

Consumer Voice and the National Center on Elder Abuse Put a STOP to Poor Care Webinar Transcription

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Robyn Grant:

Good afternoon and thank you for joining us for today's webinar, Put a Stop to Poor Care: Advocating for Quality Care. I am Robyn Grant, Director of Public Policy and Advocacy with the National Consumer Voice for Quality Long-Term Care, otherwise known as Consumer Voice. We're hosting this webinar in collaboration with the National Center on Elder Abuse, which we will refer to as NCEA. Next slide please. The purpose of today's webinar is to provide a basic framework to help you identify quality care and potential issues, not to provide an in-depth advocacy training for specific care issues. The indicators of care and advocacy steps we will discuss are not comprehensive, but they represent the core aspects of quality care and practical steps to take to address concerns.

So here's what we have planned for you. After a quick review of webinar logistics and the introduction to Consumer Voice, we will hear from Julie Schoen, Deputy Director of NCEA and then I will share some indicators of quality care and warning signs of poor care and talk about strategies to help you advocate for yourself or a loved one. Next, Kathy Bradley, a Family Member Advocate, Member of the Consumer Voice Leadership Council, and founder of Our Mother's Voice, an advocacy organization in South Carolina, will talk about how individuals can support a loved one, who is a resident of a long-term care facility. In the final part of our presentation, Amity Overall Laib, acting director of the National Long-Term Care Ombudsman Resource Center, which we call NORC, will provide an overview of the Long-Term Care Ombudsman Program including how and when to seek ombudsman assistance. We will then give you time for questions and end by letting you know about some resources that are available to you.

So, a word about logistics. First, all lines will be muted during the presentation. Second, if you have a question at any time, please post your question using the chat feature on the right side of your screen. We will keep track of incoming questions and then do our best to respond during the question-and-answer portion of the webinar. You also have the option to raising your hand to ask a question and we will un-mute your line. And one last point, this webinar is being recorded and will be available in the near future on our website along with the resources mentioned during this training. Next slide please.

For those of you not familiar with our organization, consumer voice is a national nonprofit organization that advocates for people receiving long-term services and supports in all settings, so that's in their own, assisted living facilities or in nursing homes. We have a clearinghouse of information and resources to empower consumers, families, long-term care ombudsmen and others in advocating for quality care, as we said, no matter where. We also provide technical assistance and support for state advocacy regarding long-term care services and support, and have a national advocacy action network. So that's who we are. Joining us is Julie Schoen, Deputy Director of the National Center on Elder Abuse. So, I want to give Julie a few moments to say a few words. Julie...

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Julie Schoen:

Thank you so much, Robyn. What an honor and a pleasure it has been to work with Consumer Voice. I have long been a fan of their materials and their articles and as now part of the National Center on Elder Abuse; it is just such a privilege to collaborate with them and with so many others. For those of you who aren't familiar with the National Center on Elder Abuse, I hope you can at least take this away with you today and know to come to use if you need any assistance in any issues surrounding elder abuse. I think many of you are very familiar with what we do. We are one of 27 national resource centers funded by the Administration on Community Living, and we are providing you with all types of educational resources, training curricula, research that we really, really are trying to work on and to bring up to the minute. It has been a challenge, but we are really working on that. I am most proud of our ability to work with so many great partners and make those connections. I think of NCEA as the big convener of all these great ideas throughout our country that all of you are working on and so bringing those to our attention and sharing those with us, we will put them out through our Listserv and our website and make sure that people have access to them. We are always looking for innovative models and we want to hear what you need. So, we are hoping that altogether, collaboratively, like today's webinar, we are able to advance the field and communicate this to others and make sure that people have the access to this information, as we all move forward on our respective missions. Next slide please.

And so I think these are the major things that I'd like you to take away today. I am not sure if a lot of you know that we do provide technical assistance through our phone line and through our website, e-mail, and social media. Tomorrow we have a great Twitter chat on capacity issues that are going on and that went out today to our Listserv, so if you're not a member please let us know. We make lots of news and resources available and we have a great monthly theme blog that we're doing and then a Twitter chat on the third Thursday of every month. It just amazes me the people that are on the line and we bring together. We are always again, as I mentioned earlier, looking for those promising practices and interventions and hoping to provide you with subject matter expertise, but also learn from you on a daily basis, which I am truly am. So again, my thanks to the whole Consumer Voice team. They've been nothing but a joy and professional to work with. And now let's really get into the important material they have today. Thank you so much.

Robyn Grant:

And thank you, Julie. So now, let's look at quality care. Regardless of where an individual receives long-term care services and support, they are entitled to receive quality, individualized care. So what does quality care mean? Quality care promotes resident dignity, choice, and self-determination in all aspects of life and care. So providing quality care means that each resident's care is individualized in order to meet their needs and preferences. To determine those care needs and preferences, staff must work with the resident and their family members and/or

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representatives to gain a comprehensive understanding of what is important to them in their day-to-day lives and how they can best meet their care needs. Now some residents may have limited capacity due to dementia or mental illness, but they should still be involved in their daily care and life decisions as much as possible. Next slide please. So individuals living in nursing homes and assisted living facilities maintain the same rights as individuals in the larger community, and in fact, have additional rights and protections under federal and/or state law. All residents, regardless of the type of facility, have the right to be protected from mistreatment, including abuse, neglect, and exploitation. Nursing homes have to meet federal requirements in order to participate in Medicare and Medicaid. Those requirements include residents' rights and require that residents receive services and activities that, and I'm quoting from the law here, attain or maintain the highest practice physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care. And that a facility care for its residents in such a manner and in such an environment, as will promote maintenance or enhancement of the quality of life of each resident. So that's nursing homes.

