"Five Wishes:" An Easy Advance Directive Promotes Dialogue on End-of-Life Care

Public education to promote a health and long-term care system to allow aging with dignity

SUMMARY

The Florida Commission on Aging with Dignity, a privately funded nonprofit in Tallahassee, FL, held a series of five community forums in Florida in 1996 and 1997 on a variety of aging and end-of-life issues.

Key Results

- The forums examined how health and long-term care services could be structured and managed to safeguard the dignity of people as they age and approach death. Forum topics included:
  - The aging of the U.S. population and its implications for Florida.
  - Medicaid and its role in safeguarding the elderly poor.
  - Long-term care insurance and other financial planning issues for aging adults.
  - Barriers to discussing death and dying, compassionate care, and assisted suicide.
  - At the fifth forum, Florida's governor, state supreme court justice, and their wives signed copies of "Five Wishes," an advance directive created by the project to help people discuss and make their wishes known about end-of-life care.

- The project launched the Five Wishes advance directive campaign. The initiative produced a brochure that walks people through the steps of writing down how they would like to be cared for in the event of a serious illness or injury.

- The Five Wishes advance directive is available online.

Funding

The Robert Wood Johnson Foundation (RWJF) supported the effort with a grant of $398,690, which took place between June 1996 and November 1997.
THE PROBLEM

In 1995, the state-appointed Florida Commission on Long-Term Care issued a report that proposed to move Florida's elderly and disabled populations into an integrated system of managed care.

The report recognized that fundamental ethical issues existed that, without a thorough airing, would jeopardize any future system. A public discussion of the general issues of aging and dying and some of the commission's specific recommendations could provide valuable direction to those responsible for structuring a new system.

The Foundation viewed the use of community forums in the current project as a potential model for mobilizing discussion and debate of End-of-Life issues. The proposed project shared the strategies of the Foundation's grants in its Last Acts program, which seeks to increase awareness of improvements needed in End-of-Life care. In addition, the issues raised were expected to complement those highlighted by SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), a Foundation-funded study of End-of-Life care.

Project 2010, as the current project was called, was to be conducted by the Florida Commission on Aging with Dignity, a privately funded, nonprofit organization. H. James Towey, principal investigator and commission executive director, was former Secretary of Florida's Department of Health and Rehabilitative Services and had substantial experience in health and social services, hospice care, and working with the religious community on the issues of death and dying.

Other Funding

The project also secured funds from the Claude Pepper Foundation ($85,000) and the Harry and Jeanette Weinberg Foundation ($75,000).

THE PROJECT

The project organized a series of five public forums held in Florida that involved leaders from government, private industry, the health and long-term care community, and the religious community. The forums had three purposes:

- To develop greater public awareness of the social and ethical issues surrounding aging and dying.
- To engage the people of Florida in the debate over how to devise a new system of health care and long-term care that maintains the dignity of elderly and disabled citizens.
To identify potential policy areas in the state that will address the concerns raised by the forum and will safeguard the dignity of elderly and disabled citizens.

The commission convened an advisory committee of high-level leaders in religion, business, the community, and government, including then-governor Lawton Chiles, to participate in the forums. (For a complete roster of committee members, see the Appendix.)

Several months into the project, the US Supreme Court and the Florida Supreme Court both agreed to hear cases on the constitutionality of assisted suicide. These developments initially threatened to overshadow the forums’ focus on palliative care and other End-of-Life concerns. In the end, however, the visibility of the assisted-suicide issue heightened public interest in discussions of End-of-Life care.

**RESULTS**

- **The project conducted five forums throughout the state on a variety of aging and End-of-Life issues.** Forum topics included:
  - The aging of the US population and its implications for Florida.
  - Medicaid and its role in safeguarding the elderly poor.
  - Long-term care insurance and other financial planning issues for aging adults.
  - Barriers to discussing death and dying, compassionate care, and assisted suicide.

At the fifth forum, Florida’s governor, state supreme court justice, and their wives signed copies of "Five Wishes," an advance directive created by the project to help people discuss and make their wishes known about end-of-life care.

- **The project launched the Five Wishes advance directive campaign.** The initiative produced a brochure that walks people through the steps of writing down how they would like to be cared for in the event of a serious illness or injury. The document contains a living will and a place to designate a health care surrogate. The brochure allows people to specify:
  - The kind of medical treatment they want or don't want.
  - How comfortable they want to be.
  - How they want people to treat them.
  - What they want their loved ones to know.
  - Who they want to make health care decisions for them when they cannot.

The original proposal for the project envisioned that the fifth forum would be devoted to identifying policy areas that would respond to concerns raised in the other forums. With
Foundation approval, the project instead used the fifth forum to promote the Five Wishes campaign. The director found that it was difficult to sustain public interest in the issue during the time between the forums. To maintain awareness of the project, he conducted local forums in Jacksonville and Boca Raton and gave talks about the Five Wishes campaign.

