Robert Wood Johnson Foundation

Published: October 1, 2002
Program Results Report
Grant ID: 38049

Assessment of *Last Acts* Program Provides Recommendations for Future Direction

Assessing progress and opportunities for the *Last Acts* initiative

SUMMARY

In 1999 and 2000, Balch Associates of Oak Park, Ill., assessed the Robert Wood Johnson Foundation's (RWJF) *Last Acts*® campaign for improving end-of-life care so that RWJF and other *Last Acts* stakeholders might understand the components and dynamics of the campaign and consider ways to increase their effectiveness. RWJF funded the assessment.

Last Acts is a national communications campaign RWJF began in 1995 and ended in 2005. It was a coalition of more than 800 national health and consumer groups that work to:

- Improve communication and decision making for consumers about their own death.
- Change the culture of health care institutions.
- Change American culture and attitudes toward death.

The project was part of the RWJF program, *Targeted End-of-Life Projects Initiative*, which supports projects to improve care at the end of life.

Key Findings

Balch Associates, a team of qualitative researchers, assessed the structures, strategies, products and processes of *Last Acts* to identify the kinds of impact they were having on end-of-life care. Key findings included the following:

- *Last Acts* attained some promising milestones in raising professional awareness of and engagement in improving end-of-life care.
- Partners saw *Last Acts* as an information resource on end-of-life issues, events, legislation and products; a connector with peer and complementary organizations; a community of people addressing the same issues; a catalyst for initiating or maintaining end-of-life efforts; and a coalition that gets the word out to improve end-of-life care.

- Partners realized many benefits from *Last Acts*, including comprehensive, credible, convenient and up-to-date information; inspiration; a sense of community; support and reinforcement from others in the field; and legitimacy with their members and boards.

Recommendations

The evaluators recommended that *Last Acts*:

- Maintain and build its network over the long term to change end-of-life care.
- Develop a clear identity to convey what the program stands for.
- Continue to strengthen its structure by creating a national program office.
- Become more visible, especially to the public.

RWJF made *Last Acts* a national program and set up a national program office in August 2000; the program ended in 2005.

Funding

RWJF funded the project with a grant of $238,697 between October 1999 and July 2000.

CONTEXT

The grants to the Commission on Aging with Dignity were made under RWJF's *Targeted-End-of-Life Projects Initiative*, a national program. In its effort to improve care at the end of life, RWJF has pursued three strategies:

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

This grant addresses the third strategy.

THE PROJECT

With funding from RWJF, Balch Associates assessed the *Last Acts*® campaign for improving end-of-life care, so that RWJF and other *Last Acts* stakeholders might understand the components and dynamics of the campaign and consider ways to increase their effectiveness.

Last Acts is a national communications campaign that RWJF began in 1995. It is a coalition of more than 800 national health and consumer groups that work to:

- improve communication and decision making for consumers about their own death
- change the culture of health care institutions
- change American culture and attitudes toward death.

Six task forces—family, palliative care, institutional innovation, provider education, financing and workplace—and five supporting resource committees—diversity, spirituality, standards and guidelines, evaluation and outcomes, and communications—work together to achieve campaign goals.

RWJF contracted three communications agencies—Barksdale Ballard and Company, Burness Communications and Stewart Communications—to assist *Last Acts* committees in planning and managing meetings, working with the public, managing funding and working with policy audiences and the media.

Balch Associates—a team of qualitative researchers—assessed the structures, strategies, products and processes of *Last Acts* to identify the kinds of impact they were having on end-of-life care. Their objectives were to:

- summarize relevant research
- map the paths that *Last Acts* target audiences take to or from changing end-of-life planning
- identify alignment of *Last Acts*' activities and objectives with target audiences' paths
- identify, describe and discuss stakeholder best practices for structure, strategy and tactics
- list indicators of success appropriate to the campaign's communication strategies
- propose a formal design for ongoing evaluation
- make recommendations for action regarding strategies, structures, activities, and future evaluation.

Balch Associates did not summarize the relevant research, because RWJF already had this information.

Balch Associates conducted in-depth interviews with RWJF staff, the consulting communication agencies, end-of-life experts and *Last Acts* personnel and partners; held focus groups with *Last Acts* partners; participated in program meetings; monitored *Last Acts*' website; and reviewed documents. The project was part of RWJF's *Targeted End-of-Life Initiative*, which supports projects to improve care at the end of life.

FINDINGS

Balch Associates changed evaluation strategies midcourse to reflect RWJF's changing needs and in response to information from the field; therefore the assessment varied from its proposed objectives, and findings were usually presented informally in meetings and telephone calls with RWJF and *Last Acts* stakeholders; in some instances, program improvements were implemented before research findings could be written. Key findings included the following.

- ***Last Acts* is a unique, complex, evolving social change-oriented enterprise.** It is a coalition and a growing social movement, not a hierarchy, and it is directed in a flexible, responsive and opportunistic way toward general goals, not specific outcomes.
- ***Last Acts* has been building a network and forum of key people from diverse settings that can affect end-of-life care and planning.** Partners range from small local health or human services providers to large national professional and consumer organizations.
- **The overall effort works to raise professional and public awareness and engagement in end-of-life care and planning and to promote its inclusion in professional, personal and public agendas.** For example:
  - Just before the 1999 trial of Jack Kevorkian, MD, *Last Acts* provided journalists covering the trial with information about positive alternatives to suicide, which many incorporated into their coverage.
  - *Last Acts* disseminates work that inspires organizations to copy or adopt successful programs. One such effort is *Community-State Partnerships,* RWJF's national program that supports state-based commissions to identify and implement changes in end-of-life care policy and practice.
- **Partners see *Last Acts* as an information resource on end-of-life issues, events, legislation and products; a connector with peer and complementary organizations; a community of people addressing the same issues; a catalyst to initiate or maintain end-of-life efforts; and a coalition that gets the word out to improve end-of-life care.**
- **Partners get many benefits from *Last Acts*, including comprehensive, credible, convenient and up-to-date information; inspiration; a sense of community; support and reinforcement from others in the field; and legitimacy with their members and boards.**

Recommendations

The grantee recommended that *Last Acts*:

- Maintain and build its network over the long term in order to change end-of-life care. Five years or more are needed to change the medical, social and policy cultures.
- Continue to strengthen its network by clarifying its multiple foci. Many stakeholders found themselves inundated by *Last Acts*' information and resources while also valuing its comprehensiveness. While some preferred to narrow down the focus to one that fit their own agenda, others wanted simpler ways to navigate and package information to disseminate.
- Develop a clear identity to convey what the program stands for. *Last Acts* needs to solidify agreement on its vision, mission, goals, objectives, strategy and tactics and make them readily known to stakeholders, partners and other audiences.
- Continue to strengthen its structure by creating a national program office, engaging task forces and resource committee conveners more fully, and defining and strengthening partnerships.
- Become more visible, especially to the public. Many stakeholders considered visibility crucial to changing end-of-life care and planning. *Last Acts* needs to develop consumer-based communication strategies to help partners reach *their* publics and to decide what role *Last Acts* should play in public policy and advocacy.

Communications

Balch Associates shared its findings with RWJF and *Last Acts* stakeholders in meetings and phone conversations and prepared a report entitled *Last Acts* Assessment for RWJF.

AFTERWARD

RWJF made *Last Acts* a national program and set up a national program office in August 2000. The national program office is at Partnerships for Caring in Washington.

Prepared by: Lori De Milto
Reviewed by: Antonia Sunderland and Molly McKaughan
Program Officer: Seth L. Emont
Grant ID# 38049
Program area: Quality/Equality