There are no federal regulations for assisted living facilities, which, by the way, may also be known in your states as board and care, or personal care homes. There are a host of different names for these facilities. And the requirements, because there are no federal regulations, the requirements are different in each state. But despite the regulatory differences between nursing homes and assisted living, the indicators of quality care and advocacy steps we will discuss today are applicable in all long-term care facilities. Next slide please. Quality care encompasses more than just meeting the medical or physical care needs of individual residents. It also means providing a warm, home-like environment that enables residents to participate in daily life and meaningful activities based on their preferences and choices. So I want to outline for you a few indicators of quality care and these are not only signs of quality care, they are also signs of individualized care.

So what do they include? First, quick and kind response to call lights. Resident involvement in care and daily life is encouraged, so, for example, residents are encouraged to participate in their own care plan meetings. Join resident councils. They are encouraged to provide feedback on daily life in the facility. Choose when they wake up and set the schedule for their daily life and activities. Quality care includes residents who appear clean, well-groomed, comfortable, engaged, happy, and without visible restraints. It means that the facility is clean, clutter and odor-free and maintains a comfortable temperature. Food is appetizing and residents are offered choices. The community is warm and engaging. It is a welcoming environment where staff, residents, and visitors interact with each other. Quality care is staff knowing residents and communicating respectfully. Staff know and respect individual resident preferences and routines. And finally, there are meaningful individual and group activities. Next slide please.

Regular visits and communication with and between staff, residents and family members are critical for achieving and sustaining quality care. And even if you, or your loved one, is pleased with the care and quality of life, it is still important to be involved in the community and communicate with those that live and work in the facility. So here are some tips to help keep

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those lines of communication open. Get to know other residents, especially those without family or visitors. Get involved in the resident or family council. If there isn't a family council, start one. And if you're a resident, help make sure the resident council is truly resident-led, instead of led by a staff member with limited resident involvement. And so you know, we have resources on our website to help support and empower both resident and family councils. So there is a lot of information out there. Share information about residents' rights and signs of quality care. Share the brochure that goes along with this webinar and other fact sheets or materials regarding residents' rights and individualized care with residents and families. Communicate with staff and make a point of complimenting good care. Staff and facilities don't hear about the good things they do. Far too often they just hear the negative things, so compliment good care. Learn about the Long-term Care Ombudsman Program and get to know your local ombudsman. Later we will share more information about the Long-term Care Ombudsman Program and how to contact a program so that you know where to turn. And last, if you're a family member or friend, continue to visit often and at varying times in order to observe care during different times of the week. Next slide please.

Now we're going to look at warning signs, so you often need to be aware of these. So let's talk about what indicators of care indicate that there are issues that you need to be aware of. So warning signs. The facility appears understaffed. So, for example, call lights are not answered promptly, or are turned off without care being provided. Residents' rights are not respected, so for example, there are no choices in daily routine. Residents aren't involved in care decisions. The quality of food declines. Maybe there are fewer meal options. There is less food that is served. The menu isn't followed. There is high staff turnover and staff that are not familiar with residents. Residents appear bored, less active, not engaged with others or activities. Residents and/or family members say that concerns have not been resolved. The facility is uncomfortable, so it's not clean. There is an odor. It's too cold, too hot, or too noisy. And lastly, there are medication errors. Next slide please.

So what can you do when you see these warning signs? So here are some advocacy tips to help in that situation. So, work with the resident or family council to address concerns as a group. Remember that saying there's safety in numbers? It's certainly true and councils can help with that. Become familiar with residents' rights and facility requirements. You really want to know both the federal and state requirements. Document your concerns. Discuss your concerns with the administrator or other key staff, such as the Director of Nursing. Share your observations and share your resolution goal.

Contact the Long-Term Care Ombudsman Program for assistance with your concerns. Visit frequently and vary the time of your visits and make sure to take notes of any issues you identify. And review state survey reports. These are inspection reports. See if this facility has been cited for similar issues before. Next slide please.

So as you can see, we've gone from green light to yellow and now we're at red. Red flag. These are indicators of significant care issues and concerns that need to be addressed. Here are some of

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the things to look for. You notice a significant sudden change in the resident's behavior such as lack of appetite, fearfulness, or anxiety. There are dramatic physical changes such as weight loss or decline in mobility. There are unexplained injuries or bruises. Residents are physically restrained and/or appear to be over-medicated so you might see residents slumped in wheelchairs. There is a severe lack of staff. So, for example, there is no response to call lights. There are frequent falls. There is lack of assistance for residents to use the restroom. All signs of poor care. Residents appear unclean and have body odors. Staff disregards residents and their rights. Residents are not treated with respect. Resident preferences and choices are not encouraged or honored and complaints are ignored. And finally, missing personal items or funds. Next slide please.

These red flags are indicators of serious issues in care and quality of life. Some of these red flags could lead to, or are, in fact, the result of resident mistreatment, such as abuse, neglect, or exploitation. In these cases it's really important that you speak with facility staff and/or an outside agency about these concerns as soon as possible. So here are some steps to addressing and/or reporting some of these red flags. First, take detailed notes of concerns, so write down names, dates, and times of incidents. Contact the facility owner and/or corporate office and share your concerns. Contact the ombudsman if complaints are not resolved or staff is unresponsive and/or you need information or advocacy. Contact the state survey agency to file complaints and make sure when you do that to be as specific as possible and to give as many details as possible. That really helps the investigators if they have as much information as possible. And certainly report any suspected abuse, neglect, or exploitation to the investigating agency, which could be Adult Protective Services or the state survey agency or perhaps even another agency and also report to local law enforcement. Next slide please.

