

Strategy Brief:

**The Ombudsman Program and
End of Life Issues in Long-Term Care Facilities**

Report on National Dialogue Forum #6

Prepared by the National Association of State Units on Aging



National Long-Term Care
Ombudsman Resource Center

National Citizens' Coalition for Nursing Home Reform
1828 L Street, NW, Suite 801
Washington, DC 20036
Tel: (202) 332-2275, Fax: (202) 332-2949, E-Mail: ombudcenter@nccnhr.org

December 2006

Supported by a grant from the U. S. Administration on Aging

Acknowledgements

We wish to acknowledge and thank the State Unit on Aging (SUA) directors and State Long-Term Care Ombudsmen (SLTCO) who provided their time and expertise as members of the **National Dialogue Forums' Advisory Committee** (listed in Appendix A); the **Issue Identification Panel** (listed in Appendix B) for their assistance with clarifying the focus of the this Dialogue Forum; and to those persons who participated in the two teleconferences, held March 29 and 31, 2006 (listed in Appendix C).

About the Author

Mark C. Miller, M.S.Ed., Senior Program Associate for Elder Rights at NASUA, has worked in support of the Long-Term Care Ombudsman Program since 1984. He served as a local ombudsman and as the Virginia State Long-Term Care Ombudsman for eight and a half years. Since joining NASUA in 2000 he has provided technical assistance to state units on aging and state ombudsmen concerning management and operation of the ombudsman program.

The National Association of State Units on Aging (NASUA) is a private, nonprofit organization whose membership is comprised of the 56 state and territorial offices on aging.

To Obtain Additional Copies

To obtain additional copies of this publication, contact NASUA at 1201 15th Street, NW, Suite 350, Washington, DC 20005, (202) 898-2578; FAX (202) 898-2583; email: cwellons@nasua.org

<p>This paper was supported, in part, by a grant, No. 90AM2690, from the Administration on Aging, Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.</p>

Strategy Brief:
**The Ombudsman Program and
End of Life Issues in Long-Term Care Facilities**

Report on National Dialogue Forum #6

Table of Contents

Foreword	i
Introduction	1
Promising Practices and Discussion Highlights	2
<i>I. End of life issues ombudsman programs encounter</i>	3
<i>II. Education and training activities</i>	5
<i>III. Examples of ombudsman advocacy on end of life issues</i>	8
<i>IV. Organizations and materials</i>	10
Summary	12
Appendices	
A: Advisory Committee Members	
B: Issue Identification Panel Members	
C: National Dialogue Forum Participants	

Foreword

The National Association of State Units on Aging (NASUA), as part of its work in support of the National Long-Term Care Ombudsman Resource Center (NORC), is convening a series of national dialogue forums on issues of importance to long-term care ombudsman programs and state units on aging (SUAs). The National Dialogue Forums provide a venue for state aging directors and state long-term care ombudsmen (SLTCOs) to discuss challenging issues and identify promising practices to more effectively serve long-term care consumers.

NASUA has developed a process for convening the National Dialogue Forums consisting of the steps described below.

Step 1. Convene the Advisory Committee to identify topic areas on which the forums will focus in the coming year. The Advisory Committee consists of equal representation of SUAs and SLTCOs (the membership of the Advisory Committee is listed in Appendix A). Recent dialogue topics have included:

- Advocacy in guardianship.
- Legislative advocacy.
- End of life issues in long-term care.

Step 2. Convene an Issue Identification Panel (IIP) focused on each topic. The IIP will help identify the primary questions for discussion during the National Dialogue Forums. Each IIP consists of approximately 10 representatives of SUAs, state ombudsman programs and other areas germane to the topic (e.g., Adult Protective Services, Centers for Medicare and Medicaid Services, American Bar Association, Independent Living Centers, home and community based services, etc.).

Step 3. Identify promising practices. Promising practices and information on strategies ombudsman programs use to address the dialogue topic will be solicited from SLTCOs via email prior to each dialogue forum. Additional promising practices will be identified during the dialogue forum.

Step 4. Invite all SUAs and SLTCOs to participate in the National Dialogue Forums.

Step 5. Convene the National Dialogue Forum, consisting of a series of teleconferences on each dialogue topic.

Step 6. Develop a strategy brief. Strategy briefs provide highlights of the ideas, challenges and promising practices presented during the dialogue forums and obtained via email from state ombudsman programs. A strategy brief for each dialogue topic will be prepared and disseminated to all SUAs and SLTCOs.