**Communications**

The project was featured in numerous national publications and media outlets including *The New York Times, The Christian Science Monitor, Associated Press, CNN,* and *National Public Radio.* In addition, more than 100 articles and 40 newscasts about the project appeared in state and local newspapers and broadcast outlets.

The principal investigators authored opinion-editorial pieces that were featured in *The Miami Herald, The Sun-Sentinel, The Orlando Sentinel, The Tampa Tribune,* and *The St. Petersburg Times.* As of November 1997, the commission had received 49,119 requests from Florida residents for the Five Wishes document. National exposure led to 29,249 out-of-state requests. See the Bibliography for details.

**LESSONS LEARNED**

1. **Providing the public with a concrete response can serve to underscore the issues raised during these forums.** Attendees of the third forum received a financial planning "survival kit," for example. The final forum provided attendees with the Five Wishes advance directive, and "helpful hints" on how to discuss End-of-Life care.

2. **Don't overestimate the depth of the public's awareness of End-of-Life issues.** The public has poorly formed background knowledge on the end of life and the message of similar forums may have to be simplified.

3. **Scheduling forums to maximize media coverage may limit public attendance.** Attendance at the forums, scheduled during the regular workweek to maximize television and print coverage, typically had to be limited to 100 to 200 people.

**AFTERWARD**

The Commission on Aging with Dignity received a second grant from the Foundation (ID# 033397) to adapt and disseminate the Five Wishes document in 33 other states and the District of Columbia. The commission is continuing its forums, which are underwritten by corporate donations and other foundations. The principal investigator was appointed to Florida’s statewide Panel for the Study of End-of-Life Care, which will study issues related to care provided to people at the end of life.
APPENDIX

Advisory Board Florida Commission on Aging with Dignity

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

Lawton Chiles (Chair)  
Governor, State of Florida  
Tallahassee, Fla.

Judge William Hoeveler  
US Federal District Court  
Coral Cables, Fla.

Olivia Ahyoung  
Mother & Baby Boomer  
Tallahassee, Fla.

Patsy Kurth  
State Senator  
Melbourne, Fla.

Jeb Bush  
Chairman of the Foundation for Florida's Future  
Miami, Fla.

David Lawrence, Jr.  
Publisher and Chairman, The Miami Herald  
Miami, Fla.

Robert A. Butterworth  
Attorney General  
Tallahassee, Fla.

General Robert F. Milligan  
Comptroller  
Tallahassee, Fla.

Josefina Carbonell  
President, Little Havana Activity and Nutrition Center  
Miami, Fla.

Bill Nelson  
Insurance Commissioner  
Tallahassee, Fla.

John Delaney  
Mayor of Jacksonville, Fla.  
Jacksonville, Fla.

Rev. Walter Richardson  
Sweet Home Missionary Baptist Church  
Perrine, Fla.

Rev. John C. Favalora  
Archbishop of Miami  
Miami, Fla.

Rabbi Soloman Schiff  
Greater Miami Jewish Federation  
Miami, Fla.

Bob Graham  
US Senator, Florida  
Miami Lakes, Fla.

Alvin E. Smith, MD  
Florida Medical Association  
Ormond Beach, Fla.

Donald C. Sullivan, MD  
State Senator  
St. Petersburg, Fla.
BIBLIOGRAPHY

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

Articles


Towey HJ. "Millionaires on Medicaid?" *St. Petersburg Times*, December 8, 1996.


Brochures and Fact Sheets
"In the Aging of America, Florida is at 'Ground Zero.' What Can You Do to Prepare?" Commission on Aging with Dignity, 1996.


Sponsored Conferences


"Project 2010 Forum: Long-Term Care and Other Financial Planning," March 14, 1997 in Orlando, FL.


"Five Wishes," August 15, 1997, Miami Beach, FL. Attended by six residents of Marion Towers, Catholic Housing.


"Five Wishes," August 26, 1997, Miami. Attended by 58 registered nurses as part of their program on advanced directives.


"Five Wishes," September 26, 1997, Miami. Attended by 104 people who were participating in a bioethics seminar as part of the annual meeting of the Florida Nurses Association.


"Five Wishes," October 8, 1997. Attended by 25 social workers from Baptist Hospital SW.


"Five Wishes," December 2, 1997, Miami Beach, FL. Attended by 72 residents of the Four Freedoms Tower as part of the Jewish Vocational Services, Meals on Wheels Program.

"Five Wishes," December 5, 1997, Miami. Attended by 22 members of the Kendall Rotary Club.


James Towey. Speech, Greater Pompano Beach Chamber of Commerce, Pompano Beach, FL, October 1997.

James Towey. Speech, Florida State University Course on Death and Dying, Tallahassee, FL, October 1997.


Grantee Websites


News Conferences


Press Kits and News Releases

A news release on the Project 2010 Forum in Tallahassee was distributed on September 12, 1996 to 30 newspapers, and radio and television stations statewide.