Above all, don't ignore the issue or wait too long to share your concerns because it's best to address concerns clearly, directly, and promptly. How you present the problem is really important in order to have effective communication and problem solving. So we want to take just a moment here to give you some quick tips for how to communicate with staff about your concerns.

First, before speaking with staff, define the issues. So make sure to stick to the facts, your observations and resident direction, so what the resident is telling you he or she wants to happen regarding care needs and preferences. Second tip. Focus on the problem, not the person, and avoid using emotive words that are tied to a person's perception. For instance, avoid saying "you" because that focuses on the person. And avoid asking "why" because that can make people feel they are being accused or attacked. Tip three. Be direct, specific and nonjudgmental. Describe the situation without sharing your opinion about why it happened. Be factual. And last tip; discuss your resolution goal, what you want to have happen. Document everything and then follow up with staff if the issue is not fully resolved. Next slide please.

Okay let's take a look at some examples of how you would implement the communication tips that I just covered. I am not going to go through all four of these, so I urge you to look at and

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study all four of them, but I am going to cover a few here. So, the first one I want to look at is the one at the top where it says avoid saying why are the aides so late in responding to my call light after dinner. So problems with saying it this way? First of all, the “why” is accusatory. It is kind of pointing the finger at someone and framing it that way is going to make people feel much more defensive than if you phrased it differently. And expressing it in terms of “so late”—first of all, that’s not very specific. What does so late mean? And it’s also somebody’s perception and judgment. One person’s so late is not necessarily late for somebody else. So it’s vague, also. So, instead of saying it that way, say it this way. I need assistance getting to the restroom after dinner and for the last three nights I’ve had to wait for at least 20 minutes. How will this be addressed so I get the help I need? So this lays out the facts instead of saying so late and it asks how will this be addressed instead of saying why, which again can feel like you’re being accused. And then I want to go to the third example, so you want to avoid saying the evening aide barged into the room. So the word barged has a negative connotation for most people and it really is someone’s perception. So you could consider that to be sort of an emotive word. So instead of saying it that way, say “She came in to the room suddenly while my mother was sleeping.”, so this takes the emotion and the negative judgment out and just leaves the facts. So, we can’t emphasize enough how important communication is. I think it can create a barrier or build a bridge and what you’re trying to do is build that bridge, so remember to really think about your communication. And now, I’m going to stop and it’s my very great pleasure to turn things over to Kathy Bradley to share her perspective as a family member and advocate. Kathy...

Kathy Bradley:

Thank you, Robyn. I just want to echo what Julie said about her positive experiences with the Consumer Voice. It is an amazing organization with outstanding staff and I want all the participants to know you’ve gotten in touch with a very high-quality organization when you’ve gotten in touch with Consumer Voice. A Mother’s Voice was established as a result of our family’s experience with and our efforts to secure appropriate care for our mother in her nursing home.

So, when I talk about what you can do, it is based on my experience and the experience of others that we have felt. The best thing advocates can do is to arm yourselves with knowledge of the federal and state laws and regulations governing the long-term care setting that you or your loved one is in and gain an understanding of how those laws and regulations should translate into real-life practices by the provider and experiences for the person receiving care. Learn and use the language of the regulation because when you know the laws and regulations, you realize you are not alone. You realize you are right in your concerns and that you have the power of the laws and regulations as a partner at your side when you advocate. Now, I want to say that while I speak mostly to family members advocating for loved ones in nursing homes, these principles apply equally to consumers, ombudsman and other advocates and also translate well to home and community settings. Next slide please.

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So, how do you use this knowledge to make changes? Stay involved with your family member after he or she is placed in the nursing home. As Robyn said, visit often and at varying times. Learn the plan of care and make sure it meets your loved ones needs: physical, medical, social, psychological, spiritual, and takes their personal preferences about foods, activities and daily schedules into account. Provide information to staff that will help the plan of care to be complete and meaningful. Communicate regularly with your family member's social worker and other staff. When you visit the facility, observe the surroundings. Your loved ones, other residents, the building, the staff. Note anything good and let the staff know. Note anything that doesn't seem right. Look for trends more than one occurrence of that thing. How does staff respond when a resident asks for help? Do they respond to call buttons going off and how long does it take? What does staff do if a resident wanders out of her room partially clothed? Make written notes of your observations with dates, times, names of staff present, and details of what you saw or heard. This will help to take emotion out of the equation, as Robyn mentioned earlier. It will help your memory later on and help to define specific issues clearly. I can't over-emphasize what a significant tool these notes are.

Ask questions of the staff. When does the next activity begin? What is dad's favorite activity? What is happening at shower time? How is mother sleeping? How has her appetite been lately? Work with the staff if you see anything that needs attention, even if it's not a trend, because if it's not addressed, it can become one. And by work with staff I mean for example, offering helpful tips, like when my mother gets agitated she is trying to tell us she wants to leave the activity or the room or if my mother gets resistant to personal care, try just stepping back and approaching her again later when she's calm. Working with staff is also bringing potential issues to staffs' attention when you see them. For example, I noticed that Mr. Jones was often asking for help with finding his room or I noticed this mop bucket was left in the middle of the hallway. Again, become familiar with the facility policies and state regulations that apply so that you know what should be happening. Identify specific problems or violations and talk with management staff.

Ask about the facility policy on any practice that you have a question or concern about. For example, how staff assure that personal property is used only by the resident it belongs to. Protocols for when and how to send residents to the hospital. Whatever it is that you may have a question about. By the way, you can access the federal regulations at Our Mother's Voice website, www.ourmothersvoice.org. It's at the bottom of the home page. We have a link and we also have a link at quick links, which you can access from that home page. And there are other websites where you can find those regulations, as well.

