Empowering Individuals with Limited Capacity

As experts in residents’ rights, Long-Term Care Ombudsmen (LTCO) regularly share information regarding the application of those rights for individualized, resident-centered care. LTCO often work with and for residents with limited capacity, due to dementia and/or mental health needs, and LTCO advocacy is critical in ensuring all residents are empowered to participate in their own care and make personal decisions (to the extent to which they can and want to be involved).

When working with residents with limited capacity, such as dementia, it is often the role of the LTCO to remind staff that a diagnosis of dementia does not mean that residents can’t make some decisions regarding their preferences, daily life, and care and to share best practices for comprehensive care planning and resident-centered care that supports residents' current needs and abilities. The final rule for State Long-Term Care Ombudsman Programs emphasizes the responsibility of LTCO programs to “support and maximize resident participation in the process of resolving the complaint” and provides a detailed process for seeking resident consent, participation, and resolution goals (additional information in article below).

The following resources discuss empowering individuals with limited capacity and share communication and advocacy strategies that relate to the primary role of the LTCO program as advocates for individualized, resident-centered care.

- National Resource Center for Supported Decision-Making (NRC-SDM): The NRC-SDM was established in September 2014 and provides educational programs, best practices,
and conducts research to enhance understanding of supported-decision making in order to increase self-determination for older adults and individuals with disabilities. The NRC-SDM website includes resources about supported-decision making, guardianship and alternatives to guardianship, links to state guardianship laws, and educational materials for consumers, advocates, and professionals.

- **The Fine Art of Balancing Protection with Self-Determination** (National Consumer Law Center webinar) This session will talk about recognizing the signs and signals of abuse, neglect (self-neglect) and exploitation, tools to maximize communication with persons with differing abilities, and promoting self-determination and choice through supported approaches that mitigate against risk and empower individuals. The session will explore the application of the Supported Decision Making model to assist persons in making choices, increase access to positive life outcomes, and reduce the risk of harm.

- **Transcending Tragedy: Promoting the Rights of Residents with Dementia** (presentation by Jennifer Carson, PhD, Chief Learning Officer, Alzheimer’s Resource Center and Peter Reed, PhD, Director and Professor, Sanford Center for Aging, University of Nevada, Reno)

- **Video on Interviewing Vulnerable Elders (VIVE)-CMS.** This video demonstrates best practices in interviewing residents for the revised MDS questions in 2010. Discussion and demonstration of interview techniques starts around 11 minutes and provides tips for interviewing residents with limited capacity.

- **From Institutional to Individualized Care: 4-part series created by CMS in 2006-2007 for surveyors “From Institutional to Individualized Care” includes interview examples and training resources.** They are available on this [page](#).

- **NORC Issue pages:** [Ethics](#) (LTCO program management), [Culture Change](#), [Dementia Care](#) and [Advance Care Planning and End of Life Care](#)

Visit the NORC website for more information regarding [communication skills](#) and [advocacy strategies](#).

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**Calender of Events**

**February 2, 2016**

3:00-4:30 ET: Free webinar on "Resident-to-Resident Elder Mistreatment in Nursing Homes: Findings from the First Prevalence Study." [Register here](#).

**April 10-16, 2016:** National Volunteer Week. Visit the [event page](#) to find the National Volunteer Week toolkit in the coming weeks, as well as logos, press releases and more. For volunteer recognition ideas, visit our [website](#) and read the Retention chapter and Appendices of the compendium [here](#).

**May 2016:** Older Americans Month. This year’s theme is Blaze a Trail. More information and the history of Older Americans Month is available [here](#).

**Questions or Ideas?**

Do you have any questions or challenges related to LTCO advocacy and program management you want addressed in a future newsletter?

Do you have any suggestions for articles or feedback about this issue? If so, please let us know.

**Save and Share**

We encourage you to share this newsletter with your LTCO program. You can forward this email or save and share the PDF version saved on our [website](#).

**Want to receive the Ombudsman Outlook directly?**
The Consumer Voice webinar was held in collaboration with the National Center on Elder Abuse (NCEA) in order to provide a basic framework to help long-term care residents, their family members, and other advocates identify quality care and potential issues. The webinar presenters identified indicators of quality care and warning signs of poor care, provide communication tips, and share advocacy strategies to help consumers, family members, and others advocate for individualized care. The slides can be downloaded as a PDF or as a PPT.