A news release on the Project 2010 community event in Jacksonville was distributed on October 21, 1996 to newspapers, and radio and television stations in the Jacksonville area.

A news release on the Project 2010 community event in Boca Raton was distributed on November 8, 1996 to newspapers, and radio and television stations in the Boca Raton area.

A news release on the Project 2010 forum in Tampa was distributed on December 12, 1996 to newspapers, and radio and television stations in the Tampa area.

A news release on the Project 2010 forum in Orlando was distributed on March 14, 1997 to newspapers, and radio and television stations in the Orlando area.

A news release on the Project 2010 forum in Miami was distributed on June 5, 1997 to newspapers, and radio and television stations in the Miami area.

A news release on the US Supreme Court ruling on assisted suicide was distributed on June 26, 1997 to newspapers and television stations in Florida.

A news release on the Five Wishes Living Will Campaign was distributed on July 24, 1997 to newspapers and television stations in Florida.
A news release on the Excellence in Aging with Dignity Awards was distributed on November 13, 1997 to newspapers and television stations in Florida.

A news release on the fifth Project 2010 forum in Tallahassee was distributed on November 19, 1997 to newspapers and television stations in Florida.

**Print Coverage**


"Former HRS Secretary initiates aging study," *The Times-Union*, May 30, 1996.


"Towey returns to town with a new mission," *The Tampa Tribune*, June 1, 1996.


"For Jim Towey, it's never say die," *The St. Petersburg Times*, July 14, 1996.


"For boomers, retirement may be a bust," *The Orlando Sentinel*, September 13, 1996.


"Public not facing facts on federal spending?" *The Times Union*, September 13, 1996.


"Project 2010 A.D. holds first forum on aging," The Tallahassee Democrat, September 13, 1996.

"Sounding alarms on entitlements," The St. Petersburg Times, September 18, 1996.


"City facing high elderly population," Florida Times-Union, October 22, 1996.

"Towey applies missionary's zeal to problems of aging," The Florida State Times, November 1996.


"Hospice care lets patients die with dignity, not pain," The Palm Beach Post, November 20, 1996.

"Assisted-suicide opponent advocates 'the third path,'" The Ft. Lauderdale Sun-Sentinel, November 20, 1996.


"Hospice care lifts spirits at end of life," The Palm Beach Post, November 20, 1996.

"A choice besides death or suffering," The Ft. Lauderdale Sun-Sentinel, November 26, 1996.

"Health groups decry uncaring system," The Tampa Tribune, December 4, 1996.


"Pain, death and true compassion," The Tampa Tribune, December 7, 1996.


"Senior Citizens advocates emphasize alternatives to assisted suicide," The Florida Catholic, December 12, 1996.


"Medicaid bog gets deeper," The Tampa Tribune, December 17, 1996.


"When the dying don't get the facts about their fate," *The Miami Herald*, February 26, 1997.


"Justices struggle with Hall right-to-die plea," *The Palm Beach Post*, May 9, 1997.

"Plea to state: Why not let me die in peace?" *The Orlando Sentinel*, May 9, 1997.

"Why not just let me die in peace?" *The Tampa Tribune*, May 9, 1997.


"Five Wishes' living will kits designed to offer peace of mind," *The Palm Beach Post*, July 25, 1997.


"Murder-suicide was an act of love, close friend says," *The Tampa Tribune*, October 26, 1997.


**Mass Media**

Note: Because the Commission did not have grant resources to monitor project coverage in the electronic media, the following is only a partial list and was compiled from local notices to the Commission.


WTXL-TV, Tallahassee, September 12, 1996.

WCTV-TV, Tallahassee, September 12, 1996.

All Things Considered, National Public Radio, Washington, September 13, 1996.

WFSU-TV, Tallahassee, September 17, 1996.

WBZE-FM, Tallahassee, September 17, 1996.

WIIU-FM, St. Petersburg, September 17, 1996.
WAXY-AM, Miami, September 25, 1996.
WJXT-TV, Jacksonville, October 21, 1996.
WPTV-TV, West Palm Beach, November 6, 1996.
WPLG-TV, Miami, November 18, 1996.
WJNO-FM, West Palm Beach, November 18, 1996.
WTSP-TV, Tampa, December 3, 1996.
WMNF-FM, Tampa, December 11, 1996.
WFTS-TV, Tampa, December 12, 1996.
WCTV-TV, Tallahassee, December 13, 1996.
WLTV-AM, Miami, January 9, 1997.
WINZ-AM, Miami, January 9, 1997.
WFTV-TV, Orlando, March 14, 1997.
WTVJ-AM, Miami, June 5, 1997.
WCTV-TV, Tallahassee, July 24, 1997.
WFLA-TV, Tampa, September 4, 1997.
WTSP-TV, St. Petersburg, September 4, 1997.
WTWC-TV, Tallahassee, November 13, 1997.
Conus Communications, Tallahassee, November 19, 1997.
WTWC-TV, Tallahassee, November 19, 1997.