Now if violations or problems persist approach the facility administration and then the corporate leadership if necessary. Don't feel uncomfortable doing this because if your loved one is suffering, so are others. By this time, you've already attempted to work with the staff. And this is often the only way to hold them accountable. We hear advocates say sometimes that they fear retaliation for taking a stand against problems they've identified. But retaliation is illegal and really only adds to the list of offenses. Providers know this and if advocates know it, they have a

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powerful tool. So when you approach the leadership, cite policies and regulations that are in violation and give examples of your observations and your efforts to work with the staff to correct them, your resolution goal. And this is where your detailed written notes help. You will be factual, thorough, and accurate when you approach these officials and not emotional or accusatory. Ideally, this approach should be effective and you should see positive changes, not only for your family member, but for other residents, as well. Next slide please.

However, if these efforts fail, the state regulatory agency has a complaint reporting process. The regulatory agency will refer you to their staff that take reports of complaints or violations. They will need the information you have in writing. It will be essential for them to have sufficient information to pursue your concerns. “They aren’t treating my momma right.”, is not good enough to launch an investigation, but your knowledge of the regulations and your ability to provide specific documentation of violations and specific regulations will be very useful. The regulating agency will determine whether investigation is warranted. Ask them to let you know and as they do investigate, ask them to give you an approximate time frame for their investigation and follow up with them after they’ve completed the investigation to learn what they found and learn what to expect the facility to do in response. Many facilities have family councils organized to provide families with a voice and a venue to discuss and learn and interact with the facility administration on behalf of all residents and their families. Often these councils also occasionally conduct special activities for residents and you may want to become involved with the family council. As Robyn said, if there is no family council, you may want to consider starting one. Our Mother’s Voice encourages advocates to approach the regulatory agency because they can not only impact individual situations, but address needed systems changes. And that’s the kind of advocacy that our mother engaged in her whole life. There is also a Long-Term Care Ombudsman Program in each state, which accepts complaints and responds with an individual followup to the complaint. Amity is going to tell you more about that in a minute. We have links to all the ombudsman programs available on our website as does Consumer Voice. So to wrap up, we’ve seen that following these steps has helped many families to overcome barriers to quality care and services. Typically, just knowing what to ask for and knowing and using the language of the regulations when asking is sufficient to convince providers to abide by their responsibilities. This is why we advocate teaching families the jargon. Knowing there is an agency that has the authority to hold facilities or providers accountable and going to that agency if need be is very empowering for families. And remember, although sometimes families fear the loved one will be mistreated in retaliation for complaining about problems, retaliation is illegal and fear of retaliation just allows the problems and mistreatment to continue. Only strong advocacy will effect change. And now I will turn it over to Amity.

Amity Overall-Laib:

Thank you so much, Kathy. We really appreciate hearing your perspective and your advocacy tips. So, good afternoon, everyone. As Robyn mentioned earlier, all residents have the right to quality care and to be free from mistreatment. For our part of this webinar, I am going to provide a general overview of the Long-Term Care Ombudsman Program, highlighting the role and

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responsibilities of the program. First and foremost, the ombudsman program advocates for the quality of life and care of residents in nursing homes, board and care facilities, also known as assisted living, and other similar adult care homes. And the program and the ombudsman representatives are resident advocates. As Kathy just mentioned, every state has an ombudsman program, but each state operates their program differently. Therefore, this presentation will only address the program responsibilities required by federal law, so the information is applicable in every state. At the conclusion to my presentation, you should have an understanding about what the ombudsman program does, who Long-Term Care Ombudsman represent, and how to work with the program.

The state long-term care ombudsman is responsible for operating the statewide program and the program is designed to be a local community program utilizing staff and volunteer ombudsman to visit residents in their local community. In fact, there are nearly 600 local ombudsman programs across the country and there are 53 state programs. According to the Older American Act and the new Long-Term Care Ombudsman Program regulations, responsibilities of the program include identifying, investigation and resolving complaints made by or on behalf of residents, educating consumers about residents' rights, good care practices, and other related topics, including state and federal requirements, providing information to the public regarding long-term care facilities, how to find one, explaining how the state surveys facilities and so on, resident rights, as well as legislative and policy issues that impact long-term care consumers.

The program is also responsible for educating providers about residents' rights, good care practices, preventing abuse and neglect and other issues regarding quality of life and quality of care. Ombudsman also help develop and support resident and family councils by providing information and assistance in either starting one or strengthening the current council. Ombudsman also advocate for improvement in the long-term care system globally that will benefit residents at long-term care facilities, which includes representing residents' interests before governmental agencies and seeking legal, administrative and other remedies to protect residents.

So, as I've already touched on a little bit, the primary responsibility of the program is to serve as the resident advocate. Ombudsmen support resident-centered care and residents guide all ombudsmen work. So, residents are always the touchstone that ombudsmen go back to before proceeding and during investigations of complaints. So, for example, ombudsmen need resident consent before sharing information. Residents or their legal representative's consent. The resident guides ombudsmen action. I will explain that in a couple of slides later. Ombudsmen seek to resolve complaints to the resident's satisfaction, so although ombudsmen are extremely knowledgeable in state and federal requirements, they are not resolving complaints to see if the facility is in compliance with those regulations. Rather, they are trying to advocate on behalf of the resident to reach a resolution that the resident is happy with. The ombudsman program represents residents' interests in all that they do, whether that's an individual complaint at a facility for one person, or perhaps a group of residents, maybe the resident council, in dealing with that facility, or even a chain of facilities, if there are some systems issues there, or locally or

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statewide, the ombudsmen could be looking at some systems advocacy to change how and improve the long-term care system works for residents. And of course, ombudsmen empower residents and promote self advocacy. Information is power and that is one thing that ombudsmen do really daily whenever they speak with residents is explaining their rights and how to resolve complaints and how to empower themselves in moving forward with complaint resolution.

