

The Role of the Long Term Care Ombudsman Program in Home Care Advocacy

**Prepared by
National Association of State Units on Aging**

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Introduction

This technical assistance paper updates and expands information previously collected on Home Care Ombudsman Programs. The Long Term Care Ombudsman Program's involvement in home care advocacy has changed somewhat since 1994, when ten states provided Ombudsman services to home care consumers.¹

- In 1999, in ten states - Alaska, Idaho, Maine, Minnesota, Ohio, Pennsylvania, Rhode Island, Virginia, Wisconsin, and Wyoming - the Ombudsman Program was mandated under state law to provide advocacy on behalf of consumers who receive home and community based care.
- In one state - Colorado - the Ombudsman Program previously handled some home care issues, but no longer has that responsibility.
- Two Ombudsman Programs - in Nevada and Oklahoma - may investigate concerns about home care services provided to residents of assisted living.
- Finally, two states - Nevada and Vermont - have created Ombudsman Programs with responsibilities that include home care advocacy; these programs are separate from, but work closely with the Long Term Care Ombudsman Program.

The information reported here was gathered between 1999 and 2000, via telephone and written correspondence with the Long Term Care Ombudsman Programs that have responsibility for providing home care advocacy and from other programs that foresee a future role in this arena.² The paper includes information on the scope of each Home Care Ombudsman Program's responsibilities, the types of complaints which may be reported, program funding, access issues, training, and systems advocacy activities. **A "Checklist for Ombudsman Expansion into Home Care" is included in the appendix.**

¹ National Long Term Care Ombudsman Resource Center, *Exploring Ombudsman Services for Home Care* (1994). The ten states were: Alaska, Colorado, Idaho, Maine, Minnesota, Ohio, Pennsylvania, Virginia, Wisconsin, and Wyoming.

² Identified through the National Long Term Care Ombudsman Resource Center's *Survey of the State Long Term Care Ombudsman Programs*, (1998), Question 4: "Ombudsman Program Scope."

Program Scope

The ten Long Term Care Ombudsman Programs which provide home care advocacy and complaint handling under a state statute are: Alaska, Idaho, Maine, Minnesota, Ohio, Pennsylvania, Rhode Island, Virginia, Wisconsin, and Wyoming.

- **Alaska's** enabling legislation (enacted in 1988) states that the Ombudsman Program may, but is not required to, investigate complaints related to long term care or residential circumstances of older Alaskans. Because of limited resources, the Alaska Long Term Care Ombudsman Program triages home care complaints and limits the type of complaints Ombudsmen investigate to those involving individual problems, rather than those that are systemic issues. Additionally, due to limited staff, the program attempts to handle issues by phone rather than making in-person visits.
- The **Idaho** statute that requires the Office of the Ombudsman to investigate "community complaints" has not changed since its passage in 1988. Historically, community complaints handled by the Ombudsman Program have involved not only home care services, but also issues such as access to transportation for medical appointments, public benefits eligibility problems, Medicare billing questions and housing availability, affordability and safety. The Ombudsman Program has handled few complaints specifically concerning home care, in part because of the limited availability of home and community based services in the state. However, that situation is expected to change due to a recent increase in Medicaid waiver services. In January 2001, the Long Term Care Ombudsman Program amended its guidelines to limit the "community complaints" it will investigate to those complaints involving long term care issues and services provided by the Idaho Commission on Aging.
- **Indiana's** state statute mandates the Ombudsman Program to extend its advocacy services to persons receiving in-home services, but the state legislature has not funded that mandate. In light of this situation, the Ombudsman Program continues to handle complaints only in long term care facilities as required by federal law. The program currently does not have the resources to advocate for home care clients.
- **Maine's** Ombudsman Program has had authority to handle home care complaints since 1986. Since that time, the program has responded to all requests for assistance made by home care consumers. In 1994, the state's Medicaid medical eligibility rules were changed, resulting in fewer admissions to nursing homes and an increase in consumers' use of community services. Since then, the program has experienced a substantial increase in the number of home care referrals it handles. Other factors contributing to the increased number of home care calls include changes in Medicare home health care payment and coverage brought about by the 1997 Balanced Budget Act (e.g., the move to a prospective payment system, increases in service denials and reductions in the amount of service) and the state's requirement that consumers be given information about the Ombudsman Program by the agencies that conduct assessments for home care and oversee service coordination. Two "Home Care Specialists,"

who are Registered Nurses, investigate most of the home care complaints reported to the program, although all Ombudsman casework staff have received training to enable them to investigate such cases as well.

