



STATEMENT OF

THE NATIONAL CONSUMER VOICE FOR QUALITY LONG-TERM CARE

Janet Wells, Director of Public Policy

To The

Senate HELP Committee

REAUTHORIZATION OF THE OLDER AMERICANS ACT
LONG-TERM CARE OMBUDSMAN PROVISIONS

1001 Connecticut Ave, NW, Suite 425
Washington, DC 20036
202-332-2275

The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR, the National Citizens' Coalition for Nursing Home Reform) was founded in 1975 by Elma Holder to address substandard care in nursing homes. Over time, the mission of the Consumer Voice has expanded to include individuals receiving long-term care and services in other settings. In 2010, the Board of the Consumer Voice expanded its mission and scope to advocate for individuals receiving long-term services and supports, no matter where they receive those services.

Our organization also has a long, supportive history with the Long-Term Care Ombudsman Program. As NCCNHR, the Consumer Voice staff developed training and resources for Ombudsman Development Specialists in the 1970's and have supported the work of State and Local Ombudsmen since the program's inception. Elma Holder was a member of the Institute of Medicine's 1995 study, *Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*; and our organization has been part of the National Long-Term Care Ombudsman Resource Center since its development in 1988 (more on that below).

The Long-Term Care Ombudsman Program was created in the 1970's as part of a national response to serious concerns about abuse, neglect and substandard conditions in our country's nursing homes. From the very beginning, the role of the ombudsman has been to represent the interests of residents. This role is of vital importance, because, as Dr. Arthur Flemming, a former Commissioner on Aging and the architect of the Ombudsman Program noted, the individual in the nursing home is powerless. Many residents are very frail and vulnerable and – a growing number of them have some type of dementia. It means that in many cases they may not be able to get to a phone or even pick up a phone to call for assistance. Frequently their families may be so overwhelmed that they don't know how best to help, or sadly, residents may not have any families at all. Residents need someone by their side – on their side – that will go to bat for them on both an individual and systems level. And that person is the ombudsman. There is no one else out there in the entire long-term care system that is legally mandated to be there solely for the resident and to represent residents wherever their voice needs to be heard.

The Long-Term Care Ombudsman Program is a critical resource – for information, advocacy, and support – to individuals receiving long-term care and services and their families. One of the primary responsibilities of the ombudsman is to investigate and resolve complaints. Ombudsmen also assist families and individuals to find appropriate facilities; they educate residents, families, staff and others about rights, abuse prevention, quality of care and

life, and more; and they provide the support and information for residents and families to self-advocate and feel empowered. Ombudsmen promote good care practices and person-centered, individualized care. They help stop illegal involuntary discharges; inform residents about their appeal rights; and advocate for nursing home residents who want to transition back into the community.

In addition to individual advocacy, ombudsmen work for systemic change, promoting laws, regulations, and policies that support quality, rights, and person-centered care and services. Often, Ombudsmen are the only representative of consumer interests at the table in policy discussions. Because of their important work on behalf of frail, vulnerable individuals, it is critical that there be a strong, well-funded, effective Long-Term Care Ombudsman Program in every State and community.

The Consumer Voice supports the comments and testimony of the National Association of State Long-Term Care Ombudsman Programs. There are, however, areas of particular importance to consumers that we would like to highlight.

Adequate Funding for Long-Term Care Ombudsman Programs

Sustained, adequate funding is critical for an effective Long-Term Care Ombudsman Program. Without it, ombudsmen are unable to fulfill the mandate and spirit of the Older Americans Act, including responding to complaints, maintaining a presence in facilities so that residents have regular and timely access to representatives of the program, supporting resident and family councils, representing the interests of residents before government agencies, and more.

As states continue to struggle through severe budget crises, Ombudsman Programs around the country have experienced cuts, and many are struggling with how to meet the demands of program requirements with less money, and in some cases, less staff. Right now, there are programs around the country that have so few paid or unpaid staff that they are forced to limit their activities to complaint investigation only – all they can do is put out fires. Insufficient staffing also means the program cannot respond in a timely manner – and when you are a resident waiting for help, every day that goes by is an eternity.

Because of budget constraints, programs are having to re-evaluate their workload and make cuts that will impact their ability to advocate for residents. For some programs, routine visits (non-complaint related) to facilities are being cut back; others are cutting back on training for staff. Many residents do not have the ability to file a complaint, or are afraid to do so for fear of retaliation. Regular, onsite presence in facilities-- so that an ombudsman can observe

conditions and develop relationships and trust with residents--is critical to the effectiveness of the program.