As stated earlier, ombudsmen need resident permission prior to investigating a complaint or referring a complaint to another agency. This is due to federal confidentiality requirements of the program and it is what makes the program so unique and different from other Older Americans Act programs and services. This chart will give you a better understanding of the ombudsman role compared to other agencies and programs. So, for example, ombudsmen do not conduct licensing and regulatory inspections or investigations, so like I said a slide back, they are not seeking substantiation of a complaint to see if a facility is in compliance with state or federal regulations. That is the job of the state's survey agency, also known as Licensing and Certification or Licensing and Regulatory.

Ombudsmen use the federal and state regulations and refer to them as they advocate for the highest quality of care and life for residents. And if necessary with resident consent, ombudsmen will file a complaint on their behalf or assist them and inform them how to file a complaint on their own with Licensing and Regulatory. The ombudsman program are not adult protective services investigators. They provide information regarding the prevention of, identification of, and reporting of, abuse, neglect, and exploitation, but they are not and should not be the official finder of fact, going out to substantiate a complaint of abuse to the level that APF would. They do not have the same standard of evidence that is required to do so. Again, similar to the first bullet point I mentioned with Licensing and Regulatory, if necessary, with resident consent, or permission of the state ombudsman, if the resident can't provide consent and does not have a legal representative, the ombudsman can file a complaint about alleged abuse with APF and/or Licensing and Regulatory, depending on who is that primary investigator of that specific facility site in that specific state. Ombudsmen do not provide direct care for residents. They do provide in-service training for facility staff about quality care practices and ways to enhance the quality of life and care for residents, but they don't actually provide that care or demonstrate how to provide that care. But ombudsmen certainly are a resource for staff training and provide that information.

Ombudsman programs visit residents in nursing homes and assisted living and/board and care homes depending on what they're called in your state, but in a small number of states, ombudsman programs also visit individuals that receive long-term care services and support in their own home. Ombudsmen do represent all residents in the long-term care facility. If you're familiar with Older Americans Act programs such as programs run through Area Agencies on Aging, there is an age requirement of serving individuals 60 and older, but ombudsmen do assist residents younger than 60, as that advocacy for that individual could benefit others in that facility that is over the age of 60. Ombudsmen regularly visit facilities in order to provide access to the program, but how often they visit a specific type of facility and depends on the actual program in

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the state. Sometimes ombudsmen will visit weekly, monthly, or quarterly depending on the coverage of the state, the size of the state, the type of facilities, whether the ombudsman program utilizes volunteer ombudsmen or not, and so on. There is a lot of variation there.

The next two slides are addressing kind of frequently asked questions that we get about the ombudsman complaint investigation process and so hopefully this will help provide a better framework about the ombudsmen role in complaint resolution. The ombudsmen do investigate individual complaints as well as address concerns that impact several or all residents in a facility. Ombudsmen can also act as the complainant in a complaint in order to address general concerns that they personally observed, so, like Robyn was talking about in the care indicators, if they observe an odor, if they observe environmental issues that are a safety concern or just uncomfortable, then they can discuss that with the staff.

During complaint investigations, ombudsmen cannot share information without resident consent and some residents do ask to remain anonymous whenever they ask ombudsmen to try to resolve a complaint. And that can be challenging but ombudsmen are trained with several other options for advocacy strategies in order not to reveal the resident's identity, so it is possible to still investigate and resolve that as best as possible. Ombudsmen investigate and gather facts, so they are neutral whenever they're gathering the facts to investigate a case, but they are an advocate in resolving the case and the issue to the resident's satisfaction. And ombudsmen call upon others to fulfill their responsibilities to residents. For example, ombudsmen are not supposed to do the job of a social worker in a facility, however, ombudsmen are supposed to call upon that social worker to do their job to benefit residents. So ombudsmen, their role is to encourage others and advocate for the resident in order to get other people to do their job in order to respect the residents' rights, choices, and preferences.

The resident is the ombudsman's client. Therefore complaint investigation and activities are resident-directed. The Older Americans Act requires that ombudsmen have resident consent prior to investigating a complaint or referring a complaint to another agency. When someone other than the resident files a complaint with the ombudsman program, the ombudsman must determine to the extent possible, what the resident wants. So after receiving the complaint, the ombudsman will visit the resident in order to understand the resident's capacity to make decisions before moving forward with the complaint. As Robyn said earlier, many residents, even residents with dementia are able to express their wishes. If the resident wants to the ombudsman to act on the problem, the ombudsman will investigate the complaint and continue to communicate with the resident throughout the process. However, even when a resident has limited capacity it is still important that the resident have the opportunity to participate in decisions regarding their daily life as much as possible. For example, if a resident has a family member that's their legal representative, yet the resident still has capacity and can express their wishes and preferences, the ombudsman would work with the resident and follow their wishes. If the resident cannot indicate to the ombudsman what he or she would like and is not able to provide consent, the ombudsman assumes the resident would want his or her health, safety, and welfare protected and the ombudsman will work with the resident's legal representative. Or,

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follow the ombudsman's state policies and procedures if the resident doesn't have a legal representative and cannot provide consent.