**NEW! “Put a STOP to Poor Care” Brochure**

This brochure was produced by the Consumer Voice in collaboration with the NCEA and includes indicators of quality care, warning signs, red flags of potential abuse, and advocacy tips to address concerns. It is a resource to help consumers understand quality care, learn how to identify issues, and gain action steps to advocate for the care they need and deserve.

**NEW! Advanced Care Planning and End of Life Issue Page**

The NORC website has a new issue page on this topic with two subsections: advance care planning and end of life care. The advanced care planning section includes information about physician orders for life-sustaining treatment (POLST) as well as resources such as an overview of POLST, and “POLST Programs in Your State.” The end of life section includes a new resource produced by Medicare, “10 FAQs: Medicare’s Role in End-of-Life Care.”

**NEW! Long-Term Care Ombudsman Services to Tribal Elders (TA Brief: Technical Assistance for LTCO Practice)**

This brief includes prompts to consider in order to gain a better understanding of the tribal elder population in your state, communication and coordination tips from LTCO programs currently working with tribal elders, and additional resources.

**UPDATED! “Long-Term Care Ombudsman Program: History, Role, and Responsibilities” Presentation**

The section titled “The Long-Term Care Ombudsman Program: History, Role and Responsibilities” on the About Ombudsman page of the website was updated this January. The presentation provides a general overview of the Long-Term Care Ombudsman Program highlighting history, role and responsibilities of the program. LTCO can use this presentation when training potential LTCO, during Resident Council and Family
Council meetings, community education and in-services for staff. The presentation can be downloaded as a PDF or PPT.

**UPDATED! Program promotion page now includes newsletters**

Marketing for ombudsman programs is important in order to help residents and family members know the kind of work you do and how you can assist them. Ombudsman programs like Georgia and Iowa used newsletters to spread awareness throughout their state and network. The NORC website has a new section on the program promotion page titled “Brochures, Posters & Newsletters.” State newsletters will be featured where we will be featuring states newsletters so other programs can use them to help think of ideas for their own newsletter. If your program has a newsletter, send it to NORC to be featured on our website. Please add NORC to your distribution list.

**News from the Network...**

**Program Promotion and Residents’ Rights Education** (Anne Arundel County Department of Aging, Maryland LTCOP)

In December, the Maryland Ombudsman Program held a training, “Ombudsman Advocacy: Moving Forward with Regulations and Successful Practices.” One of the sessions involved a local ombudsman sharing how she was able to promote residents’ rights and share her local program contact information.

Paula Currence, from the Anne Arundel County Department of Aging, purchased 1,000 notebooks with an attachable pen and handed them out to residents in her county. On the cover of each notebook is the contact information for her office and on the first page of the notebook are the residents’ rights. Paula encouraged residents to use the notebook to document their concerns and said they could call her at any time and share what they have written and any other issues. Paula said this practice has been very successful and several residents have pulled out the book and read what had been going on when she visited them in the facility.

**Best Practice with Internship Program** (Baltimore County Department of Aging, Maryland LTCOP)

Lynn McCamie, Ombudsman Program Manager with the Baltimore County Department of Aging, has developed a strong internship program in her county, with clear guidelines and projects for each intern. She
currently has five interns at either the undergraduate or graduate level. Each intern receives a 24-hour training about how to provide quality Ombudsman services. The internship program will allow the students to learn about how to be a strong advocate for the residents, they will make long-term care facility visits, complete documentation and input data in the Ombudsmanger system. The interns will also have the opportunity to attend and present the Ombudsman Program at resident or family councils.

During each student’s internship they are responsible for at least one project. The project is something they can show and talk about to future employers as something they completed from start to finish during their internship. Projects that were created in the past were an electronic version of “Lending Library” which were educational aging DVDs and games, resident and family council brochures, and CMS Diet Requirement Fact Sheet. Interns are a great way to teach others and have additional help to improve your program.

**Sexuality and Aging Fact Sheet (Iowa LTCOP)**

The Iowa State Long-Term Care Ombudsman Program created a fact sheet about sexuality and aging. The purpose of the fact sheet is to clarify how older adults experience sexual desire; how dementia and other age-related health issues impact an individual’s ability to express desire for consent to sexual acts; and whether older adults forfeit their right to intimacy once they move into a long-term care facility. Read the fact sheet [here](#).

