

Elder Rights & Elder Justice

Panel Presentation

Older Americans Act Reauthorization Listening Forum

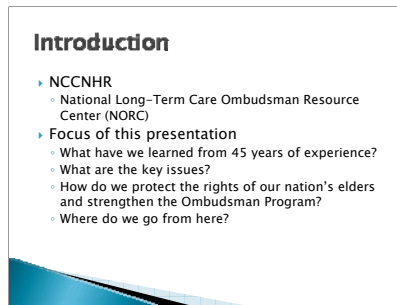
February 25, 2010

Alexandria, VA

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Introduction

Good morning and thank you to Assistant Secretary Greenlee and the Administration on Aging for this opportunity. My name is Sarah Wells and I am the Executive Director of NCCNHR, formerly the National Citizens' Coalition for Nursing Home Reform.

I bring two perspectives to this panel:

- First, as the head of NCCNHR, a national organization that advocates for the consumer in all long-term care settings.

NCCNHR was formed in 1975 because of public concern about substandard care in nursing homes. Members of NCCNHR are from across the United States and comprise a diverse coalition of consumers, citizen advocacy groups, state and local long-term care Ombudsmen, professional groups, families, workers and other stakeholders. NCCNHR provides information and leadership on federal and state regulatory and legislative policy development and models and strategies to improve care and life for residents of nursing homes and other long-term care settings.

- NCCNHR's second perspective on reauthorization comes from operating the National Long-Term Care Ombudsman Resource Center.

The National Long-Term Care Ombudsman Resource Center provides support, technical assistance and training to the 53 State Long-Term Care Ombudsman Programs and their statewide networks of almost 600 regional programs. The Center's objectives are to enhance the skills, knowledge, and management capacity of the State programs to enable them to handle residents' complaints and represent resident interests. Funded by the Administration on Aging (AoA), the Center is operated by NCCNHR in cooperation with the National Association of State Units on Aging (NASUA).

- I will start off with an overview of a few things we have learned from several decades of experience with the Older Americans Act – and focus on: what are some of the key issues for the aging network, how do we strengthen the long-term care Ombudsman Program and where do we go from here?



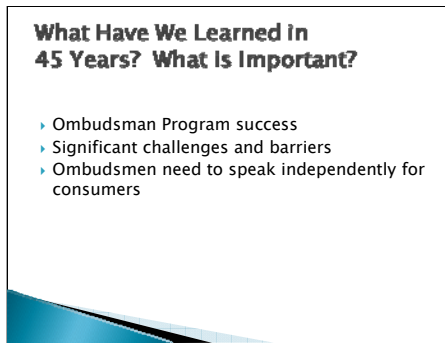
What have we learned in the past 45 years? What is important?

- We have learned that quality of care in nursing homes must be addressed from all angles: regulatory, legal, advocacy, and within the nursing home itself – this is called Culture Change. Our challenge as a network is to promote what the consumer wants, not just what we think is best for them.
- At NCCNHR, our members have advocated for and implemented Culture Change in many ways:
 - For example, Ombudsmen advocate for residents and their right to make choices to direct their own care. A really important part of the energetic advocacy Ombudsmen have been able to do comes from their absolute focus on the consumer.
 - Citizen advocacy groups have developed coalitions and regularly provide information to consumers and other advocates to promote Culture Change.
 - NCCNHR has worked directly with residents to promote the principles of Culture Change, to learn what consumers want from their long-term care experiences and to make sure that consumers help shape the Culture Change movement.

Culture change involves rethinking values and practices of a nursing home from top to bottom, inside and out. Consumers should have a choice in their care and the options available must be quality care options.

Culture Change is exciting for the changing landscape of long-term care as the core values can be applied absolutely and immediately to all settings.

- We have also learned that **Vulnerable Elders** are often unable to access services and benefits. We know that a major challenge for the network is figuring out how we protect individuals who have no way of voicing their complaints, problems or who want to assert their legal rights.



What have we learned in the past 45 years? What is important?