Federal law grants ombudsmen access to resident information, again with resident permission. And ombudsmen are required to keep that information confidential. In accordance with federal law, facilities must provide ombudsmen with immediate access to the residents, as well, so they cannot block resident access to the ombudsman program and residents need to have that access by phone and have them visit in person and not have that access restricted.

Ombudsmen handle a variety of complaints about quality of life and care. The most frequent complaints usually include complaints about the discharge or eviction process, the failure to respond to calls for assistance, so otherwise call lights in nursing homes, residents are not treated with dignity and respect, medication errors, accidents, resident conflict, resident-to-resident conflict, and care planning process, either the resident wasn't included in the care planning process or the facility is not following the care plan, and complaints about food. Not all complaints are about the care provided by the facility. Some complaints that ombudsmen receive and handle are about outside agencies, services, or individuals, such as the Medicaid process and getting those Medicaid benefits. Ombudsmen can receive and respond to complaints from individuals other than the residents such as from a family member or another friend or another advocate, but ombudsmen still need resident permission to investigate and share information.

Nationwide in 2014, the ombudsman program investigated 191,533 complaints in nursing homes and board and care facilities. So as you can see, ombudsmen handle a variety of complaints and concerns and truly are resident advocates in all aspects of their work. To get more information about the ombudsman program or find out how you can contact your state or local program, please visit the National Ombudsman Resource Center website. You can use the map--the image is on the screen—to search for your state and local ombudsman program, as well as your state survey agencies, Adult Protective Services Agency, Medicaid agencies and other state entities. And just so you know, nursing homes are required to post contact information for the ombudsman program in the facility so you may want to look for that during your visits. And some states also require the same for the assisted living or boarding care. So please visit our website, the National Ombudsman Resource Center. There is a lot of information there, as well as some resources that Robyn will go over at the end that are available at the Consumer Voice website. So, I'm going to move directly into our question and answer portion of the webinar so let me open up the chat. I could see that the chat messages were coming in as I was speaking, but couldn't address them while I was talking. So let's see what we have here.

I did see this question earlier and would like to ask Julie if you could respond to this question, Julie, by un-muting your line in a moment. The participant asked if there is a link to join the NCEA Listserv that you mentioned. How do you join that?

Julie Schoen:

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Yes, you can absolutely email us. I think you will be seeing the website coming in at the end of the resources and then you can go on our website and it will have the contact us area. Just go on there and then you will be able to contact us about subscribing to the Listserv. We would love that.

Amity Overall-Laib:

Great. Thank you so much, Julie and thanks for that question.

Julie Schoen:

Thank you.

Amity Overall-Laib:

Okay. Just one second. Let me, yes, if someone asked about printing out the slides. I can answer that one for you right now. Yes, the slides and the webinar recording, as well as additional resources that we mentioned today will be on the website and you'll be able to print them from your computer. So, we had another question and I did respond to it via chat, but I would like to address it on the phone, as well. The question was "Does individualized care include dietary preferences within an assisted living facility?", and like I said I responded individually to the person that asked the question. And thank you for asking that question. It is a really good one. I wanted to share it with everybody, too, because other people on the line may have this question. My response was yes, individualized care should include dietary preferences, whether you're in a nursing home or an assisted living facility. However, the caveat is that all states, like I said earlier, have different regulations and resident rights whether you're in assisted living compared to nursing homes, so you would really need to go back and refer to your state requirements when it comes to resident choice, preferences, dining, meal options, and so forth. So I know that doesn't really drill down to that level for your question, but you would need to check with your state regulations and requirements. Again, you can actually link to that information or speak with your state or local ombudsman program. They would be a great resource for that. So, thank you for that question.

Let's see. And if you have any questions, I'm going to go through the chat questions we've already received, but if you have them, just keep them coming in or raise your hand and I can call on you and un-mute your line, as well. Okay, so, this is a question and maybe Robyn you can help me out with this response, as well. This is a pretty common question. Can a resident be discharged from physical therapy because her medical insurance no longer pays for this service, yet the resident feels additional therapy would be beneficial? So, it depends again what the insurance is and who that provider is that's covering the physical therapy, but just to use an example, if the resident is in a skilled nursing facility that's providing physical therapy and Medicare is paying for those services and let's say that the nursing home says that the payer source, Medicare, that they have exhausted all those payment days for physical therapy and

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they'll no longer be receiving that, yet the resident feels they benefit from it, there is an appeal process for Medicare and for those services. And your ombudsman program would know that appeal process is for your state because it is state-dependent about that appeal process and who to talk to. And that appeal information should be in the notice that the facility gives the resident that the physical therapy would be discontinued, that skilled therapy.

If that happens, and if the appeal isn't won and Medicare is not going to pay for that, there still are some steps that should be incorporated in that resident's care plan to help range of motion and make sure that they don't decline further, that they should maintain whatever level and even improve, if possible, from where they were when their physical therapy was discontinued. So, Robyn, do you have anything to add to that?

Robyn Grant:

Oh, I'd be happy to. You did a great job of answering that question, Amity, so I'm just going to add a couple of additional points. One is that if the facility is going to stop providing those therapy services, as Amity says, you must, the resident must receive a notice that services will be stopped. This is separate from any kind of discharge notice that must be issued if the facility is going to discharge the resident to another—or transfer them to another facility. So two different notices here. And as Amity said, I just want to stress, on that notice there should be information—there is required to be information about how to appeal. So, yes, there definitely is recourse. The other thing, it's a slightly different issue, but I just want to re-enforce that families and residents often hear in therapy that, well the resident is not improving anymore, the resident is plateauing, so we cannot provide any more therapy services. So we cannot stress enough that this is not true. It never has been true. But it became such a pervasive myth that, in fact, the federal government was sued to clear that mess up. So, it's called the Jimmo case. I want to stress that if you ever hear that therapy is being discontinued because the resident can't benefit from it anymore that is not the case and you should bring that up and you should notify your ombudsman for assistance if you continue to have difficulties with that. Therapy can be continued if it helps to maintain a resident's abilities, so I just wanted to add that point because despite a lawsuit and information that has been distributed to Medicare and to providers, this continues to be a problem.

