

Strategy Brief:

**The Ombudsman Program and
Caregiver Support**

Report on National Dialogue Forum #7

Prepared by the National Association of State Units on Aging

National Long-Term Care
Ombudsman Resource Center

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About the Author

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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.

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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.

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Introduction

The information presented in this paper is based on promising practices identified by state ombudsmen in response to an email sent to all programs in May, 2006 and information provided during the National Dialogue Forum. The National Dialogue Forum consisted of two teleconferences held on May 16 and 18, 2006.

An Issue Identification Panel (IIP) comprised of state ombudsmen, state unit on aging representatives, and representatives from 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 caregiver support*. The IIP met via teleconference on April 20, 2006. See Appendix B for the list of IIP members.

The three 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:

1. How does the ombudsman program help family caregivers adapt to a different type of caregiving role when a relative moves to a long-term care facility (e.g., educational presentations at family councils meetings or caregiver coalitions, helping establish support groups, working with caregiver coalitions, one-on-one consultations, etc.)?
2. How does the ombudsman program and the family caregiver support program (FCSP) work together at the state and local levels (e.g., joint training / in-service for program staff, information sharing, referrals, collaboration on community education campaigns, etc)?
3. What written materials does the ombudsman program use to help caregivers whose relatives have moved from home to a long-term care facility (e.g., a regional ombudsman program in Kentucky provides a copy of the book *Nursing Homes, Getting Good Care There* to families of nursing home residents)?

A total of 30 persons from 14 states and the District of Columbia participated in the two teleconferences, including:

- 8 representatives from state units on aging
- 19 state ombudsman program representatives
- the director of the National Ombudsman Resources Center
- two representatives from the Administration on Aging.

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

The National Family Caregiver Support Program

Rick Greene, Director of the National Family Caregiver Support Program (NFCSP) at the Administration on Aging, provided dialogue participants with an overview of the NFCSP.

The National Family Caregiver Support Program was created under Title III E of the Older Americans Act in 2000. The program serves two populations --- caregivers of persons age 60 and older and grandparents, or another relative age 60 or older, caring for grandchildren 18 years old and younger. A family caregiver may be a blood relative, spouse, domestic partner, neighbor or friend.

The program authorizes five categories of services:

- information about caregiver services in the community
- assistance accessing services
- caregiver training, support groups, and counseling
- respite care (at home, in the community, or in institutional settings)
- supplemental services.

Supplemental services are not specifically defined, so states and area agencies on aging have flexibility to respond to the individual needs of caregivers. This allows family caregiver support programs to pay for home modifications, incontinent supplies, nutritional supplements and equipment such as microwaves, meals on wheels and transportation. Some area agencies on aging have been extremely creative in responding to the needs of caregivers. For instance, one AAA in Iowa purchased walkie-talkies for a farmer who was fearful of leaving his wife, who has dementia, alone while he worked in the field. The walkie-talkies enable him to keep in touch with her, which is reassuring to both of them and allows him to continue working.

Respite care and supplemental services are the two types of assistance most in demand from the National Family Caregiver Support Program.

Rick Greene
Director, NFCSP

States may choose to implement consumer-directed care options with NFCSP funds, whereby the caregiver gets a voucher or cash to purchase

respite care or supplemental services from a provider of their choice. In most states, the area agencies on aging serve as the local entry points for family caregiver support services. The FFY 2006 appropriation for the NFCSP was \$162 million, of which \$155 million went to the states and territories and \$7 million went to the Native American Family Caregiver Support Program as direct grants to eligible tribes.

Promising Practices and Discussion Highlights

This strategy brief is divided into three sections that correspond to the questions asked during the National Dialogue Forum conference calls. Section I identifies the types of *assistance ombudsman programs provide family caregivers* when a relative has entered a long-term care facility; Section II provides examples of *coordination between the ombudsman and family caregiver support programs*; and Section III lists *written materials ombudsman programs provide to caregivers* and families of long-term care residents.

Family caregiving does not stop at the nursing home door

For many families, nursing home placement is a last resort, considered only after other options have been exhausted. It is an emotional and difficult decision. Family members who have provided care to a loved one for many years often feel a sense of failure or guilt. However, many families discover that caregiving does not stop at the nursing home door.

Dialogue participants discussed how an increasing number of nursing homes are beginning to embrace elements of the culture change movement. This includes taking a more comprehensive view of the admission process to include the resident's family, as well as increased efforts to involve the family as part of the care planning team. And, whereas the traditional perception is that that family caregiving stops at the nursing home door, facilities are now becoming more open to family members assisting residents at meal times and with other activities.