The Ombudsman Program has worked:

- The Ombudsman Program has been in the Older Americans Act since the 1970's – in 1992, amendments to the Older Americans Act strengthened the Ombudsman Program and transferred it to Title VII – which also included Programs for the Prevention of Elder Abuse, Neglect and Exploitation and other provisions.
- The Ombudsman Program is one of the “**core services**” under the Older Americans Act.
- The program started out as a demonstration project in a few states and is now utilized by thousands of consumers. While conditions have improved in Nursing Homes, these Ombudsmen continue to be essential to protect the rights of the most vulnerable.
- The Ombudsman Program is a network of 8,700 volunteers certified to handle complaints and more than 1,300 paid staff. Nationally, in 2008, the Ombudsman Program investigated over 271,000 complaints made by over 180,000 individuals and provided information on long-term care to another 327,000 people.
- The Ombudsmen tell us that the National Long-Term Care Resource Center has been a critical support for the Ombudsman Program success and development.
- Ombudsmen are in facilities and working with residents and families on a daily basis – they are often able to help resolve problems before they escalate or become serious.

However, we have also learned that the Ombudsman Program continues to face significant challenges and barriers:

- We know that key components of ensuring elder justice and rights remain dramatically under-funded and are often hampered by politics.
- For example, Ombudsmen aren't able to fulfill their full advocacy potential because of lack of support for aggressive advocacy.
- When Ombudsmen have to play a variety of roles, this impacts the effectiveness of services – advocacy for elder rights and providing social services is often coupled with providing long-term care services, adult protective services and other roles.

•Reports show us that the Ombudsman Programs that have been or are the most effective are those that are truly independent. Independence is a key component of advocacy – independence may be related to where the program is located, but it isn't just about that, it is about wherever the Ombudsmen are located they need to be able to speak independently about the issues that impact residents.

Is the Ombudsman Program Doing What it Should?

- ▶ Ombudsmen make a difference
- ▶ Tensions around role as an advocate inhibit Ombudsmen from fulfilling mandate
- ▶ Resource constraints
- ▶ Conflicts of interest
- ▶ Wearing multiple hats
- ▶ Consumer confusion

Is the Ombudsman Program Doing What it Should?

- NCCNHR hears regularly how important the Ombudsmen are to consumers.
- However, as I mentioned, Ombudsmen face major challenges.
- Ombudsmen face lobbying restrictions, concerns over taking sides and the inability to make public comments on issues, policies and regulations that affect residents.
- Significant state budget cuts are holding back Ombudsmen from being able to do what they already are mandated to do, let alone respond to the changing landscape of long-term care.
- The Federal recommendation is one full-time Ombudsman for every 2,000 nursing beds/boarding care beds. Nationally we have not yet achieved that goal on average. And in fact, in some states Ombudsmen have to cover twice that number of residents.
- Ombudsmen are advocates – and becoming service providers challenges that role.
- Wearing multiple hats stretches Ombudsmen thin.
- The multiple hats can cause confusion for consumers – i.e. some individuals are a part-time Ombudsman, part-time case manager/benefits counselor.

What Do Ombudsman Programs Need?

- ▶ Resources
- ▶ Oversight
- ▶ Training
- ▶ Support and independence
- ▶ Resolve conflicts, remove barriers

What Do Ombudsman Programs Need?

- Programs need to be clearly defined and adequately resourced so they perform well.
 - In addition to reauthorization, appropriations need to be made to adequately fund the Ombudsman Program.
 - That said, in the Older Americans Act, the maintenance of effort and minimum funding requirements have greatly assisted during this time of state budget cuts. Keeping those provisions in the Older Americans Act helps ensure basic support for the Ombudsman Programs, particularly in this time of deep budget cuts.
- Ombudsman Programs need good oversight of how programs are carried out – where Ombudsmen are not able to be effective, the Administration on Aging should step in and hold the state accountable.
- Ombudsmen need ongoing training to respond to the changing landscape of long-term care – we need to continue to build support for the Elder Justice Act, and the provisions in the Act that include Ombudsman training.
- States need to allow the programs to be implemented the way the law says.
- Conflicts of interest need to be resolved, parameters and boundaries need to be set.

Should Ombudsman Programs be Authorized for HCBS?