As such, in this reauthorization of the Older Americans Act, the Consumer Voice supports language proposed by NASOP related to maintenance of effort for funding the ombudsman program. Without adequate funding, frail, vulnerable individuals, many of whom cannot speak for themselves and have no one else to do so, will not receive the education regarding their rights, advocacy and protection they need and are entitled to receiving.

Regulations for the Long-Term Care Ombudsman Program

It is critical that consumers receive the same high quality ombudsman services no matter in which state they live. Unfortunately, programs vary enormously from one state to another. As a means of increasing consistency among ombudsman programs across the country, and to provide clarity to State and Local Ombudsmen, State Units on Aging, Area Agencies on Aging, and others, it continues to be important that the Administration on Aging issue regulations regarding the Long-Term Care Ombudsman Program. As Long-Term Care Ombudsman Programs, and the state and local agencies that house them, struggle with complex issues such as conflict of interest, program cohesiveness, and systemic advocacy, regulations would offer needed clarity regarding ombudsman program management, oversight, and scope of advocacy.

Systems Advocacy

In addition to individual advocacy, ombudsmen at the State and Local level are to engage in systemic advocacy and promote systems change that will benefit residents as a whole. Ombudsmen are specifically directed by the Older Americans Act to represent the interests of residents before governmental agencies and seek administrative, legal, and other remedies to protect residents. Additionally, they are directed to analyze, comment on, and monitor the development and implementation of laws and regulations, as well as policies and other governmental actions that affect residents and long-term care facilities.

Too often, the Long-Term Care Ombudsman is the only one speaking on behalf of consumers and what they need and/or want. Thus it is critical that ombudsmen have the freedom to express their perspective and experiences. Situations exist, however, where Ombudsmen have not been permitted to take systemic advocacy actions, such as communicating with legislators, policy makers, or the media, either at all or without prior approval from the agency in which they are housed, particularly if the position that the ombudsman would take is contrary to that of their agency or administration. Inhibiting this legal

ombudsman function does a grave disservice to residents who are unlikely to have any other way to raise their issues.

To that end, the Consumer Voice recommends that the Older Americans Act language be amended to make it clearer that Long-Term Care Ombudsmen have the authority to engage in legislative, regulatory, legal and other forms of advocacy, with communication and coordination with their housing agency or administration but without the need for prior approval. Without such autonomy, the program cannot truly represent the interests and concerns of residents.

Consumer Access to the Ombudsman

The Older Americans Act says that residents shall have regular, timely access to representatives of the ombudsman program and timely responses to their complaints and requests for assistance. For purposes of clarity, the Consumer Voice would recommend that the language be amended to include private, unimpeded access around the clock. We hear from ombudsmen and residents about challenges ombudsmen experience in gaining access to residents, particularly in assisted living and board and care facilities, and in finding an adequate place to communicate privately with a resident. No matter what time of day or night, both the ombudsman and the resident need to know that the ombudsman will have access to both the facility and the resident.

Conflict of Interest – Organizational and Individual

One factor that influences the effectiveness of the ombudsman is the trust a resident has in that person. It is paramount that the resident trusts the ombudsman to listen to what they want and advocate for the resident to the best of their ability. If the ombudsman shows competing interests, either real or perceived by the resident or family, it will inhibit the trust the resident has in him or her and affect the ombudsman's effectiveness in handling their problem. Conflict of interest can lie with the individual, or with the organization. It causes confusion for the resident and family as to whose interest the individual serving as the ombudsman will be promoting in any given situation at best, and at worst, undermines the credibility and hence the effectiveness of the ombudsman to act on behalf of residents.

Individual conflict of interest can exist if the individual ombudsman also serves in other roles that affect the same resident. For example, a representative from an agency might provide counseling about options to an individual who is interested in moving out of a nursing home. The person makes choices based on the counselor's recommendations and options presented. Services are very slow in taking place, however, and the resident files a complaint with the ombudsman. When the ombudsman shows up, it is the same person who

provided options counseling to the resident. Situations such as this create confusion for the consumer and mistrust in the individual wearing multiple hats.

Individuals working as ombudsmen around the country serve in numerous positions for which there is the potential for real or perceived conflict of interest, including guardians, protective service workers, benefits counselors, and more. It is recommended that the Older Americans Act language provide more clarity regarding potential conflicts of interest, and guidance for eliminating or remedying of conflicts.