Strategy Brief:

The Ombudsman Program and End of Life Issues in Long-Term Care Facilities

Report on National Dialogue Forum #6

Introduction

End of life care and services can be thought of as the ultimate elder rights issue. As a common, shared experience, how we die is as important as how we live.

In 2005 and 2006, the NASUA Board of Directors identified end of life as a key area for action and education. Of particular interest to the aging network are initiatives to improve pain management, palliative care, and the provision of quality end of life care in both community and institutional settings.

There is growing interest across the United States in improving end of life care and choices for everyone, including nursing home residents. End of life care is an important issue for ombudsmen and long-term care residents because:

- 20% of older persons die in a nursing home
- 30% die in hospitals shortly after being transferred from a nursing home¹
- Debates surrounding end of life issues often are played out in long-term care facilities.

Ombudsman programs are sometimes drawn into situations which involve family disputes over ‘do not resuscitate’ (DNR) orders or care plans; residents with untreated chronic pain; residents’ rights to refuse treatment; and residents whose decisional capacity is called into question when there is no surrogate decision-maker.

The information presented in this paper is based on promising practices identified by state ombudsmen during the National Dialogue Forum and information provided in response to an email sent to all programs in March 2006. The National Dialogue Forum consisted of two teleconferences held on March 29 and 31, 2006.

An Issue Identification Panel (IIP) comprised of state ombudsmen, state aging directors, and representatives from the American Bar Association’s Commission on Law

¹ Sandra H. Johnson, “Making Room for Dying: End of Life Care in Nursing Homes,” *Improving End of Life Care: Why Has It Been So Difficult?* *Hastings Center Special Report* 35, no. 6 (2005): S37-S41.

and Aging, the National Association of Adult Protective Service Administrators, the Administration on Aging and the National Ombudsman Resource Center helped develop a set of questions for this National Dialogue Forum on *the ombudsman program and end of life issues in long-term care facilities*. The IIP met via teleconference on January 31, 2006. See Appendix B for the list of IIP members.

The four questions (listed below) were emailed to all state aging directors and state ombudsmen prior to the calls, and were used to guide the discussion during the teleconferences.

The National Dialogue Forum addressed the following questions:

What types of end of life issues has the ombudsman program encountered or been involved with (e.g., treatment disputes, pain management/palliative care concerns, hospice concerns, etc.)?

What types of education and training activities is the ombudsman program involved in with residents, families, program and facility staff concerning end of life issues?

What advocacy efforts has the ombudsman program engaged in around end of life issues (e.g., participation in coalitions, care plan consultation regarding pain management/palliative care, involvement in ethics committees, legislative advocacy, etc.)?

What materials does the ombudsman program use with residents, facilities and staff to address end of life issues (e.g., tool kits, values history forms, books, videos, advance directives forms, etc)?

A total of 37 persons from 22 states participated in the two teleconferences, including:

- 16 representatives from state units on aging
- 20 state ombudsman program representatives
- the director of the National Ombudsman Resource Center.

Representatives from both the state unit on aging (SUA) and the ombudsman program in six states participated in the Forum. National Dialogue Forum participants are listed in Appendix C.

Promising Practices and Discussion Highlights

This strategy brief is divided into four sections that correspond to the questions asked during the National Dialogue Forum conference calls. Section I identifies the types of *end of life issues ombudsman programs encounter* in long-term care facilities; Section II describes ombudsman program *education and training activities* concerning end-of-life issues; Section III provides *examples of ombudsman advocacy on end of life issues*; and

Section IV lists *end of life organizations and materials* ombudsman programs have used to help residents, families and facilities.

I. End of life issues ombudsman programs encounter

What types of end of life issues has the ombudsman program encountered or been involved with (e.g., treatment disputes, pain management/palliative care concerns, hospice concerns, etc.)?

Ombudsmen encounter end of life issues on a daily basis. These issues are typically presented as questions or complaints² by residents, families and facilities about a variety of concerns such as:

- access and delivery of hospice services
- disputes about care plans and treatment expectations
- lack of facility knowledge about the dying process
- advance directives.

Access and delivery of hospice services

Several ombudsmen identified the availability of hospice services in long-term care facilities as an area of concern, specifically:

- limited access to hospice services
- underutilization of hospice benefits
- lack of care coordination and planning between nursing home staff and hospice programs.

