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Examining the Older Americans Act: Promoting Independence and Dignity for Older Americans

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Chair Bonamici and Ranking Member Comer, Chair Scott and Ranking Member Foxx, and members of the subcommittee, I am pleased to present this testimony on behalf of the Texas Long-Term Care Ombudsman Program (Ombudsman Program) and in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). Thank you for your ongoing support of state long-term care ombudsman programs, authorized by Title VII of the Older Americans Act, which addresses Vulnerable Elder Rights Protection Activities.

As you know, the Older Americans Act authorizes state long-term care ombudsman programs to protect the health, safety, welfare, and rights of some of our nation's most vulnerable citizens who live in nursing homes and assisted living facilities. Some amazing people

live in facilities in your communities. Residents are rocket scientists, industry leaders, teachers, religious leaders, truck drivers, grocers, plumbers, politicians, veterans of World War II, Korea, Vietnam, and Gulf wars, and people from all walks of life. They are also our grandparents, parents, aunts and uncles, sisters and brothers, neighbors, and friends.

It is my privilege to have served as the Texas state ombudsman for 12 years, and for three years prior as a local ombudsman in Dallas County. The Texas Ombudsman Program operates independently within the Texas Health and Human Services Commission, which is the agency designated as the state unit on aging. For decades, our program has operated in conjunction with 28 area agencies on aging, which house the local operations so that ombudsman services are delivered quickly and effectively. This system works for us to ensure that ombudsmen can be in facilities throughout the state to interact with as many residents as possible, and to observe, investigate, and resolve complaints on behalf of residents.

Most other states operate similarly to ours — an office of the state long-term care ombudsman is located within the state unit on aging, and the office contracts with area agencies on aging or non-profit organizations to operate local ombudsman offices. Some states have the office located within the state unit on aging, but do not contract with other agencies to operate local offices, and other states are operating in an independent agency or a state agency that is not the state unit on aging. Flexibility in the location of a state long-term care ombudsman program is necessary to ensure the program is in the best organization to operate independently of functions that may conflict with the ombudsman's role as a resident advocate and to ensure that state and federal funds are used efficiently and effectively.

The need for long-term care is growing as the population of older Americans grows. By 2030, adults age 65 and older are projected to make up more than 20 percent of the total U.S. population, and a significant portion of that population will need care in a facility. Over 92,000 older Texans live in a nursing home and over 45,000 live in an assisted living facility. Title VII of the Older Americans Act ensures that the voices of these citizens are heard, and their rights are protected.

In 2018, with about 100 staff and 400 volunteers, the Texas Ombudsman Program investigated 16,544 complaints and resolved 78 percent of them to the satisfaction of the resident. Volunteers donated over 31,000 hours to the program. That donated time consists of training, visiting residents, and resolving complaints. As you might imagine, the role of a volunteer ombudsman is challenging and meaningful. Volunteer and staff ombudsmen must engage in conflict and deal with complicated and emotional issues, including the loss of many residents.

Today, I appreciate that the Ombudsman Program, with our work to protect residents' rights and prevent abuse, is recognized among our Older Americans Act colleagues as part of the Act's system to promote independence and dignity. I imagine, however, that many Americans don't think about an assisted living facility as a place where a person can be independent, but it can and should be. I imagine that many don't think a nursing home is a place where a person lives a dignified life, but it must be. Program staff and volunteers are onsite in facilities to the maximum extent possible to ensure facilities are creating opportunities for residents to have independence, and to call out instances of indignity and hold a facility accountable to correct its mistakes.

Nationally the most common complaint ombudsmen receive is about discharge from a facility. Because a nursing home is a residence – that is, an individual's home – a resident has a right not to be discharged except for certain valid reasons. And, to protect that right, a resident has a right to appeal to the State Medicaid agency and nursing homes are required to notify the resident and the ombudsman of the discharge. Ombudsmen help residents who want to stay in their home file an appeal and represent the resident in an appeal. We can also negotiate with the facility to find a solution other than discharge.

I want to provide an example of why protection from discharge is so important and why ombudsmen are so passionate about protecting rights. A resident in a secure dementia care unit was issued a discharge notice for being a "threat" to others in that facility. The facility provided no evidence of what that "threat" was. The resident had recently fallen, had limited mobility, limited vision, and dementia. The facility pointed to one incident of his disrobing in public, a common symptom associated with dementia, as the reason they were pursuing discharge. The guardian appealed the discharge, and while awaiting the hearing, got a phone call from the facility at 6pm on a Friday to say the resident had been discharged to a behavioral hospital. The facility had gotten a court order to involuntarily commit him without contacting the guardian. The hospital conducted an assessment, determined the resident posed no danger to anyone and was not appropriate for placement in the hospital because he was experiencing the effects of dementia, not a mental illness. The facility refused to take the resident back and the resident remained in the behavioral hospital for a month before being transferred to a new nursing home where he died a week later. The guardian believes the stress of the discharge contributed to a quick decline in his condition, and while the resident's case prevailed in the fair hearing, the result came too late to benefit the resident. With permission from his guardian, we share this story to honor the resident and inform our lawmakers about the effects of improper discharge.

Confidentiality

Confidentiality is a core principle of individual rights and the ombudsman program, and confidentiality is fundamental to the program's ability to carry out its mission and mandate. Confidentiality requirements are explicitly set out in the Older Americans Act, including strict confidentiality of ombudsman program records. To preserve the fundamental inviolable trust relationship between the resident and the ombudsman that enables residents to feel safe in reaching out with their problems, no resident-identifying information is released without the consent of the resident. For this reason, ombudsmen cannot be mandated reporters of abuse, neglect, or exploitation. With a resident's permission, ombudsmen can and do report abuse, as most residents reveal a problem to us because they want our help to report and keep the resident safe. Ombudsmen also consistently strive to help residents understand the value and importance of reporting abuse. When a resident does not consent to disclosure, the ombudsman seeks resolution approaches that protect the resident's identity, monitors the situation, and works to end the abuse. Ombudsmen also remind facility staff and family members of their status as mandated reporters of abuse.