Most complaints involve reduction, termination or changes in publicly funded (i.e., Medicaid, Medicare, state funded) home care services. The program has a high success rate in resolving home care cases, with the result that consumers usually are able to retain services or their services are improved. In Maine, complaint data is not available for the years prior to 1998, when the data was first computerized; however, the Ombudsman states that prior to 1996, the program handled very few home care cases. In State Fiscal Year (SFY) 1999, 159 home care complaints were reported. During SFY 2000, the program handled 219 home care complaints out of a total of 1,923 complaints for the year. The Ombudsman reports that home care complaints tend to be "time consuming;" thus, the number of home care complaints alone does not adequately reflect the program's activities on behalf of individual home care consumers. Most complaints require a home visit to assess the situation. In addition, the program either provides representation directly or consults with legal services when home care consumers appeal decisions to terminate or reduce their services.

- In **Minnesota**, the legislation that created the Home Care Ombudsman Program was enacted in 1989, beginning first as a pilot project. The program continued to expand, with funding, to all but 7 metropolitan counties in the state in 1993. The most recent expansion, in 1998 to the remaining counties, resulted in the provision of Home Care Ombudsman services statewide. The Ombudsman Program has authority to handle complaints regarding in-home services (including homemaking, home health aide, nursing, therapies, social services and home-delivered meals); adult day care; elderly adult foster care and in-home services for adult foster care for younger adults; hospice (non-nursing home setting); assisted living services; durable medical equipment; and public benefits relating to in-home and community services.

Most of the home care complaints the program receives concern consumer rights, quality of care, and lack of staff. In FY 1999, the program handled 123 home care complaints, compared to 42 acute care complaints and 1,986 long term care facility complaints. The number of home care complaints handled by the program has been slowly increasing, with the exception of FY 2000, when the overall number of complaints reported to the Ombudsman Program declined. This may have been due, in part, to staff turnover in the program during FY 2000, when the program handled 54 home care complaints, 76 acute care complaints, and 1,742 long term care facility complaints. Since the Minneapolis-St. Paul area now offers Home Care Ombudsman services, an increase in the volume of complaints is still expected. Also, in preparation for a new software system, the program is examining its casework and data entry system to help ensure the accurate recording of complaint data, including home complaints.

- **Ohio's** Ombudsman Program, through its enabling legislation, has the authority to handle complaints about community based long term care services provided to persons aged 60 and older under the Medicaid waiver and state-funded programs. The Ohio program also handles complaints about unlicensed agencies that provide home care. Home care complaints encompass concerns about any health or social service provided in the older person's home or community care settings, including, but not limited to, case management, personal care, home health, homemaker or chore services, respite care, adult day care, home-delivered meals, and therapies (physical, occupational, speech). The number of home care complaints handled by the program has increased somewhat. In the early 1990s (c1993), the Title III and state Senior Community Services Block Grant programs began requiring providers to inform their clients about the Ombudsman Program, resulting in an increase in home care complaints in at least one region of the state.
- The **Pennsylvania** Ombudsman Program has had responsibility for providing advocacy services to home care consumers since its inception. The state's Ombudsman law, unchanged since its enactment in 1988, specifies the program's responsibility for investigating long term care complaints regardless of the setting. Because the program's home care advocacy role is not as well publicized as its work in nursing homes, the percentage of home care complaints the program handles is minimal in comparison to those from consumers in long term care facilities.
- In 1999, the **Rhode Island** Ombudsman Program received a legislative mandate to begin providing advocacy services to home care consumers, following completion of a successful pilot project operated under a grant funded by the legislature. The first year was spent organizing and setting up the program with the assistance of an advisory committee comprised of representatives from various state agencies, independent home care providers and the Rhode Island Partnership for Home Care (a trade organization which represents both for profit and non-profit home care providers). Currently, the number of home care complaints received represents a very small percentage of the overall number of complaints handled by the program. However, this percentage is expected to increase once the Ombudsman Program's telephone number is listed on the *Client Bill of Rights* given to home care recipients, beginning July 1, 2001.
- In 1984, **Virginia** mandated that the Ombudsman Program handle complaints concerning home and community based services, funded by Medicare, Medicaid, state funding, other federal funds or private means. The legislature has not provided specific funding for the program's home care advocacy activities, with the result that the program responds to complaints but does no outreach to home care consumers. A few (less than 5% of the total) home care complaints are reported to the Ombudsman Program each year.
- **Wisconsin's** Ombudsman enabling legislation gives the program authority to handle complaints from long term care consumers who receive home health care, hospice, adult day services, and home and community based services provided under the Medicaid waiver. In 1999, the legislature gave the Ombudsman Program authority and funding to provide, under contract with the state's managed long term care pilot program, Ombudsman services to