Some nursing homes do not encourage, and may resist, the use of hospice services for dying residents because they do not have a contract with a hospice provider or because they have concerns about reimbursement. When a Medicaid beneficiary utilizes hospice services the hospice agency becomes the primary payer, reimbursing the nursing home for non-hospice related services (i.e., room and board). This can mean a delayed or slightly reduced payment to the nursing home. The Massachusetts ombudsman program, which educates facilities about the residents' right to utilize hospice services, reported that some nursing homes have addressed this concern by becoming licensed hospice organizations.

Residents benefit significantly from the end of life care provided by hospice programs.

Jenny Beaujean
Ombudsman Program, Massachusetts

² The National Ombudsman Reporting System (NORS) does not have a specific complaint code for “end of life” issues. Complaints may be captured under codes for right to refuse treatment (D 28), care planning (F 42), symptoms unattended, including pain, pain not managed, no notice to others of changes in condition (F 48), family disputes (P 120), advance directives (P 122) and hospice services (Q 130).

Accessing hospice services may be particularly difficult for residents in assisted living. For instance, California prohibited the use of hospice services in board and care and other residential care facilities until recently, when the licensing agency created a waiver for persons who do not need skilled care to remain in a residential facility and receive hospice services.

The Maine State Ombudsman reported that hospice services are underutilized in the state's nursing homes. To address this concern, the ombudsman program and the state unit on aging are working together to develop and fund a part-time staff position dedicated to working on hospice issues. The staff person will establish a stakeholders group (comprised of the Maine Healthcare Association, the Homecare Alliance of Maine, and other interested parties) to examine ways to encourage the use of hospice services and develop a consumer guide for hospice services in Maine. The position will be housed with the ombudsman program. The ombudsman program also plans to use the part-time staff person to educate ombudsman staff and volunteers about hospice care and related issues.

Some dialogue participants identified poor coordination between nursing home and hospice staff as a significant issue. There are also conflicts between hospice and nursing home staff regarding who is responsible for specific aspects of a resident's care. The Texas ombudsman program has helped hospice agencies and nursing homes clarify their roles in caring for dying residents to ensure that care needs are met and rights and choices are respected.

The Montana State Ombudsman described a case involving an individual who began hospice care while at home and was later transferred to a nursing home. Under the hospice program, he was enrolled in the Montana Marijuana Program, which permits patients with a physician's order to use marijuana to ease pain. However, the nursing home to which the resident was transferred had a no smoking policy and the resident's declining condition made it increasingly difficult for him to smoke outside. The ombudsman program worked with the licensing agency, the hospice program and the nursing home administrator to facilitate a successful resolution by addressing a variety of health and safety issues through the care planning process, with the goal of helping control the resident's pain. The solution: the resident received his marijuana treatments through a special vaporizer.

Disputes about care plans and treatment expectations

Disagreements periodically occur among family members or between family members and the nursing home about the type of care and treatment to be provided to a dying resident. Most ombudsman programs, including the programs in Florida, Massachusetts, Missouri, New York and Wyoming, handle disputes over care plans

There is a basic lack of communication about the end of life, and that often results in wide differences between what families want and what facilities feel they should provide in terms of care for dying residents.

Virginia Moore-Bell
State Ombudsman, Alabama

and treatment expectations by providing the parties involved with information about residents' rights concerning care and treatment choices and consultation to help the parties resolve the specific issue. For instance, the Missouri Ombudsman Program works with the Center for Practical Bioethics to offer residents, families and facilities consultation on issues such as feeding tubes, palliative care and the right to refuse treatment.

Lack of facility knowledge about the dying process

Nursing facilities often struggle with issues of residents' rights to refuse treatment versus their responsibility to provide care as required under state and federal regulations. Dialogue participants generally agreed that many facilities do not know how to deal with terminally ill residents who refuse to take their medicines or to eat.

Facility staff are not generally well trained about the dying process.

Arlene Franklin
State Ombudsman, Indiana

Advance directives

Several ombudsman programs, such as the Arizona State Long-Term Care Ombudsman Program, refer residents that have questions about advance directives and living wills to legal service providers for information and guidance. In California, the ombudsman program is required by law to witness advance directives executed by residents of skilled nursing facilities (the Delaware State Ombudsman Program has a similar statutory responsibility). The program witnesses 4,000 – 5,000 advance directives each year. California ombudsmen are mandated not to discuss the contents of the advance directive or attempt to influence the decisions residents make. Their primary responsibility is to ensure the person is acting on his/her own free will, is not being coerced in any way, and that s/he appears to have the capacity to execute such a document. Training for ombudsmen focuses on how to have a conversation with residents and families about the importance of completing an advance directive.