When a facility admits a resident they need to admit the whole family.

Carol Scott
State Ombudsman, Missouri

However, while ombudsmen acknowledged the benefits of greater family involvement in the care planning process, they identified some pros and cons of family involvement in providing direct care to residents. For example, a spouse who wishes to continue to play a caregiver role for the resident may routinely assist with care tasks such as assisting the resident with eating a meal or walking to an activity. On the one hand, this type of regular family involvement, which has benefits to both the family member and the resident, frees up facility staff to provide care to other residents. The downside is that staff can become overly reliant on the family providing resident care at certain times or with certain activities, leading to failure to provide such care if for some reason the family does not show up. Nonetheless, ombudsmen generally agreed that continued

caregiver involvement, particularly in the care planning process, helps to maintain the family bond and ensure a continuity of care for the resident.

I. Assistance ombudsman programs provide family caregivers

How does the ombudsman program help family caregivers adapt to a different type of caregiving role when a relative moves to a long-term care facility?

Ombudsman programs routinely provide assistance to family caregivers who are searching for a nursing home for a relative. After placement many programs also help family caregivers by:

- providing information and support to help families understand residents’ rights and how the nursing home works
- developing and supporting family councils
- working on special projects (as described on page 5).

Providing information and consultation to individuals

In 2005, ombudsman programs nationwide provided more than 342,000 consultations to individuals.¹ Many of these involved family caregivers seeking information about how to choose a nursing home or asking questions about quality of care standards and residents’ rights. Ombudsman programs typically provide information to help people select a long-term care facility; some programs provide information about complaints the program has verified against each facility. After they choose a home, the ombudsman program provides them with information about residents’ rights, the care planning process and how to be an advocate for their relative. Some examples include the following:

We provide families with the tools to be good advocates and caregivers in the nursing home by educating them about resident assessment, care conferences and care plans.

Jim Dostal
Ombudsman Program
Minnesota

The **Colorado** Ombudsman Program encourages families to participate in the resident’s plan of care when their relative has entered a nursing home. According to the state ombudsman, this is a natural continuation of a common role for the family caregiver and also helps with the transition process for both the family and the care recipient. In **Ohio** and **Texas**, as well as other states, local ombudsmen frequently go to care plan meetings with families as part of their advocacy work.

The **New York** State Ombudsman points out that caregiver support groups help caregivers reach out and talk to other caregivers of nursing home residents about similar issues and feelings in a supportive environment. Caregiver support groups deal more with the emotions of guilt and loss caregivers often sense after placing a relative in a

¹ 2005 National Long-Term Care Ombudsman Program Data, U.S. Administration on Aging.

nursing home, whereas family councils deal more with residents' quality of care and quality of life in the facility.

Developing and supporting family councils

Ombudsman programs in Illinois, New York, Ohio, Texas and Wisconsin work to establish and support family councils as a way to assist persons who were caregivers for a family member when they lived in the community. Many of the ombudsman programs that participated in the dialogue make presentations at family council meetings, educating families about regulations, residents' rights, the care planning process and how to address problems and concerns. In 2005, ombudsman programs nationwide attended 6,352 family council meetings in long-term care facilities.² The following are some examples of how ombudsman programs help develop and support family councils.

- ❖ In March, 2006, the **Illinois** Ombudsman Program conducted a statewide, two-day training to educate and empower family councils. The training included sessions demonstrating how care plan meetings work and how residents and families can participate.
- ❖ In **New York**, the ombudsman program assigned a volunteer ombudsman to help establish family councils in nursing homes. The state ombudsman program requires each of the 45 local ombudsman programs to choose one activity to focus on each year. Some of the local programs have chosen to work on developing family councils during the current program year (April 1, 2006 – March 31, 2007).
- ❖ In 2006, the **Ohio** State Ombudsman secured a VISTA volunteer for a one-year commitment to develop a technical assistance resource center for resident and family councils.
- ❖ Regional ombudsman programs in **Wisconsin** target one home each quarter that does not have a family council. The regional ombudsman then works with the facility to convene a family education session. Sessions include information about care plan meetings, problem resolution and an offer from the ombudsman program to help them organize a family council, if they choose.