managed long term care recipients. Most complaints reported to the program come primarily from clients of the Medicaid waiver program. Only about 5% of the program's total complaints are home care issues. However, with the long term care focus moving from institutional care to home care, the Ombudsman Program expects to see an increase in the number of home care complaints it receives.

- **Wyoming's** Ombudsman Program has had a legislative mandate to investigate home care complaints since 1985. Because of already stretched resources, the program had not advertised its home care advocacy services. With the increase in people staying in their homes and receiving long term care services in the community and the increase in home care agencies providing services in the state, the Ombudsman Program is promoting its advocacy services to home care consumers much more extensively. As a result, the program has seen an increase in home care complaints, although many of these are referred to Adult Protective Services for investigation.

One Ombudsman Program previously handled home care complaints, but no longer has that responsibility.

- Under an informal agreement with the State Agency on Aging, the **Colorado** Ombudsman Program responded to complaints that were made against case managers in the Medicaid funded home and community based services program. Few such complaints were handled by the program. In 1999, the informal agreement was discontinued, so the Ombudsman Program no longer handles home care complaints.

Two Long Term Care Ombudsman Programs - in Nevada and Oklahoma - do not have specific regulatory authority to investigate home care complaints. However, since home health agencies are permitted to provide services in residential care facilities in these states, these programs may respond to complaints or concerns about the services provided by home health agencies.

- **Oklahoma's** new assisted living statute permits non-nursing home, long term care facilities to arrange nursing services for its residents, most likely through home health agencies. The Ombudsman Program provides advocacy services to residents of such facilities, as required by the Older Americans Act, and will investigate complaints that are reported against home health agencies providing services to assisted living residents.
- Like Oklahoma, the **Nevada** Long Term Care Ombudsman may investigate home health agencies that provide services in residential care facilities, even though they do not have a mandate to handle home care complaints.

Two states - Nevada and Vermont - have created new Ombudsman Programs to handle concerns about community services provided to older persons. These programs are separate from the Long Term Care Ombudsman Program, although the programs have a close working relationship.

- **Nevada's Community Ombudsman Program** has a legislative mandate to handle all complaints from elders 60 years and older, living in the community. While both the Community Ombudsman and the State Long Term Care Ombudsman are located in the Division of Aging, these are separate programs with separate enabling legislation.
- **Vermont's Health Care Ombudsman** handles complaints from elders receiving home care services through Medicaid, Medicare or other insurance programs. The Health Care Ombudsman and the State Long Term Care Ombudsman are located in the same private, nonprofit agency, yet they function independently of one another.

Program Funding

The federal Older Americans Act defines the scope of Ombudsman services to include nursing facilities, skilled nursing facilities, board and care and "similar" adult care homes. Thus, programs that provide home care advocacy rely on state general revenues or other sources of funding to support their work in this arena.³ Typically, state funds supplement the Ombudsman Program's federal funding and are not earmarked specifically for home care.