II. Education and training activities

What types of education and training activities is the ombudsman program involved in with residents, families, program and facility staff concerning end-of-life issues?

In 2005, ombudsman program representatives attended 31,972 resident and family council meetings, provided 9,083 training sessions for long-term care facility staff and 136,729 consultations to facility staff and managers.³ Information and training provided by ombudsman programs to these groups included end of life topics such as advance directives and palliative care. In addition, some ombudsman programs provide regular or periodic training to staff and volunteers specifically focused on end of life issues.

³ Long-Term Care Ombudsman Report FY 2005, U.S. Administration on Aging.

Ombudsman program training for staff and volunteers

Most of the ombudsman programs that participated in the teleconference calls provide state staff and regional ombudsmen with information on advance directives, guardianship, hospice, palliative care and other end of life issues, through orientation, annual training, or periodic in-service training. Training is often coordinated with other organizations and entities such as legal service providers and hospice organizations. End of life issues are addressed in ombudsman training in a variety of ways, as evidenced by the following examples:

Training modules focused on end of life issues

- Annual ombudsman program training in **Arizona** and **Virginia** includes modules on end of life issues. The Arizona training emphasizes helping residents who want know more about advance directives by connecting them with legal services.
- In **New York**, most local ombudsman programs offer an in-service from a hospice provider as part of their required staff and volunteer training. In addition, in 2005 the statewide ombudsman training included a workshop on hospice services.
- In **South Carolina**, ombudsman program staff receives training on advance directives and end of life issues at the annual Summer School of Gerontology, sponsored by the state unit on aging in partnership with an area university and the South Carolina Geriatric Center. The training is mandatory for new ombudsmen.
- The **Wyoming** Ombudsman Program regularly provides training and education to its staff about end of life issues and hospice services.

Coordination with end of life organizations to offer specialized training

- In 2003, the **California** Coalition for Compassionate Care conducted training on advance directives for local ombudsman program coordinators. The ombudsman program is currently working with the Coalition (which was a Robert Wood Johnson grantee) on a proposal to the Archstone Foundation, to develop training for ombudsmen on how to recognize good end of life care.
- In 2003, the **Massachusetts** Ombudsman Program coordinated with the Massachusetts Federation of Hospice and Palliative Care to conduct a series of 14 regional workshops for paid and volunteer ombudsmen and hospice staff. One of the goals of the workshops was for the programs to educate each other about their respective roles and to discuss the types of

issues each was encountering. As a result, many local ombudsman programs continue to meet regularly with hospice organizations.

- Regional ombudsmen in **Montana** received train-the-trainer education on end of life decision making from the state's End of Life Institute. (The institute, whose funding ended in December 2005, was housed in a hospital in western Montana and served as an electronic repository for people to file advance directive documents.) At the local level, ombudsmen provide community education, coordinating with hospice programs in some of the larger communities to conduct community education presentations.

Training on legal issues related to end of life

- In 2002, the **Colorado** Bar Association provided training to the ombudsman program on advance directives and guardianship.
- The **Florida** Ombudsman Program has provided training on advance directives to volunteer coordinators. In the past the program has used experts in guardianship to provide this training.

Resident and family councils

Ombudsman programs in **Alabama**, **Arizona**, **Montana**, **New Jersey** and **South Carolina** provide educational sessions and information on residents' rights and advance directives to resident and family councils in long-term care facilities. The New Jersey Ombudsman Program annually distributes thousands of advance directive brochures (see section IV) at family council meetings and other community education events around the state.

Nursing facility staff

Regional ombudsman programs in **Massachusetts** educate nursing home staff about advance directives and residents' rights to choose services such as hospice. The **Missouri** Ombudsman Program offers train-the-trainer sessions to nursing facilities with an emphasis on developing palliative care goals. The program uses a training manual, *Guidelines: End of Life Care in Long-Term Care Facilities*. (See section IV.)