Similar situations exist as to organizational conflicts of interest. Often the Ombudsman Program is located in an agency that also provides other services which could be the cause of a complaint to the ombudsman – such as placement or transition services, protective services, guardianship, eligibility determination, and more. When this happens, the ombudsman's ability to advocate on behalf of a resident may be jeopardized by agency pressures. Indeed, Consumer Voice staff often hears from ombudsmen that they find it challenging to resolve a complaint from a resident against another program within their agency. In other instances, residents may not even bring a complaint if they feel that the ombudsman can't be fair. Organizational conflicts of interest can also mean that ombudsmen do not or are not permitted to speak out against policies from "sister agencies" that harm residents. The Consumer Voice supports NASOP's recommendations related to organizational and individual conflict of interest.

Disclosure and Confidentiality

As mentioned earlier, trust and confidence in an ombudsman is of paramount importance. It affects what information a resident or family member is willing to share and ultimately affects the ombudsman's effectiveness in being able to advocate for that person. One aspect of that trust is confidentiality; the resident must trust that the ombudsman will keep the resident's identity or information shared confidential unless the resident gives permission to disclose the information to others. Without that trust, residents are less likely to divulge their complaints or concerns to ombudsmen, for fear of retaliation or repercussions from others.

This confidentiality must include the identity of the resident and any communication the resident has with the ombudsman, and must extend to Ombudsman information, including records, files, and notes. The Consumer Voice supports the language proposed by NASOP with respect to confidentiality.

National Long-Term Care Ombudsman Resource Center

Ombudsmen must be well-equipped and well-trained to do their jobs. Ombudsmen must be able to perform in various environments and often under tremendous amounts of pressure. They must be skilled enough to communicate with a confused or fearful resident in her room one moment and go up against a corporate attorney to defend the residents' right to remain in the home the next. To do this successfully and effectively, ombudsmen must have knowledge, a range of skills, the latest information and immediate answers to questions.

Ombudsman programs receive all of this and more from the National Long-Term Care Ombudsman Resource Center. Every day, the Center's work translates directly into better ombudsman help for residents. The National Long-Term Care Ombudsman Resource Center provides training, technical assistance, and support for the 53 State and 473 Local Ombudsman Programs across the country. The Consumer Voice operates the National Ombudsman Resource Center, in partnership with the National Association of States United for Aging and Disabilities, through a grant from the Administration on Aging. Through its clearinghouse of information, the Resource Center gives ombudsman programs access to the best practices and successes of other programs and provides on-demand technical assistance on a wide range of topics. Center staff field more than 30 requests a week on increasingly complex issues being faced by ombudsmen. They provide the only training program specifically for State Long-Term Care Ombudsmen, including a national yearly conference and in-person orientation and conference calls for new State Ombudsmen.

Ombudsmen need to understand and be conversant about a broad range of issues, including care and service options, Medicaid eligibility, rules for transfer and discharge, state and national initiatives, including Money Follows the Person, culture change, residents rights, and more. The National Long-Term Care Ombudsman Resource Center provides support on all these issues, yet Center funding has not been increased in more than a dozen years. Thus, Center funding has fallen behind the growing needs of the ombudsman program and the people served by the program. Several ombudsmen have recently told Center staff that due to budget constraints, their programs are increasingly unable to afford training programs and paying to attend conferences, so they rely on the free resources and trainings available through the Ombudsman Resource Center. Additional resources for the Center would be used to expand and enhance training for state and local ombudsmen, including interactive on-line training, as requested by numerous State and Local Ombudsmen. As the complexity of the work being faced by State and Local Ombudsmen continues to grow, the support, training and assistance

offered by the Resource Center continues to increase in importance in promoting strong, effective Long-Term Care Ombudsman Programs.

Provisions to Support a Cohesive, Unified Program

Strong, effective ombudsman services should be available to every resident within a state – regardless of where the resident lives. This can only be achieved if there is uniformity of standards, capacity to run a statewide ombudsman program and direct State Ombudsman authority over program management issues. In this Reauthorization of the Older Americans Act, there is an opportunity to provide clarity and direction to promote cohesion and oversight of the statewide Ombudsman Program.

In many states, local ombudsman programs are housed in or contracted out through agencies which hire and provide direct management of local ombudsmen. State Ombudsmen, however, are responsible for statewide operation of the program, and for that reason should have direct management responsibility over ombudsman duties and responsibilities and over individuals serving as representatives of the Office of the Ombudsman, even if personnel management is provided by the housing agency.