- The **Ohio** Ombudsman Program receives both state general revenue funds and monies collected from long term care bed fees, but these funds support the program's advocacy in nursing and residential settings as well as in home care.
- In **Maine**, state funds account for approximately 43% of the Long Term Care Ombudsman Program's budget (\$248,465 in FY 2000), a portion of which is used to investigate home care complaints.
- **Minnesota** receives approximately \$348,000 in state general funds per year to handle complaints in settings other than nursing facilities including, but not limited to, home care. These funds also support the Ombudsman Program's handling of hospital access and discharge complaints on behalf of Medicare beneficiaries. The Ombudsman Program's home care work includes assisted living, which is licensed as a home care service under state statute.
- **Rhode Island** provides \$50,000 per year in state funds specifically to support the Long Term Care Ombudsman Program's home care advocacy efforts.

New funding for home care advocacy may be on the horizon. The **Alaska** program hopes to use Medicaid waiver funds to support its home care work in the future, and **Wisconsin**, in 1999, provided funding and gave the Ombudsman Program authority to provide advocacy

³ Funds authorized and/or appropriated under the Older Americans Act for the Long Term Care Ombudsman Program may not be used for ombudsman services in settings other than those included in the program as defined in the Act: nursing homes, board and care homes and similar adult care facilities (Section 102(a)(32)). This includes Title III funds taken "off the top" by the state under Section 304(d)(1)(B); Title VII, Chapter 2 ombudsman funds and state and other funds included in the required minimum funding levels under Sections 307(a)(9) and 306(a)(9) of the Act. (See AoA PI 94-02, issued April 5, 1994.)

services to consumers in the state's managed long term care pilot program. That program is currently in operation.

Access

Several states attribute the low number of home care complaints to the Ombudsman Program's lack of access to home care consumers. Unlike long term care facilities where information about the Ombudsman Program is posted or an Ombudsman can drop by unannounced, the home care setting does not afford easy access. Further discussion is needed about how to give Ombudsmen access to a person's home to investigate concerns about quality services without impinging on personal privacy.

Two states - Maine and Minnesota - report having a higher percentage of home care complaints than the other Ombudsman Programs that handle home care issues, due at least in part, to requirements that home care consumers be given information about the Ombudsman Program's services.

- In **Maine**, consumer assessments to determine eligibility for home and community based services are conducted by one agency for the entire state; care coordination for these programs is the responsibility of a different statewide agency. As a condition of their contracts with the state, both of these agencies are required to give consumers information about the Ombudsman Program, both upon entry into the program and when there is a decrease or termination of services. This policy has greatly added to the visibility of Maine's Ombudsman Program and has led to an increase in the number of home care complaints the program receives. The program has produced a separate home care brochure to provide information to consumers.
- In **Minnesota**, the home care licensing law requires home care agencies to inform their clients about the Ombudsman Program as a resource for resolving complaints, specifically when services are being terminated or when their services fees are being increased.

Training

Most Ombudsman Programs with responsibility for home care complaints cross-train their staff to handle complaints in all settings. Typically, training on home care regulations and issues is incorporated into the mandated training program for new Ombudsmen.

- The **Maine** Home Care Specialists have trained other Ombudsman staff to handle home care complaints, but currently handle most of the home care complaints reported to the program. The program has developed a home care advocacy training program for registered nurses and attorneys who volunteer to assist with gathering information and representing consumers at administrative hearings.

- As each of the state's regions was added to the Home Care Ombudsman Program, **Minnesota** trained Ombudsmen in the region to handle home care complaints. The Ombudsman Office offers training to its statewide staff every other month and devotes at least two hours in each session to a home care topic. Additionally, Ombudsmen attend the Department of Human Services' annual training on publicly funded home care services.
- The 100-hour curriculum for new Ombudsmen mandated by the **Ohio** Ombudsman Program includes a study of home care regulations. New Ombudsmen in Ohio also have the option of completing the twenty-hour provider orientation required by the program with a home care provider instead of in a nursing home or residential care facility. A proposed revision in the training guidelines would require new Ombudsmen to understand specific home care issues and complete a three-day home care orientation with a home care provider. The orientation includes observations of general operations, an admission, a home health aide visit and a supervisory visit.
- In **Rhode Island**, Ombudsman volunteers receive 2 hours of training specific to home care issues as part of their 36 hours of initial training.