This “News from the Network” article will appear in every issue in order to highlight your work and news. We invite and encourage you to send your advocacy successes, best practices, program management examples, and resources so we can learn from you and share your experience with your peers.

**LTCO Volunteer Management**

*Welcome and Orientation*

How do you welcome new volunteers into your program? Examples of how programs welcome new volunteers and introduce them to the program include:

- Highlighting the volunteer(s) in newsletters, via social media, and email (GA LTCOP newsletter example).
- Sending a welcome letter acknowledging the completion of their training and recognizing their certification.
• Adding the new volunteer to the volunteer contact list that is shared with volunteers in the same region.
• Inviting the volunteer to join the program listserv.
• Join the volunteer in an introductory meeting with the administrator of the volunteer’s assigned facility and share a letter/fact sheet with the volunteer’s name and a brief overview of the role and responsibilities of the LTCO program (IA LTCOP example).
• Post the volunteer’s name and LTCO program contact information on a flyer or poster in the volunteer’s assigned facilities.
• Sending an email to the state legislators of the district where the volunteer will be assigned to recognize the volunteer to explain the role of the LTCO program, share some of the LTCOP activities, and recognize their constituent’s service (OR LTCOP example).

“Are You a New Ombudsman?” Webpage

The “Are You a New Ombudsman?” webpage was developed to provide a warm welcome to new staff and volunteers of LTCO programs, help new LTCO feel part of the national LTCO network, and introduce them to NORC. This page includes information on the history of the long-term care ombudsman program, the ombudsman program in federal law and regulations, who are the key stakeholders in the long-term care ombudsman network, and an overview of the resources for long-term care ombudsmen found on the NORC website. The page can be accessed by the “New Ombudsman?” tab at the top of the NORC homepage or by using this link. LTCO programs are encouraged to share this link with new LTCO.

Join the LTCO Volunteer Management Network today to connect with your peers, exchange ideas, share resources and talk about LTCO volunteer management.

Technical Assistance Hot Topic

Informed Consent

The final rule for State Long-Term Care Ombudsman Programs reinforces the requirement of LTCO to obtain informed consent from a resident, or the resident representative, prior to investigating a complaint or disclosing information and follow resident direction throughout the complaint investigation and resolution process.
The rule provides the following requirements for duties of the representatives of the Office (representatives are the employees or volunteers designated by the State LTC Ombudsman to fulfill the duties of the LTCO program) regarding obtaining informed consent and providing advocacy for residents unable to provide informed consent.

1327.19 Duties of the representatives of the Office

(b) Complaint Processing

(1) With respect to identifying, investigating and resolving complaints, and regardless of the source of the complaint (i.e. complainant), the Ombudsman and the representatives of the Office serve the resident of a long-term care facility. The Ombudsman or representative of the Office shall investigate a complaint, including but not limited to a complaint related to abuse, neglect, or exploitation, for the purposes of resolving the complaint to the resident’s satisfaction and of protecting the health, welfare, and rights of the resident. The Ombudsman or representative of the Office may identify, investigate and resolve a complaint impacting multiple residents or all residents of a facility.

(2) Regardless of the source of the complaint (i.e. the complainant), including when the source is the Ombudsman or representative of the Office, the Ombudsman or representative of the Office must support and maximize resident participation in the process of resolving the complaint as follows:

(i) The Ombudsman or representative of Office shall offer privacy to the resident for the purpose of confidentially providing information and hearing, investigating and resolving complaints.

(ii) The Ombudsman or representative of the Office shall personally discuss the complaint with the resident (and, if the resident is unable to communicate informed consent, the resident’s representative) in order to:

(A) Determine the perspective of the resident (or resident representative, where applicable) of the complaint;

(B) Request the resident (or resident representative, where
applicable) to communicate informed consent in order to investigate the complaint;

(C) Determine the wishes of the resident (or resident representative, where applicable) with respect to resolution of the complaint, including whether the allegations are to be reported and, if so, whether Ombudsman or representative of the Office may disclose resident identifying information or other relevant information to the facility and/or appropriate agencies. Such report and disclosure shall be consistent with paragraph (b)(3) of this section;

(D) Advise the resident (and resident representative, where applicable) of the resident’s rights;

(E) Work with the resident (or resident representative, where applicable) to develop a plan of action for resolution of the complaint;

(F) Investigate the complaint to determine whether the complaint can be verified and

(G) Determine whether the complaint is resolved to the satisfaction of the resident (or resident representative, where applicable).