Special projects

In **California**, one area agency on aging received a three-year grant (through September 2003) from the Administration on Aging, to conduct a pilot project called "Providing Assistance to Caregivers in Transition." The project identified individuals entering long-term care facilities and provided support and education to their caregivers during the first three months following placement in the facility. The goal was to make

² 2005 National Long-Term Care Ombudsman Program Data, U.S. Administration on Aging.

the transition from home to the facility more stable. The project also helped the resident and caregiver identify options for returning to the community. Continuing to provide services and support to caregivers while the care recipient was in a long-term care facility resulted in the project successfully transitioning some residents out of facilities and back to their homes and communities. An interdisciplinary team of professionals, including nurses, social workers, area agency on aging staff and the local ombudsman, provided support and education to caregivers of residents who were unlikely to return to the community, to help with the process of adjusting to the nursing home.

The **North Carolina** Ombudsman Program developed a “Family Empowerment Initiative” consisting of a one-day training to educate family caregivers about issues and decisions that need to be made prior to placement in a long-term care facility and how to negotiate the nursing home system once the person moves to the facility.

II. Coordination between the ombudsman and family caregiver support programs

How does the ombudsman program and the family caregiver program work together at the state and local levels?

The dialogue participants discussed coordination activities between ombudsman and family caregiver support programs, including:

- use of family caregiver support program funds by ombudsman programs
- coordination between local ombudsman programs and family caregiver support programs
- opportunities for future coordination.

Use of family caregiver support program funds by ombudsman programs

In **California**, family caregiver support program funds (Title III E) were provided to a local ombudsman program by the area agency on aging to work with gay, lesbian, bisexual and trans-gender (GLBT) caregivers whose partners entered long-term care facilities. The local ombudsman program developed an educational seminar to address nursing home issues specific to GLBT caregivers, such as challenges to their right to make health care decisions for their partners.

In **Illinois**, one local ombudsman program received a grant from the area agency on aging (Title III E funds) to develop a statewide conference in support of the Family Council Coalition. Entitled *Hand-in-Hand: Quality Care & Citizen Involvement in Nursing Homes*, the conference included sessions on filing a complaint, being an effective legislative advocate, family involvement in the survey process, culture change and strengthening family councils and building statewide coalitions.

Three local ombudsman programs in **Texas** received family caregiver support funds (Title III E), on a one-time basis, from their respective area agencies on aging to hire extra staff to help organize family councils in nursing homes. In order to promote and expand coordination between the ombudsman and family caregiver support programs, the state ombudsman has talked with the state's area agency on aging association about how Title III E funds could be used to help identify and assist nursing home residents who are able to transition back to the community.

Coordination between local ombudsman programs and family caregiver support programs

A local ombudsman program in **Alabama** coordinates with the family caregiver support program to provide training to families and caregivers who have a relative entering a nursing home. The training addresses families' questions about care expectations, participating in care plans, visitation, and residents' rights.

Having the two programs housed in the AAAs makes coordination easier and more efficient.

Dennis Streets
Director, Div. of Aging & Adult Services,
North Carolina

In **North Carolina**, when regional ombudsman programs identify a family who wants to transition their relative back to the community from a nursing home, they make a referral to the regional family caregiver specialists for assistance and support. According to the state aging director, having regional ombudsman and family caregiver support programs housed together in the area agencies on aging makes information sharing and referrals easier and more efficient.

Opportunities for future coordination

Rick Greene, Director of the National Family Caregiver Support Program at the Administration on Aging, explained that because of the great demand for services, family caregiver support programs generally give priority to caregivers in the community who are providing 24-hour care. In some communities there may be waiting lists for services. Limited resources of local family caregiver support programs may mean less attention is given to caregivers who want to move their relatives out of a nursing home. This situation provides an opportunity for the family caregiver support program and the ombudsman program to explore ways to work together to identify these persons and help them access the support and assistance they need to care for their relatives when they return home.

We want to work with the ombudsman program because they can help direct individuals to the local family caregiver support program.

Joel Weeden
Family Caregiver Support Program, California

California's Family Caregiver Support Program views families who do not identify themselves as caregivers as a major challenge.

Families with a loved one in a rehabilitation facility or nursing home for a short-term stay may not be prepared to take on caregiver responsibilities when the person returns home. The program focuses on outreach to such families, who are at the doorstep of caregiver responsibility, to let them know that there is a support system to assist them with transitioning their relative back into the community. The California Family Caregiver Support Program operates a community outreach initiative called Making the Link. Outreach is conducted through medical offices to reach persons who do not identify themselves as caregivers, although they provide care to a family member. The program plans to expand the initiative to nursing homes in order to prepare families for caregiving responsibilities when a relative is transitioned back to the community. The ombudsman program will serve as an important link in this effort.

