Healthcare Ethics focused on integrating end-of-life topics into medical and nursing education.

• The Center on Aging, a research and education center at the University of Hawaii Medical School, took responsibility for research and evaluation and for developing culturally appropriate resources for churches and temples.

According to former project director Joanna Crocker, Kokua Mau members and participants decided early on not to establish a freestanding program or resource center that might disappear once RWJF funding ended. Instead, they focused on strengthening existing institutions to carry out work in end-of-life care in the hopes that the work would become a permanent part of these institutions’ regular activities. All of the partner organizations contributed additional funding. (See the Appendix for partner organizations and their contributions.)

RESULTS

• **Kokua Mau members developed a public awareness campaign to increase the use of advance directives.** The start of the grant coincided with adoption of two new laws in Hawaii in 1999 that: (1) made it easier for citizens to make their wishes known and followed concerning their care at the end of life; and (2) required all health plans in the state to guarantee room-and-board reimbursement in hospice facilities.

Project participants seized on this period of changes to educate professionals and residents of Hawaii about advance care planning and end-of-life care. Staff at the Hawaiian Islands Hospice Organization created a speakers bureau comprised of volunteer health care professionals. In the period 1999 to 2001, 17,000 people statewide attended a speakers bureau event. Audiences ranged from Hawaii’s Retired Chinese Federal Accountants Club to grand rounds at the largest trauma hospital in the Pacific.

To help engage lay audiences, project staff developed an eight-minute video that featured Hawaii citizens of different ethnic backgrounds and ages talking about their choices for end-of-life care. This team also crafted radio and television public service announcements containing advance directive information.

• **Project staff encouraged residents of Hawaii to add an advance directive designation to their driver's license or civil identification card.** This is a designation similar to an organ donor's, indicating that they have completed an advance health care directive form. During 2000, a new state law ended the use of social security numbers as identifiers on drivers' licenses and state civil identification.
The change meant adults in the state had to obtain a new driver's license or identification.

With urging from the project staff, Hawaii's Executive Office on Aging encouraged the state's Division of Motor Vehicles and Hawaii's Civil Identification Branch to allow citizens to add an "AHCD" designation (Advanced Health Care Decision) on their driver's license or civil identification. The DMV supplied advance directive short forms as well as posters and brochures on advance directives to all drivers' license stations in the state. A project partner also developed an Internet-based program that scans and stores (or "banks") an individual's advance directive. Under this system, the individual's drivers license or civil identification card with an "AHCD" designation instructs health care providers in Hawaii (and on the U.S. mainland) to access the individual's stored advance directive when he or she is admitted to a health care facility.

- **Project staff helped Hawaii's network on aging bring end-of-life care information and resources to its constituency—primarily people 65 and older.**
  The federal Older Americans Act of 1965 created a network of state aging units and area agencies on aging to help with an array of services for Americans over 65, including meals on wheels, personal care and transportation.

  These agencies typically employ hotlines to direct callers to resources, but staff them with people who have no training or information on end-of-life care resources, including advance directives and hospice care. During the RWJF grant period, the Archstone Foundation provided matching funds leveraged as the result of the RWJF grant to coordinate the training of members of Hawaii's aging network in just these end-of-life issues, and to replicate this model nationally.

  Hospice staff trained both staff and volunteers from county-area agencies on aging and from Hawaii's State Health Insurance Program on end-of-life issues and resources. They developed an issues advocacy guide and resource kit about end-of-life care and sent it to every state unit on aging in the country as well as to relevant national organizations. They also trained staff in the state units on aging in Arizona, New Mexico, Utah and Washington.

- **The Center on Aging developed and disseminated training materials for clergy to use with their congregations.** In interviews with ethnic minority adults in 1999, many respondents said they had not thought much about end-of-life issues and would look to their churches for guidance. Subsequent Kokua Mau interviews with clergy across all cultural settings, however, suggested that many were not up-to-date on advance directives and end-of-life care, and they did not have the training and resources to lead discussions or provide end-of-life counseling.

  In 2000, the Center on Aging created and introduced "The Complete Life Course," two 12-session guidebooks that help groups explore issues related to dying and bereavement. The course can be adapted to the needs of various groups. Those using the course during the grant period included 35 physicians, 128 community service
providers, 90 faith-based outreach workers (including clergy) and more than 105 senior citizen members of local AARP and related groups.

As of December 2001, approximately 30 faith communities and 300 congregants across the major islands of the state had completed the course.