- ▶ All consumers need an advocate
- ▶ Ombudsman support available in facilities, but limited in-home support
- ▶ Ombudsman Program in HCBS
 - Resource concerns
 - Systems issues
 - Boundaries are critical
- ▶ Utilize the Ombudsmen to develop strategies for services and support in HCBS

Should Ombudsman Services be Authorized for Home- and Community-Based Services?

•No matter where an individual receives long-term care, services and supports, they need access to a strong, independent advocate.

•In the vast majority of states, Ombudsman services are available for elders who receive services in long-term care facilities but similar services are not available for consumers of long-term care in their own home. Many of these individuals have no access to an Ombudsman to resolve their complaints as they would have in a nursing home.

•Twelve states have state funding and/or authorization to provide Ombudsman services in homes.

•The expansion of the Ombudsman Programs into home- and community-based services in every state is a challenging issue requiring serious consideration.

•In terms of practicality of Ombudsmen entering HCBS, resource concerns are significant.

•For example, studies show that residents of 17% of nursing homes and 53% of all board and care/assisted living homes did not receive regular visits from an Ombudsman in Fiscal Year 2009 (National Ombudsman Reporting System). Residents in more than half of our nation's board and care and assisted living facilities are still not receiving regular access to an Ombudsman, nearly three decades after the Older Americans Act mandated Ombudsmen to provide this service. It is clear that the Ombudsman Programs cannot do more without more resources.

•But this is not just a resource issue, it is a systems issue too.

•We know conflicts of interest exist now – this will be even more of a concern if Ombudsmen move into home- and community-based services. Any conflict, whether real or perceived needs to be addressed.

•The issue of Ombudsman Program expansion is a challenging issue that require serious consideration and dialogue. I think it is important to say that many Ombudsmen have skills and knowledge that are transferable to other long-term care settings and we have much to gain from working with Ombudsmen to figure out how to fill the gaps in advocacy for individuals utilizing home- and community-based services.

Where Do We Go From Here?

- ▶ Put consumers first
- ▶ Ombudsmen are a core service of the Older Americans Act
- ▶ Integration of elder rights programs
- ▶ Elder abuse protections
- ▶ Better coordination
- ▶ Advocacy for the consumer in HCBS important

Where Do We Go From Here?

- We need to keep stating the obvious so it is not forgotten. **Put the consumer first**
 - Culture Change and consumer choice should direct and inform the services we provide and our advocacy efforts.
- The Ombudsman program is a core service of the Older Americans Act and must be implemented in the way it was intended –
 - Ombudsmen need support to be strong advocates for elders.
 - The Ombudsmen and the agencies that house them must develop mechanisms to resolve conflict of interest and tensions.
 - Congress needs to expand appropriations to provide adequate support for the Title VII Ombudsman Programs.
 - Ombudsmen are an integral partner for the aging network and can provide valuable information and insight about the long-term care system and the needs of consumers.
 - The selection of a National Long-Term Care Ombudsman is one very important step to strengthening the Ombudsman Program – thank you to Assistant Secretary Greenlee for making this a priority.
- In addition, we also need to integrate elder rights programs into state plans and area plans.
- Furthermore, elder abuse protections need to be better coordinated and advocacy for the individual needs to be the priority.
- Finally, we should continue to explore how the aging network can promote the rights of the individual regardless of long-term care setting.
 - Advocacy for the consumer is very important in home- and community-based settings as infrastructure is still in development and these consumers often live in isolated settings.



Thank you for the opportunity to speak with you today about Elder Rights and Elder Justice issues that are important to NCCNHR and to our work through the National Long-Term Care Ombudsman Resource Center. I believe the topics Bob & I have discussed should be important to all of us in the aging network, particularly as we look to the reauthorization of the Older Americans Act.

Other potential speaking points:

- Comprehensive data collection system (NORS) has provided us with good information about not only the Ombudsman work but the issues residents face in nursing homes and board & care facilities, but that the data collected is not without its challenges. (Challenges include consistency in reporting.)
- Should Medicare/Medicaid chip in to pay for the Ombudsman program – YES – the vast majority of residents living in nursing homes and increasingly in board & care have their care paid for or supplemented by Medicare/Medicaid, Ombudsmen are providing services and information to all of those people.
- Are we asking for changes in the reauthorization of the OAA? Not asking for changes, but asking for stronger implementation and appropriations.