Community education

The dialogue yielded examples of ombudsman programs' community education efforts and activities focused on end of life issues. Local ombudsman programs in **Alabama** coordinate with legal service providers to offer training and community education on advance directives and healthcare proxies. The **Missouri** Ombudsman Program conducts public seminars and conferences on end of life issues, using materials

prepared by the Practical Bioethics Committee and the Office of the Attorney General to discuss topics such as advance directives and pain management. (See section IV.)

III. Examples of ombudsman advocacy on end of life issues

What advocacy efforts has the ombudsman program engaged in around end of life issues (e.g., participation in coalitions, care plan consultation regarding pain management/palliative care, involvement in ethics committees, legislative advocacy, etc.)?

Legislative Advocacy

In 2005, the **Wyoming** Ombudsman Program successfully advocated for legislation creating a new Healthcare Advance Directive Form that addresses withholding hydration, nutrition, pain and physician involvement at the end of life. According to the ombudsman program, the form has been very useful in helping people talk about their wishes in end of life situations.

The **Missouri** Ombudsman Program is currently supporting legislation to expand state law to allow ‘do not resuscitate’ (DNR) orders in settings other than hospitals. The proposed law would apply to nursing homes and permit a resident, or his/her power of attorney, and the resident’s physician to sign a DNR order.

Ombudsman programs also track legislation dealing with end of life issues. Examples of bills the ombudsman program has monitored include:

- **Colorado:** a bill that amends the state’s manslaughter statute to provide criminal immunity for licensed medical caregivers who, with consent, provide palliative care to terminally ill patients.
- **California:** a bill based on Oregon’s Physician Assisted Suicide Statute.
- **Idaho:** a bill to establish an advance directive registry.

Ethics committees

In 1985, the **New Jersey** Supreme Court ruled on a case involving the withdrawal of a feeding tube from a nursing home resident, Claire Conroy. In a lengthy decision, the Court, recognizing the lack of ethics committees in nursing homes, specifically identified the ombudsman program as the entity that should oversee end of life decision making in long-term care facilities, and required that all decisions to withhold or withdraw treatment be submitted to the Office of the State Ombudsman for review. Since that decision, the ombudsman program has created a network of 14 regional ethics committees, which are available to serve all long-term care facilities in the state. The committees are comprised primarily of providers and community members. The

ombudsman program trains persons to serve on the committees. The state ombudsman has formed the committees into a consortium and meets with them on a bi-monthly basis to keep them current on legal developments, such as the 2005 Terri Schiavo case in Florida.

Coalitions and partnerships

Ombudsman programs in **Alabama, Colorado, Missouri, Montana, New Hampshire, Virginia** and **Wyoming** participate in coalitions and other partnerships that have a focus on end of life issues. These groups are involved in legislative advocacy, community education and quality care initiatives. Dialogue participants generally agree that end of life issues could be addressed through culture change initiatives since they can be considered part of resident directed care.

The state ombudsman in **Missouri** serves on the board of the Missouri End of Life Coalition and is the chair of the Community Education Committee. She also served on the planning committee for the 2005 End of Life Policy Summit, which brought together more than 150 persons to discuss state laws, regulations and policies concerning end of life matters.

In January, 2006, the **Montana** General Assembly passed a law establishing a state end of life registry to electronically store advanced healthcare directives and make those documents accessible to healthcare providers, as well as persons who submit a healthcare directive to the registry. The state ombudsman serves on the End of Life Advisory Committee, created by the legislature as part of the law. The committee is charged, in part, with examining ways to further public education about the availability of the registry. The repository accepts any advance directive that is signed by two witnesses. A specific form is not required; however, a standard form is available on the Office of the Attorney General's website. The state unit on aging's website provides a link to the website as well.

In **New Hampshire**, the ombudsman program participates in a coalition that supports unification of the state code regarding advance directives, powers of attorney and 'do not resuscitate' (DNR) orders. The coalition is comprised of hospitals, nursing facilities, ethicists, physicians, emergency medical personnel (EMTs), advocates, and other interested parties.

The **Virginia** Ombudsman Program is involved in a newly forming coalition concerned with the changing face of medicine in America, including greater recognition of end of life issues. The coalition is exploring the possibility of producing a local public TV program to examine how the delivery of medical care is evolving, including the options for care at the end of life and the impact of advance planning tools.

The **Wyoming** Ombudsman Program participated in an end of life coalition, led by the state chapter of the AARP, which developed a guide entitled *Make Your Wishes*

Known. The guide helps people plan for incapacity and end of life decisions. The guide is widely distributed and available through local senior centers.