**Findings**

Data reported in 2001 by the University of Hawaii Center on Aging, a member of Kokua Mau, revealed progress on several measures important to this project:

- The number of residents of Hawaii over 65 years old completing advance directives increased 10 percent from 1998 to 2000, as measured by the statewide Behavioral Risk Factor Surveillance Survey.
- Some 21 percent of all renewed Hawaiian drivers' licenses in 2002 carried the AHCD, or advanced health care directive, designator.
- Statewide hospice admissions increased 20 percent from 1999 to 2001, and referrals at the state's largest hospice increased 48 percent during 2002.

**Communications**

In addition to the educational activities listed above, project staff established a website, which provides information about Kokua Mau and how to improve end-of-life care in Hawaii. The site offers a downloadable advance directive form, "The Complete Life Course" materials for clergy and others and additional resources.

Project members spoke about their work at national conferences, most significantly the December 2001 National Association of State Units on Aging. Members also authored a chapter of a book, *Cultural Issues in End-of-Life Decision Making,* and journal articles about their work, including one in the 2001 *Journal of the American Geriatrics Society.* Another article by them is scheduled for publication in the *Journal of Palliative Medicine* (see the Bibliography for details).

**LESSONS LEARNED**

1. **Use reliable information to focus or direct the work of mission-driven project partners to achieve project goals.** Because of their funding status, project staff could not lobby or request changes to laws, but they could provide reliable information. For example, when project staff informed staff in the government Office on Aging that, according to the Department of Motor Vehicles, adding an AHCD designator to licenses would have minimal impact on their operations, the Office on

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2 **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.
Aging was able to recommend legislation so to have the AHCD designation added to the law that prescribes the content of the driver's license. (Project Director)

2. **Do not try to start a separate resource center or organization; instead strengthen an existing institution.** Pursuing the latter is a lot cheaper, it is an effective way to develop partners, and the work that project staff put in place is not as vulnerable to the vagaries of funding. (Project Director)

**AFTERWARD**

Kokua Mau's partnering organizations have incorporated much of the project's work into their missions and strategic plans. In 2003, the department of geriatric medicine at the University of Hawaii joined Kokua Mau as a partner. The department dedicated one full-time medical staff member who is certified in hospice and palliative care to integrate end-of-life care into the school's mission and, in particular, into the medical education of all medical students and residents in Hawaii.

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APPENDIX

Other Funders

(Current as of the end date of the program; provided by the program’s management; not verified by RWJF.)

The Executive Office on Aging (EOA)

- $70,000 in-kind support Governor’s Blue Ribbon Panel on Living and Dying with Dignity, 1997–1998. $63,000 in-kind and cash each year from 1999 through 2002
- $20,000 award from the Ford Foundation
- $5,000 from the Atherton Family Foundation
- $199,000 from the Archstone Foundation ($99,000 of this to support a project that runs through March 2003)
- $25,000 from the Hawaii Medical Services Association Foundation to staff Aging Network projects

Total matched by EOA: $438,000

University of Hawaii Center on Aging (UH COA)

- $101,420 from the HMSA Foundation
- $75,000 from the Soros Foundation
- $10,000 from Hawaii Community Foundation
- $394,277 from the Administration on Aging
- $130,000 from HMSA Foundation (2002–2005)

Total matched by UH COA: $710,697

International Center for Healthcare Ethics, St. Francis (ICHE SF)

- $20,000 from St. Francis Healthcare System Foundation
- $296 from Borthwick Mortuary
- $150,000 in-kind

Total matched by St. Francis: $170,296
**Hawaiian Islands Hospice Organization**

- $20,000 in subcontract from UH COA (from HMSA and Soros funds)
- $15,000 from the HMSA Foundation through 2002
- $105,000 from other local foundations through 2002 (G.N. Wilcox, S.W. Wilcox, Frear Eleemosynary Trust and the McInerny Foundation)
- $30,000+ in-kind for air buys on seven television stations and all radio stations on all islands from the Hawaii Association of Broadcasters

Total matched by HIHO: $170,000

Total matched by all partners 1999–2002: $1,488,993
BIBLIOGRAPHY

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

Books


Book Chapters


Articles


Reports

Braun K. Evaluation of a Statewide Effort to Improve End-of-Life Care. Honolulu: Center on Aging, Center of Public Health Studies, John A. Burns School of Medicine, University of Hawaii, 2002.


Grantee Websites

www.kokuamau.org provides information about Kokua Mau and how to improve end-of-life care in Hawaii, including a downloadable advance directive form, materials, and resources to order, grief and bereavement network contacts statewide, and links. Honolulu: Kokua Mau, revised and upgraded December 2002.