Amity Overall-Laib:

Thank you so much, Robyn. That was really helpful. I knew you'd be able to add a lot more background to that, so thanks. Another question that some of you may have that received was where do you find the star rating for a facility? And that's the Nursing Home Compare. That's the five-star rating system that I believe you're talking about and you can access that on Medicare.gov and then look for nursing home compare, so I hope that helps. Let's see. We received another—it's not really a question. It's a statement, but I did want to share it with you because I don't want some of you to walk away with misinformation, but someone made the

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comment that APS will only respond to nursing homes if financial abuse occurred while the client was in the community and/or if continuing that financial exploitation is continuing once the resident is in the nursing home due to jurisdictional issues in that state. Thank you so much for sharing that. Yes, again, APS—every state runs their APS program differently and provides services differently, almost similar to the ombudsman program and how every state—how they operate those services are slightly different.

So, for example, in one state, APS will go into nursing homes, like you said, to investigate financial exploitation if the person exploiting the nursing home resident is not a staff member of that facility. So, for example, if the family member is supposed to be paying the resident bill out of the resident's account and they don't do that and they mismanage the funds or use the resident's funds, then APS would investigate that. APS in some states also goes into assisted living and board and care homes to investigate abuse, neglect and exploitation. So, again, just so you walk away with this, every state, their structure for investigating abuse, neglect, and exploitation, does, it operates differently. So, APS will have different jurisdiction and licensing and certification and not only will they have different jurisdiction, they'll have different responsibilities when it comes to investigating abuse, neglect, and exploitation, So, again, that's one of those state-specific things that you need to go back to your state and figure out who does what and how they do it and what it really looks like in your network. So, I hope that helps. Julie, if you have anything to add about that, feel free to jump in.

Julie Schoen:

I think you handled that perfectly. That was my comment--that every state is different and the way the APS functions varies definitely.

Amity Overall-Laib:

Great. Thank you. Let's see. A good question. So many good questions. Are there any regulations, state or federal, governing so-called adult independent care communities? Robyn, you want to take that one?

Robyn Grant:

Adult independent care communities. So, I'm going to interpret that as meaning independent living and for the most part, and I can't guarantee this, but for the most part, well there are certainly no federal regulations at all. And to my knowledge, there are not state regulations, either. So, to the extent that I know, there is nothing governing those independent living centers. Amity, would that correspond to your experience?

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Amity Overall-Laib:

Yes, it does.

Julie Schoen:

This is Julie. Also, just remember that those people would be contacting Adult Protective Services because they would be out in the community, so depending on, like, in California, there are some, depending on their status as a resident care facility or depending on the varying degree, where there might be some oversight, but yeah, I think for the most part anything independent in like an apartment building would have a landlord-tenant type of situation happening.

Robyn Grant:

Right, and sometimes if services are brought in—for example, maybe through a home care agency, then the home care agency is likely to be licensed and perhaps certified, so there could be some oversight there, but as Julie said, in essence, they are apartments.

Amity Overall-Laib:

Yes, thank you so much, Julie and Robyn. To second that, yes, look at landlord-tenant laws, contact APS in those situations if it's involving abuse, neglect, or exploitation. If it's a complaint about accommodations, then it is possible, maybe, there is some ADA compliance issue that could be addressed, so maybe contact the state protection advocacy or another disability advocacy organization in your state or locally. That would be another way to approach that for federal regulations and state requirements. So, good questions. Let's see. One more question. What's the best tool for advocacy when residents are not happy with menu options and have voiced concerns but facility states they must follow the menus the corporate office provides and then the corporate office will not change the menu? Great question. From an ombudsman advocacy perspective, what I've seen work in facilities in the past came from the residents.

There was one ombudsman that was working with a particular facility that actually helped the residents start a petition about the menu choices and options and wanting to have more snacks available and more varieties of snacks and more options for meal choices and so forth. And then that petition was presented, of course to the facility administrator, as well as the corporate office. So when, and I completely understand. I'm sure these residents probably even worked with resident council or maybe as a group, but for some reason that petition spoke volumes and they were able to make some changes.

Another option was having the residents communicate directly with the corporate office. Track down the contact information for that corporate office and work with the residents in communicating their concerns directly with the corporate office instead of going through the facility administrator in sending that message up to the corporate office. Those are the two things

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that have worked in the past. Another example would be some facilities that have really embraced culture change, which culture change is simply a way of making sure that the environment is more resident-centered and resident-directed in all aspects of care, including menu planning. Some residents were successful in getting on a menu planning/food committee and they would work together with the facility staff in planning out the menu, making sure that there were some special resident choice only days where they got to choose, you know, vote on a meal, in the resident council and that would be on the menu. So there are a lot of advocacy strategies that could be used and it's really, really powerful when it's coming from a group of residents. It speaks really loud and really clear. So, those are some options. Of course, if the residents are not seeing that the corporate office is responding to their concerns, and that is a requirement in the federal requirements that they have to respond to concerns, then they could also speak with the state survey agency and lodge a complaint to the state survey agency. So those are just a few strategies. There are a lot more empowerment and advocacy strategies available on the Consumer Voice website, as well as some examples of culture change and getting residents involved in menu planning and that quality of life. So, Robyn, did you have anything you'd like to add, or Kathy?