Ombudsman programs in **Alabama**, **Colorado** and **Virginia** have been working with the Quality Improvement Organizations (QIOs) in their states on initiatives that address palliative care and pain management.

IV. Organizations and materials

What materials does the ombudsman program use with residents, facilities and staff to address end of life issues (e.g., tool kits, values history forms, books, videos, advance directives forms, etc)?

The organizations and materials listed below were recommended by dialogue participants.

Organizations:

- **California Coalition for Compassionate Care.** (www.finalchoices.calhealth.org). Funded in part by the Archstone Foundation, the mission of the Coalition is to advance institutional change by improving end of life care in California's nursing facilities. It offers numerous publications and educational materials focused on nursing facility residents and staff.
- **Caring Connections.** (www.caringinfo.org). Sponsored by the National Hospice and Palliative Care Organization, this program provides free information and resources about advance care planning, caregiving, hospice and palliative care, grief and loss and other end of life issues.
- **Community Alliance for Compassionate Care at the End of Life.** (www.missouriendoflife.org). This not-for-profit organization, whose members include healthcare professionals, educators and members of religious, business and civic communities in the Ozarks region of Missouri, works to enhance community awareness of end of life issues, promotes quality care for dying persons and supports healthy bereavement experiences for families and friends.
- **Kokua Mau: A Partnership Improving Care at the End of Life.** (www.kokuamau.org). Based in Hawaii, this statewide partnership of more than 250 individuals and organizations works with the general public and leaders in healthcare and government to improve end of life care. The website includes information and resources about advance care planning, hospice and palliative care, pain management and grief and bereavement. A curriculum designed to help care workers improve end of life care can be downloaded.

- **Physicians Orders for Life Sustaining Treatment (POLST).** (www.polst.org). This organization promotes the use of a standardized POLST form which a person can sign to specify comfort measures they wish to have at the end of life. The form essentially converts a person's wishes into physician's orders. First developed in Oregon, POLST forms are now used in Washington and West Virginia as well as parts of Georgia, Michigan, Minnesota, New Mexico, New York, Pennsylvania, Utah and Wisconsin.
- **The U.S. Living Will Registry.** (www.uslivingwillregistry.com). This organization electronically stores advance directives, organ donor information and emergency contact information, and makes them available to health care providers across the country, 24 hours a day. The service is available free of charge to individuals when they register through a registered provider or partner.

Materials:

Many of these materials are used by ombudsman programs as they work to address end of life issues.

- **Advance Directives.** This brochure was developed by the New Jersey Office of the State Long-Term Care Ombudsman and includes a list of additional web resources. It is available on line at: http://www.nj.gov/health/ltc/documents/advance_directives_brochure.pdf.
- **Go Wish.** A deck of cards designed to facilitate communication between individuals and families about end of life issues and wishes. Available from the CODA Alliance at: www.codaalliance.org.
- **Guidelines: End of Life Care in Long-Term Care Facilities.** This training manual for facilities to use to discuss end of life issues emphasizes the development of palliative care goals. Produced by the Missouri Department of Health & Senior Services. Available online at: <http://www.dhss.mo.gov/showmelongtermcare/endoflifemanual.pdf>.
- **Life Choices.** This 36-page guide helps individuals plan for end of life with step-by-step information and forms on how to communicate their wishes concerning health care decisions. Printed by the Missouri Office of the Attorney General, it is available online at www.ago.mo.gov (click on consumer protection publications).
- **Making Choices: A Guide to End of Life Planning.** This 30-page guide is designed to help individuals make informed personal decisions about end of life care and understand how to make those wishes known to others. Produced by the Florida Department of Elder Affairs, it is available on line at: <http://elderaffairs.state.fl.us>.

Summary

Thirty-seven (37) persons representing 22 states participated in the National Dialogue Forum on end of life issues in long-term care facilities. The discussions revealed that ombudsmen deal with end of life issues on a daily basis, addressing questions and complaints related to issues such as access and delivery of hospice services, disputes over care plans and treatment expectations, lack of facility knowledge about the dying process, and advance directives. As a result, many programs provide state and local ombudsmen with training on advance directives, guardianship, hospice, palliative care and other end of life issues. Ombudsman programs also provide information and consultation on end of life issues to resident and family councils, nursing facility staff and the general community.