(iii) Where the resident is unable to communicate informed consent, and has no resident representative, the Ombudsman or representative of the Office shall:

(A) Take appropriate steps to investigate and work to resolve the complaint in order to protect the health, safety, welfare and rights of the resident; and

(B) Determine whether the complaint was resolved to the satisfaction of the complainant.
(iv) In determining whether to rely upon a resident representative to communicate or make determinations on behalf of the resident related to complaint processing, the Ombudsman or representative of the Office shall ascertain the extent of the authority that has been granted to the resident representative under court order (in the case of a guardian or conservator), by power of attorney or other document by which the resident has granted authority to the representative, or under other applicable State or Federal law.

Informed consent is not defined in the final rule and in response to a comment asking for a definition the Administration on Aging provided the following response, “we believe that the term “unable to communicate informed consent” improves the clarity of the term “unable to consent” which is used in the Act, related to Ombudsman program access to resident records. Section 712(b)(1)(B)(i)(II) of the Act. Our expectation is that States will operationalize the use of this term by incorporating it into the Ombudsman program’s procedures for resident records and complaint processing. We are also available to provide States with technical assistance should the need arise for further clarity on how to operationalize this term within Ombudsman program operations.”

Resident empowerment and supporting resident decision-making ability to the greatest extent possible is a core responsibility of LTCO program advocacy. However, conducting an assessment to determine capacity does not fall under the responsibilities of the LTCO program. LTCO use communication skills such as active listening and observation to ensure a resident understands her rights, choices, potential outcomes, and can express her wishes in order to obtain consent and direction.

Visit the NORC website for more information regarding ethical considerations, communication skills and advocacy strategies, and promoting resident-centered care.

Quick Tips!
In response to the requirement of the Affordable Care Act of 2010 for CMS to ensure that nurse aides receive annual training on caring for residents with dementia and preventing abuse, CMS created the Hand in Hand: A Training Series for Nursing Homes toolkit. According to CMS, the mission of the Hand in Hand training is to provide nursing homes with a high-quality training program that emphasizes person-centered care in the care of persons with dementia and the prevention of
abuse. The toolkit has six modules (listed below) and a training guide.

- An Introduction for Facilitators and Administrators
- Module 1: Understanding the World of Dementia: The Person and the Disease
- Module 2: What is Abuse?
- Module 3: Being with a Person with Dementia: Listening and Speaking
- Module 4: Being with a Person with Dementia: Actions and Reactions
- Module 5: Preventing Abuse
- Module 6: Being with a Person with Dementia: Making a Difference

Although the toolkit was created for nurse aide training, LTCO programs can benefit from the use of these materials in a variety of ways.

- **LTCO Program Training:** Materials from the toolkit could be used for self-study and group training in order to refresh ombudsman knowledge related to communicating with individuals with dementia, person-centered care practices, and preventing abuse. For example, Module 3 may be of particular interest to you in regards to interviewing residents with dementia or other cognitive issues and providing resident-directed advocacy (even when a resident has a health care POA or other legal representative).

- **Improve LTCO Program Training Techniques:** The first DVD, An Introduction for Facilitators and Administrators, provides an overview of effective training techniques for adult learners. The video demonstrates the techniques that are used in the training guide and LTCO programs could apply these techniques to enhance how they train LTCO, facility staff, and others on this topic and other issues.

- **Consumer Education:** Use individual modules, or clips from them, during presentations to family members and others to increase understanding of individuals with dementia, improve communication, how to meet their needs with resident-centered care, and prevent abuse.

- **Facility Education:** Facilities are required to provide training for nurse aides on the topics discussed in this toolkit; however, LTCO programs could use clips from these videos during in-service training since the content applies to many topics such as residents' rights, resident-centered care, communication, and abuse prevention.
More information about using these videos in LTCO program training and advocacy is available in this brief tip sheet. The link to this toolkit and more resources regarding dementia care is available on the NORC website and the training series is available to download on the CMS website.

State and local long-term care ombudsmen receive this email. If you do not want to receive this e-mail update, unsubscribe here. Clicking the unsubscribe link will remove you from all Consumer Voice and NORC email lists.

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