Systems Advocacy on Home Care Quality

Several Home Care Ombudsman Programs are involved in activities related to promoting quality in home and community based settings.

- **Idaho's** Ombudsman participated in a workgroup which developed a quality assurance pamphlet, listing consumers' rights and home care resources. The pamphlet is being distributed to all clients of the new Medicaid waiver program.
- **Indiana's** State Ombudsman participates in a number of home care task forces, serving as an advocate for home care consumers.
- In **Maine**, the Ombudsman Program participates in several groups that focus on home care issues. The program initiated a *Home Care Advocacy Coalition*, consisting of providers and professionals, which meets quarterly. The Home Care Specialist attends quarterly *Quality Assurance Meetings* in the state's five regions; these meetings also are attended by the state's home and community based care assessment and care coordination agencies, home health agencies, a representative of the Bureau of Elder and Adult Services and the State Ombudsman. The group conducts case reviews and shares new information regarding home care services. The Ombudsman Program uses these meetings to discuss and problem-solve on particular trends and issues. Additionally, the State Ombudsman serves as a resource for the *Long Term Care Steering Committee*.

The Ombudsman Program also advocates for home care legislative change, providing testimony regarding long term care legislative proposals that potentially impact home care quality. The *Home Care Advocacy Coalition* identified the need for a personal care attendant (PCA) registry as a priority issue. As a result, the Ombudsman Program and the Home Care

Alliance, a trade organization, brought together a work group to develop legislative language. The Ombudsman Program also submitted legislation to make home care services an entitlement, and was successful in getting many of its ideas incorporated into long term care legislation developed by the Health and Human Services Legislative Committee.

Finally, the Maine Ombudsman Program has successfully advocated for home care consumers' right to appeal when the plan of care for home services is deemed inadequate. The program plays an active role in ensuring that home care consumers are represented at informal conferences and administrative hearings in cases where publicly funded home care services are either reduced or terminated. Representation at appeal hearings may be provided directly by the Ombudsman Program to consumers of Medicaid services who are younger than age 60 or consumers of state-funded services. For consumers aged 60 and older who file appeals, the program works closely with Legal Services for the Elderly, which is mandated to serve this population, to ensure that representation is provided. The Ombudsman Program also provides consultation to legal services on the medical and assessment issues involved in such cases. To address the issue of representation at appeal hearings more systematically, the program is recruiting law students, attorneys and other professionals as volunteers and has developed an extensive training program to prepare attorney and other professional volunteers for their role in assisting consumers with appeals.

- As a means of assuring quality care for individual consumers, **Minnesota** State Ombudsman staff meet regularly with home care provider staff for problem resolution. When appropriate, Ombudsmen also attempt to influence agency policy changes, especially in terms of improving provider/staff education. The program's Home Care Specialist serves on all state Health Department work groups dealing with licensure of home care services and on an Education Work Group that will educate providers statewide on the state's new assisted living regulations. The Home Care Specialist previously served on a task force to develop licensure standards for personal care attendant services and a work group to develop licensure standards for assisted living home care providers.
- While **Ohio's** Ombudsman Program does not mandate specific quality assurance activities, the State Ombudsman and staff of the PASSPORT home and community based waiver program have held joint discussions on quality assurance issues. In one region of the state, the regional Ombudsman program director regularly reviews the "provider feedback logs" used in the PASSPORT program to identify problems that require Ombudsman investigation and resolution.
- The **Pennsylvania** Ombudsman reports that the program's Operation Restore Trust activities, promoting an anti-fraud agenda, have had an impact on quality assurance in home care.
- The **Rhode Island** Ombudsman Program participates in a task force concerned with home care issues, provides training to staff of home care agencies concerning client rights, and has conducted a day-long seminar on sexual abuse for long term care providers, including home care agencies. In addition, the program has produced a home care consumers' rights brochure which includes information about how to resolve a concern or complaint.