III. Written materials ombudsman programs provide to caregivers

What written materials does the ombudsman program use to help caregivers whose relatives have moved from home to a long-term care facility?

Written information available from the ombudsman program for families and caregivers looking for a long-term care facility, or who have already placed a family member in a long-term care facility, consists primarily of guides on how to choose a nursing home or other long-term care facility and residents' rights brochures. In some states, these materials have been translated into several languages. Examples of written materials distributed by ombudsman programs include:

- ❖ *Nursing Homes: getting good care there*³ is routinely provided to consumers who contact the ombudsman program in Illinois, Kentucky and Ohio. The Minnesota Ombudsman Program gives a copy of the book to all their volunteer ombudsmen.
- ❖ *Caregiver Handbook*, developed by the Denver Regional Council of Governments, includes a section on “caregiving when your relative is institutionalized.”

Summary

Thirty (30) persons, representing 14 states and the District of Columbia, participated in the Nation Dialogue Forum on the ombudsman program and caregiver support. The dialogue focused on the types of assistance ombudsman programs provide to family caregivers transitioning a relative to a long-term care facility and ombudsman program coordination with the family caregiver support program. A representative from the Administration on Aging provided dialogue participants with information about the National Family Caregiver Support Program.

³ Sarah Greene Burger, Virginia Fraser, Sara Hunt, Barbara Frank. *Nursing Homes: getting good care there*. (California: Impact Publishers, Inc.). 2002.

The dialogue revealed that ombudsman programs routinely provide information and consultation to family caregivers about how to choose a long-term care facility and how to advocate for their relatives through the care planning process. Ombudsman program participants also discussed their activities developing and supporting family councils in nursing homes. This strategy brief identified examples of how ombudsman programs use family caregiver support program funds (Title III E) and examples of coordination between local ombudsman and family caregiver support programs. Dialogue participants agreed that there are opportunities to expand coordination between the two programs in the future.

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 Caregiver Support

Issue Identification Panel Members

Panel Task: Identify primary questions of interest to address during the National Dialogue Forum on the ombudsman program and caregiver support.

SUA Representatives:

Georgia

Cliff Burt
Aging Services Coordinator
Division for Aging Services

North Carolina

Chris Urso
Family Caregiver Support Program
Division of Aging & Adult Services

Utah

Sonnie Yudell
Family Caregiver Support Program
Division of Aging & Adult Services

Maine

Brenda Gallant
State Ombudsman

Michigan

Sarah Slocum
State Ombudsman

North Carolina

Sharon Wilder
State Ombudsman

Others:

Administration on Aging

Rick Greene
National Family Caregiver
Support Program

National Ombudsman Resource Center

Lori Smetanka, J.D.
Director

Ombudsman Program Representatives:

Colorado

Pat Tunnell
State Ombudsman

Iowa

Jeanne Yordi
State Ombudsman

Kentucky

Sherry Culp
District Ombudsman

APPENDIX C

National Dialogue Forum Participants

The Ombudsman Program and Caregiver Support

National Dialogue Forum Participants

Alabama

Virginia Bell
State Ombudsman

Letha Stuckey
Cares Coordinator
Department of Senior Services

California

Joe Rodrigues
State Ombudsman

Joel Weeden
Family Caregiver Support Program
Department of Aging

Colorado

Steve Evans
Division of Aging & Adult Services

Pat Tunnell
State Ombudsman

Connecticut

Roberta Gould
Department of Elder Affairs

District of Columbia

Jerry Kasunic
State Ombudsman

Illinois

Neyna Johnson
Ombudsman Program

Kansas

Deborah Merrill
Department on Aging

Minnesota

Jim Dostal
Lori Goetz
Cheryl Hennen
Maria Michlin
Sherilyn Moe
Paula Wieczorek
Ombudsman Program

Missouri

Carol Scott
State Ombudsman

Sally McKee
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New York

Marty Haase
State Ombudsman

Susan Root
Ombudsman Program

North Carolina

Dennis Streets
Director
Division of Aging & Adult Services

Sharon Wilder
State Ombudsman

Ohio

Beverley Laubert
State Ombudsman

Rhode Island

Paula Parker
Department of Elderly Affairs

Texas

John Willis
State Ombudsman

Cheryl Cordell
Ombudsman Program

Wisconsin

Thomas La Duke
Ombudsman Program

Administration on Aging

Sue Wheaton
Ombudsman Program Specialist

Rick Greene
National Family Caregiver
Support Program

National Ombudsman Resource Center

Lori Smetanka, J.D.
Director