To have it otherwise promotes local ombudsmen and local programs that are not accountable to the State Ombudsman Program, creating confusion and inconsistency for consumers about responsibility for the actions of local Ombudsmen. Additionally, it leads to fragmentation within the statewide Ombudsman Program and among individuals serving as ombudsmen, who sometimes find themselves divided between the agency that employs them and the Office of Ombudsman. Providing clarity in the Older Americans Act will promote consistency and cohesion among the ombudsmen by establishing that they are all part of the same program. The Consumer Voice supports the language proposed by NASOP that the Ombudsman be responsible for the management of the Office.

Support of Resident and Family Councils

Ombudsmen are charged not only with advocating on behalf of residents receiving long-term care services, but also in empowering them to self-advocate whenever possible. One way to do this is through the support and development of resident and family councils. Through councils, both residents and families can share information and concerns in a forum with others having like experiences.

Numerous resident and family councils have effected change in facilities by joining together and presenting their concerns to facility staff and administration. Further, since facilities are required by Medicare and Medicaid law to have resident councils and to permit formation of family councils, ombudsman should not only be a resource and provide technical assistance to resident and family councils, but also support their development by encouraging resident and family participation, and serving as a resource to the councils as needed.

The Consumer Voice has extensive experience in working with both resident and family councils and has observed that councils need assistance when forming to ensure that members are informed of their rights to meet privately and to advocate. For this reason, ombudsmen should actively promote and support councils, in addition to serving as a resource and providing technical assistance.

Legal Counsel for the Ombudsman Program

The Older Americans Act requires that adequate legal counsel be available to state and local ombudsman programs for advice, consultation, and representation when necessary. Unfortunately, for many programs, legal counsel of record for the program has little or no knowledge of Long-Term Care Ombudsman Program requirements or operations, or of the issues the Long-Term Care Ombudsmen deal with on behalf of residents. Ombudsmen face a number of legal challenges, including being subpoenaed to provide testimony in lawsuits or to provide records and files. In addition, programs and program representatives have been sued by disgruntled facilities and families, and under law, Ombudsmen can be appointed as Patient Care Ombudsmen in bankruptcy cases. This leaves Ombudsmen in a very vulnerable position and needing legal advice and support. Additionally, the Older Americans Act mandates that Ombudsmen analyze, comment on, and monitor the development and implementation of laws, regulations, policies, and actions that impact residents, and facilitate public comment on such laws, regulations, policies, and actions.

The Consumer Voice recommends that stronger language be included in the Older Americans Act related to the provision of Legal Counsel for Long-Term Care Ombudsmen. Such language should require that State and Local Ombudsmen have immediate access to counsel that has experience and expertise in nursing home-related laws and regulations so they can obtain advice and consultation on a variety of issues, including, but not limited to:

- clarifying nursing home laws and regulations to assist in solving residents' problems;

- interpreting laws and regulations about Medicaid, Medicare, advance directives, and guardianship
- assisting in pursuing strategies that benefit residents;
- analyzing existing and proposed laws, regulations, and policies from the resident perspective to ensure that such laws, regulations and policies do not adversely affect residents;
- providing counsel to pursue legal remedies on behalf of residents, including actions against state agencies;
- and where a conflict of interest exists, as determined by the State Ombudsman, provide legal counsel to the Ombudsman through an independent attorney.

Expansion of the Ombudsman Program

There are proposals being discussed relating to expansion of the Long-Term Care Ombudsman Program to home care. Currently, Ombudsman programs in about a dozen states have expanded using state funding. With consumers wanting to stay at home as long as possible, and with the expansion of state and federal initiatives including Money Follows the Person and Medicaid Waivers , more services are available in the community. Consumers who need a nursing home level of care, as a result, are both staying in the community longer and also transitioning out of nursing homes to community settings. Because these individuals can be just as vulnerable as nursing home residents and experience problems with quality care and other issues, they also require advocacy services. Yet in most states, there is no program like the Ombudsman Program for those receiving services in the community.

The Consumer Voice supports expansion of the Long-Term Care Ombudsman Program to home and community based services in a prudent fashion, which means it should be well thought out and adequately funded. We support NASOP's recommendation for a demonstration project to evaluate the feasibility and impact of expanding the program to serve consumers in home care.

Conclusion

The Long-Term Care Ombudsman Program is a critical and valuable resource for long-term care consumers in understanding their rights, self-advocating, and receiving quality care. Efforts to strengthen and support the Program through this Reauthorization of the Older Americans Act should be promoted as a means of protecting the frail, vulnerable elders who depend on them.