Robyn Grant:

This is Robyn. I think you did a fabulous job of covering the range of options. I would just add that getting back to strength in numbers, I have seen times when resident councils and family councils have joined together, so that might bring some extra weight to communicating with the corporate office. But I think you've covered all that I can think of.

Amity Overall-Laib:

Great, thank you, excellent tips. Kathy did you have anything to add?

Kathy Bradley:

Yeah. I would just add that facilities are also supposed to accommodate individual preferences and don't necessarily have to change a whole menu to satisfy one or even a number of residents who have individual preferences that are not in the routine menu. They are supposed to accommodate those individual preferences, as well.

Amity Overall-Laib:

Yes, thank you.

Kathy Bradley:

And again, you've got the weight of the regulations behind you in advocating for that. We had to do that with our mother, as a matter of fact.

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Amity Overall-Laib:

Exactly. Thank you very much, Kathy. So there was a comment that came up and I think it was based on the question about the independent care communities saying that HUD subsidized facilities do have regulations and you're exactly right, so thank you for bringing that up. So if those apartments are receiving HUD support and they're subsidized facilities then there are some federal regulations for that. So, let's see. I think we have time for one more question, then we are going to move back to Robyn, so she can share some resources and close it out. So, let's see. The question was, "Does this apply to Medicaid, as well as to Medicare?". Yes and no. If you are a resident or have a loved one in a nursing home, then yes. If the facility is certified for Medicaid and Medicare, then all of those federal regulations apply, so, and it not only applies to the residents receiving Medicare and Medicaid, it applies to all residents in that facility regardless of payer source. So if there is a resident living in a nursing home that is paying completely out of pocket, they are completely private pay, all of those rights and regulations apply to that individual, as well, because that facility is certified in both Medicaid and Medicare. So, and then there are also very new home and community-based services requirements that apply to Medicaid spending in the community for some community services. Robyn, did you want to just briefly touch on that and then let them know where they can get more information for that on the Consumer Voice website, then I will hand it back to you.

Robyn Grant:

So like Amity said there are new rules that apply to folks who are receiving services in the community through Medicaid waivers and also that would apply to basically assisted living facilities that are receiving Medicaid. And a lot of the—there is a real focus on person-centered planning in these regulations, so they really re-enforce the fact that it's the consumer who should be guiding the process and they really support what the individual wants and their preferences in putting together the care plan. There are also regulations that speak about choice and privacy and involvement in the community. I would say that in a residential setting there are an additional set of requirements that apply and some of those include the fact that there has to be privacy. There has to be a locked door. There has to be access to food 24 hours a day. So, the effort here and the intent here is to really make the services that are home and community-based truly like what those of us who live in our homes would receive and not to really treat folks who are receiving these services differently as if they were not part of the community or as if they were in an institutional setting. So, you should be able to find this information on our website. I can't exactly remember the link, but if you go on to the Consumer Voice website and look under issues I think you should be able to find it or do a search for home and community-based services.

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Great. Thank you Robyn. So that's going to wrap up our Q and A portion of the webinar, but if we did not get to your question, I'm sorry about that. We have a ton of great questions and thank you so much for your participation. We will be available via e-mail and you could always contact Consumer Voice or NORC to follow up with the additional questions. So, I'm going to pass it back to you, Robyn, to cover some resources.

Robyn Grant:

Okay. Well thank you, Amity. So, in addition to the information in this webinar, we wanted to provide you with some resources to help you in advocating for quality care. Next slide. Oh, sorry. I think we're there. So in collaboration with NCEA we produced this new trifold brochure that we're very proud of. The brochure has the information that we reviewed today, as well as recommendations for seeking help and reporting complaints. It also has contact information for NCEA and the elder care locator, which can be used to be find local aging and disability services. So we really want to encourage you to use this brochure. If you're a resident, please share this with your peers, both individually and in resident council meetings. Talk about what quality care means to you and how to advocate for your needs. If you're a family member, use this resource to inform your observations during visits. It gives you ideas about what to look for. And also, use the brochure to help you in advocating for quality care. And if you're an ombudsman, you can distribute the brochure and use it to start a conversation about residents' rights and quality care during visits. So next slide.

So, Consumer Voice is the leading national advocacy organization for consumers receiving long-term care services and support. We have a wealth of information available to support consumers, family members and others in advocating for quality care.

So you see the red circle on the screen and that shows you that we have specific information for long-term care consumers, family members, and advocates. And when you click on those tabs, you will be directed to a variety of material. There is information available for residents in nursing homes, assisted living, and for those who are receiving home and community-based services. Next slide. Here you see just a few examples of the types of resources that Consumer Voice has available for consumers, family members, and advocates. So, I just want to stress again we have a wealth of information and this is just a sample of what's available on our website. Next slide please.

As we shared earlier, this webinar and the new brochure are products developed in collaboration with NCEA and you can find the NCEA online at their main website, their blog, Facebook page, and Twitter. Next slide. So, in closing, I want to thank NCEA, for their support and collaboration on this webinar and specifically, Julie for her presentation earlier. I want to thank Kathy for sharing her insights as a family member and advocate and I want to thank all of you for taking the time to join us today. So, webinar recording and all the materials will be posted on our website soon. And finally, for additional resources, as we said, visit our website and connect with us on Facebook and Twitter. If you're looking for something specific or have any questions

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or comments, please let us know how we can help you. And also, once the webinar ends, you will be directed to a quick evaluation and we really encourage you and hope that you will complete the evaluation because your feedback is extremely important to us and we take it very seriously. So, with that, we wish you success in your advocacy and enjoy the rest of your day. Thank you so much.