- The **Wisconsin** Ombudsman Program was successful in obtaining additional authority and funding to handle managed long term care complaints from the legislature in 1999.
- The **Wyoming** State Ombudsman believes the Ombudsman Program plays an important role in home care quality assurance. Providers' knowledge of the Ombudsman Program's mandate under state law to investigate home care complaints has, in the Ombudsman's opinion, increased home care providers' responsiveness to their consumers.

Summary

Most of the Ombudsman Programs with home care responsibility have been unable to expand their advocacy activities on behalf of home care consumers since 1994, when the Center previously gathered information on these programs. The two greatest barriers facing Long Term Care Ombudsman Programs that provide home care advocacy remain: (1) the lack of resources to fully meet the needs of these long term care consumers, and (2) a lack of access to home care consumers.

Giving the Ombudsman Program specific legislative authority to handle home care issues is a necessary prerequisite for establishing a Home Care Ombudsman Program. However, the experience of seven of ten Ombudsman Programs with such authority would indicate that this clearly is not enough to assure a strong advocacy presence.

Having resources earmarked for home care advocacy or substantial non-federal funding that may be used for home care advocacy is crucial to success. However, it is noteworthy that both the Maine and Minnesota Ombudsman Programs have been successful in expanding their home care advocacy in recent years, and are actively involved in home care quality assurance activities. Both have also experienced an increase in home care complaint activity and anticipate more complaints in the future.

The characteristics of the Maine and Minnesota programs may provide insight into conditions, other than funding and a legislative mandate, that are necessary for establishing an effective Ombudsman presence in home care. These include:

- Specific staff assigned to home care issues: both of these programs have full-time Home Care Ombudsmen at the state level.
- Mandatory provision of information about the Ombudsman Program to home care consumers: by the agencies that assess consumers and coordinate home care services in Maine, and by all home care providers in Minnesota.
- Recognition of the Ombudsman Program's role in home care advocacy and quality assurance efforts: in both states, the Ombudsman Program is "at the table" when home care regulations and program policies are developed and participate actively in work groups that address problems and consumer concerns regarding home care services.

Given the resurgence of interest in assuring quality in long term care, we believe it is important to identify what makes an effective home care advocacy program. The Long Term Care Ombudsman Programs in Minnesota and Maine may serve as models for other states considering expanding the program's scope into the home care arena. A **Checklist for Ombudsman Expansion into Home Care**, provided in Appendix A, is designed to assist states to identify ways to develop a successful Home Care Ombudsman Program.

CHECKLIST FOR LONG TERM CARE OMBUDSMAN PROGRAM EXPANSION INTO HOMECARE

Based on our discussions with State Ombudsmen who have responsibility for home care complaints, we have compiled a checklist for states considering expansion of their Ombudsman Program into home care advocacy.

4 Essential Components of a Successful Home Care Ombudsman Program

- **Funding:** Establish specific, sufficient additional funding to expand the program so that expansion does not dilute ombudsman services to residents of long-term care facilities and to provide ongoing support for home care advocacy.*
- **Authority:** Enact legislation giving specific authority to the Long Term Care Ombudsman Program to investigate home care complaints and define the scope of that responsibility (e.g., all home care services or only publicly funded home care).
- **Systems Advocacy:** Ensure Ombudsman involvement in developing home and community based services regulations and policies.
- **Consumer Information:** Require (either legislatively or through regulations) that home care consumers be given information about the Ombudsman Program's advocacy services in home care.

Other Considerations for Expanding Ombudsman Programs into Home Care

- **Scope:** Determine the scope of the Ombudsman's responsibilities (i.e., advocating for individuals and/or systemic issues; quality assurance role; advisory role; only state/federally funded programs; all home care agencies [licensed and unlicensed], etc.)
- **Staff/Training:** Determine whether there will be designated staff for home care or if all staff will be cross-trained to handle home care complaints.
- **Conflicts of Interest:** Consider possible conflicts of interest, especially where Ombudsmen are located in agencies that also provide or administer home care services and take steps to remove any conflicts that are identified.

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