Federal law requires ombudsman programs to share aggregate program data and other information in an annual report and upon request. Sharing of non-confidential information regarding long-term care issues and trends is consistent with the program's systems advocacy and community education role.

Preventing Abuse, Neglect, and Exploitation

Long-term care ombudsmen serve residents, advocating for quality care that ranges from basic needs like the right to nutritious food to serious issues of abuse. Ombudsman programs coordinate with law enforcement, the Centers for Medicare and Medicaid Services, state licensing and regulatory agencies, adult protective services, provider associations, and others to advocate for quality care for all residents, which includes that residents are protected from abuse, neglect, and exploitation. We train residents, family members, and facility staff on how to prevent, identify, and report abuse. Put simply, ombudsmen are eyes and ears in a facility. Each onsite visit made — which in 2017 was over 29,000 visits nationwide — prevents abuse. Each visit is an opportunity for residents to speak up about abuse or for an ombudsman to witness subtle signs of abuse that can be addressed with residents and the facility.

Nationally in 2017, ombudsman programs investigated over 5,000 cases of abuse, neglect, or exploitation in assisted living facilities, and over 11,000 cases in nursing homes. This year in Houston, Texas, a volunteer ombudsman was the first person a nursing home resident told about sexual abuse she experienced while being bathed by a staff member. The ombudsman worked as her advocate to help the resident report to the administrator and law enforcement, which led to the termination and prosecution of the employee. Ombudsmen are on the front lines of preventing abuse in facilities, because we build trust with residents and are someone residents can turn to for a person-centered response to any problem.

Fear of retaliation is prevalent in long-term care facilities. If you rely on someone to take you to the bathroom and you complain about how staff treated you – how will you be treated the next time you need help? Will you be left longer and forced to go to the bathroom on

yourself? These are real questions that one resident told his ombudsman keeps him from reporting some problems. Our role is to respect the choices of each resident and stay resident-centered because, at the end of the day, we go home to the safety and security of our own homes, and residents stay in theirs. Choice and control are essential to protection of a resident's right to dignity.

As a resident advocate, it's important to empower the resident, especially in abuse circumstances. This is similar to the role of a victims' services advocate, giving the resident — and not the ombudsman program — the authority to make the decision about when, where, and how the resident's information can be disclosed by the ombudsman program. Therefore, ombudsmen are an important part of the elder justice system. We educate the public about residents' rights and reporting requirements, respond to and support the resident when abuse happens, and inform the public and law makers about what needs to change in the system.

Systems Advocacy

Based on the problems we observe in facilities, our program is also charged with the responsibility to represent the interests of residents to decision-makers in state and federal agencies and legislatures. We are charged with making recommendations and providing comments and context to policies, explaining the impact a policy or action has on residents themselves. Efforts at efficiency, provider burden reduction, and even rule-making can have unintended negative consequences that decision-makers need to know. Our efforts to act as a voice for residents – which ombudsmen call systems advocacy – is aimed at quality of care and quality of life and provides the government and its citizens with an accountability service for residents, most of whom are Medicare and/or Medicaid eligible. The field of advocates for

older adults is relatively small, but the work is important to improving the systems in long-term care. Long-term care ombudsmen are – and need to be – at the forefront of advocacy for long-term care residents, many of whom can't advocate for themselves. And when a resident can advocate, it's our responsibility to help the resident's voice resonate.

<u>Assisted Living Advocacy</u>

The Older Americans Act added responsibilities to state long-term care ombudsman programs in 1981 to include advocacy for residents of assisted living, board and care, and similar community-based long-term care settings. Since then, the assisted living facility industry has boomed, with nursing facility numbers in some states being overtaken by assisted living facility numbers. While the mandate to serve residents in assisted living facilities was added to our mission in the Older Americans Act, there have been no appropriations for this function. As a result, state programs are unable to adequately serve residents in assisted living, and that's evidenced by the difference in our national data of facility visits. While ombudsman programs make routine onsite visits (one every three months) to 70 percent of nursing facilities, programs only visit 31 percent of assisted living facilities with the same frequency. Without ombudsmen in these buildings, residents are at greater risk of abuse, neglect, and exploitation, and other rights violations. As validation of the risks to residents of assisted living facilities, the Government Accountability Office released a study in 2018 about the severity of quality of care

problems in assisted living facilities. The study revealed that abuse, assault, and even unexpected or unexplained deaths are not well monitored or reported.¹

Conclusion

Finally, I'd like to acknowledge the importance of the National Ombudsman Resource Center. The National Ombudsman Resource Center, which is modestly funded, provides valuable and reliable technical assistance and support to state and local ombudsman programs, and is more important than ever as the Administration for Community Living reorganizes and adapts to the needs of the aging network. State ombudsmen rely on our resource center for its research and training services. We need Congress and the Administration for Community Living to continue to support and strengthen the role and availability of resources through the National Ombudsman Resource Center.

Thank you for the opportunity to participate in today's hearing. Again, I thank this Subcommittee and the Committee on Education and Labor for its past and future support of the Older Americans Act. Thank you for preserving the independence and dignity of older Americans across the continuum of long-term services and supports, including when living in an institution and when victimized by abuse, neglect, or exploitation. On behalf of the Texas Long-Term Care Ombudsman Program and my colleagues in every state, with the Older Americans Act, we will be here for residents now and in the future to protect residents' rights and prevent their harm.

¹ https://www.gao.gov/products/GAO-18-179