Dialogue participants offered examples of ombudsman programs' efforts to improve end of life care for nursing home residents by conducting legislative advocacy, developing ethics committees and participating in coalitions and partnerships. Participants also identified a list of organizations and materials used by state units on aging and ombudsman programs to provide information about end of life issues to nursing home residents, facility staff and the larger community.

APPENDIX A

Advisory Committee Members

National Dialogue Forum Advisory Committee

Advisory Committee Members

SUA Representatives:

Kentucky

Jerry Whitley
Executive Director
Office of Aging Services

Maine

Chris Gianopoulos
Director
Bureau of Elder & Adult Services

New Mexico

Michelle Lujan-Grisham
Secretary Designate
State Agency on Aging

Utah

Helen Goddard
Director
Division of Aging & Adult Services

Ombudsman Program Representatives:

Missouri

Carol Scott
State Ombudsman

Ohio

Beverly Laubert
State Ombudsman

Texas

John Willis
State Ombudsman

Wisconsin

George Potaracke
State Ombudsman

APPENDIX B

Issue Identification Panel Members

The Ombudsman Program and End-of-Life Issues in Long-Term Care Facilities

Issue Identification Panel Members

Panel Task: Identify primary questions of interest to address during the National Dialogue Forum on the ombudsman program's involvement in end-of-life issues in long-term care facilities.

SUA Representatives:

Hawaii

Pat Sasaki
Director
Executive Office on Aging

Minnesota

Jim Varpness
Executive Director
Board on Aging

New Mexico

Debbie Armstrong
Secretary
Department of Aging & Long Term Care
Services

Hawaii

John McDermott
State Ombudsman

Illinois

Sally Petrone
State Ombudsman

New Jersey

William Isele
State Ombudsman

New Mexico

Walter Lombardi
State Ombudsman

Ombudsman Program Representatives:

Florida

Brian Lee
State Ombudsman

Georgia

Becky Kurtz
State Ombudsman

Others:

American Barr Association

Charles Sabatino
Director, Commission on
Law and Aging

National Association of Adult Protective Service Administrators

Joanne Otto
Director

Administration on Aging

Sue Wheaton
Ombudsman Program Specialist

**National Ombudsman Resource
Center**

Lori Smetanka
Director

APPENDIX C

National Dialogue Forum Participants

The Ombudsman Program and End of Life Issues in Long-Term Care Facilities

National Dialogue Forum Participants

Alabama

Virginia Bell
State Ombudsman

Arizona

Ray De La Rosa
Aging & Adult Administration

Robert Nixon
State Ombudsman

California

Joe Rodrigues
State Ombudsman

Colorado

Paulette St. James
Division of Aging & Adult Services

Steve Evans
Division of Aging & Adult Services

Pat Tunnell
State Ombudsman

Connecticut

Lynn Noyes
Adult Protective Services
Department of Elder Affairs

Florida

Brian Lee
State Ombudsman

Idaho

Cathy Hart
State Ombudsman

Illinois

Mary Mayes
Department on Aging

Indiana

Arlene Franklin
State Ombudsman

Maine

Brenda Gallant
State Ombudsman

Barbara Damren
Bureau of Elder & Adult Services

Massachusetts

Liz Bradley
Ombudsman Program

Jenny Beaujean
Ombudsman Program

Missouri

Vicki Keller
Division of Senior & Disability Services

Susan Tonarely
Ombudsman Program

Montana

Kelly Moorse
State Ombudsman

Nevada

Kay Panelli
State Ombudsman

New Hampshire

Don Rabun
State Ombudsman

New Jersey

William Isele
State Ombudsman

New York

Marty Haase
State Ombudsman

South Carolina

Dale Watson
State Ombudsman

Ethyl Corley
Office on Aging

Texas

Cheryl Cordell
Ombudsman Program

Julie Frank
Government Relations
Department of Aging & Disability Services

Camille Hemlock
Department of Aging & Disability Services

Dr. Leslie Cortes
Department of Aging & Disability Services

Virginia

Joani Latimer
State Ombudsman

Wisconsin

Gail Schwersenska
Deputy Director
Bureau of Aging and LTC Resources

Wyoming

Beverly Morrow
Director
Aging Division

Vereen Bebo
Aging Division

Lura Crawford
Aging Division

Tim Ernst
Aging Division

Charlie Simineo
Ombudsman Program

National Ombudsman Resource Center

Lori Smetanka, J.D.
Director