

Testimony for  
Pennsylvania House Aging & Older Adult Services Committee  
Public Hearing on Proposed Assisted Living Regulations  
Regulation No. 14-514

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Good morning. My name is Diane Menio and I am the Executive Director of CARIE, the Center for Advocacy for the Rights and Interests of the Elderly. Thank you for sponsoring today's public hearing about the proposed assisted living regulations and for the opportunity to comment.

As a member of the Assisted Living Workgroup of the Department of Public Welfare (DPW), I appreciate being part of the process DPW undertook and understand the challenge of trying to address the concerns of a variety of stakeholders, many with opposing views, in drafting the regulations. As the formal regulatory review process begins, the tug of war over conflicting ideas will no doubt continue. However, Pennsylvania can benefit from the best practice experiences of other states as well as the lessons learned when Pennsylvania had weak and poorly enforced personal care home regulations.

***As a member of the Pennsylvania Assisted Living Consumer Alliance (PALCA), we fully support the detailed comments and recommendations submitted by PALCA.***

We hope DPW will retain key improvements over current personal care home regulations and make needed modifications to ensure the safety and well-being of residents as recommended by PALCA.

Founded in 1977, CARIE is a non-profit organization dedicated to improving the quality of life for frail older adults by working to protect their rights and promote awareness of their special needs and concerns. CARIE provides long term care ombudsman services to residents of over 155 nursing facilities and personal care homes in north, west, south and central Philadelphia. The following comments reflect CARIE's experience as ombudsman that will hopefully help support the need to ensure that the

regulations address the needs of residents. Assisted living residents and applicants, particularly those who are vulnerable, need regulations that clearly define assisted living in an understandable way and work to ensure they receive the care they need.

***Developing a core package of services is essential so that consumers and their families can better understand what is covered at a minimum and can more effectively compare costs among providers.*** Most older adults and their families know very little about long term care options until there is a crisis or other life changing event that prompts the need to address care needs. Assisted living offers a combination of housing and services that are appealing to many. It is important that the regulations more clearly define what assisted living means in language that is understandable to the public. As currently stated, the regulations do not make clear distinctions between assisted living and personal care homes and the difference may be lost on the consumer in need of long term care services. The proposed regulations would make it difficult for consumers to compare costs and services. One facility may appear to cost less than another facility but may in fact cost the consumer more when adding in extra charges that may have been included in a competitor's rate.

***Clear marketing standards need to be established.*** We have experience coordinating a statewide Medicare fraud prevention project and has witnessed the impact of marketing abuses on consumers as well as the cost to the system. While considering placement in a personal care home my mother, I was told that my mother would have a single room and was referred to the on-line tour. When I asked what would happen if my mother ran out of money, I was told that the facility does not "put anyone out" and that my mother would be moved to a "low-income" room. That room was described as a

room with four beds—it was not shown on the on-line tour. This is just one way in which consumers who may not know all of the questions to ask may be misled upon admission. Stressed caregivers and older consumers contemplating a major move to an assisted living facility can be easily confused by deceptive marketing techniques and promises. Questionable marketing practices have been well documented through the work of Carol Cirka and Carla Messikomer of Ursinus College in their study, *Ethical Perspectives in Assisted Living: A Leadership Role for Pennsylvania*. Among other recommendations, they suggest establishing standards for ethical marketing practices that focus on consumer disclosure and advertising policies.

***A comprehensive assessment must be completed prior to admittance and implemented upon admission to ensure quality of care.*** The lack of a required comprehensive assessment prior to admission needs to be remedied in the regulations. The screening tool described in the regulations would not help determine whether the consumer's needs could be met or what the actual cost of care would be for the consumer. As advocates and ombudsman, we know how traumatic a move into a residential setting can be. Transfer trauma can occur when residents need to move from one facility to another. The emotional trauma is often coupled with a decrease in functional ability that may or may not be recovered after a move. The need to ensure the best possible match between the capacity of a facility to care for a particular applicant and the needs of a consumer is essential. Consumers and their families should also be clear about the costs and how the costs may change to once again help consumers make the best possible choice. As proposed, the facility has up to 15 days to complete a comprehensive assessment and up to 30 days to develop a care plan. Since assisted living

residents and applicants will typically be older adults coping with multiple chronic conditions, a delay in implementing a needed component of their care identified by assessment could cause a decline in their functioning.

***It is imperative that the proposed regulations be modified to identify the specific rights of assisted living residents, that residents be informed of all their rights and how to use them in an understandable manner, and ensure they are free to exercise these rights without repercussions.*** As ombudsman, we routinely deal with issues related to resident rights for residents of nursing facilities and personal care homes as well as problems with inappropriate discharges. We often field inquiries from both hospitals and families about problematic discharges from personal care homes. Unfortunately, we typically receive these calls after the discharge occurred. For hospitals, the problem is usually that the facility sent a resident to the hospital but is refusing to let them return. When we hear from families, they were often unaware of the discharge process or their rights and are trying to resolve the problems associated with inappropriate discharges. It is also a common complaint to hear from residents that the facilities threaten to discharge them if they do not comply with a particular request or policy. The threat of discharge or being punished for complaining is a fear many residents and families have that can impact their quality of care and life. In one personal care home, each time our ombudsman visited, he learned that afterward, residents were “grilled” as to what they had discussed. On several occasions, after returning to that facility, residents *withdrew* their complaints. We need to make sure this does not happen and that residents and families feel comfortable voicing concerns.

***We strongly recommend the addition of the following rights:***

1. A resident has the right to choose healthcare providers, subject to limitations on the choice of supplemental healthcare providers pursuant to §2800.142(a).
2. A resident has the right to refuse treatments or services prescribed or recommended.
3. A resident has the right to manage his or her own financial affairs.
4. A resident has the right to reside and receive services with reasonable accommodation of individual needs and preferences, except where the health or safety of other residents would be endangered.

***The requirements for a 30 day notice and an “appropriate” discharge need to be expanded to include specific appeal rights or an appeal process to ensure that residents can challenge a facility’s decision regarding discharge. The resident should be guaranteed the right to stay in the facility during the appeal process and if the facility facilitates an inappropriate or unsafe discharge, penalties should be imposed.***

For example, a facility should not be permitted to discharge a resident to the home of a caregiver unable or unwilling to care for the resident, a homeless shelter or an unlicensed boarding home. Facilities should also provide a list of residents’ discharge rights when issuing a discharge notice since this information is given upon admission and is often forgotten when a discharge notice is issued.

***Resident rights should be expanded to address the need for Resident and Family Councils.*** The regulations grant residents the right to “freely associate, organize and communicate with friends, family, physician, attorney, and other persons.” Residents should be able to organize and meet in the facility in a private space without the presence

of staff unless invited by the group. The facility should designate a staff person to assist the group and respond to any written requests from the meetings. The facility should respond to any complaints or recommendations made by the council. The same rights should be granted to family members wishing to organize and meet about the care and services provided in a facility. Resident Councils and Family Councils have proven effective means to help residents and their families discuss concerns and resolve problems. The councils also allow for guest speakers to attend meetings and provide education on topics identified by the group. The addition of Resident and Family Councils fits with the Department's description: "The proposed rulemaking protects consumers' health and safety, privacy and autonomy ...."

***Facilities should be required to ensure full accessibility for wheelchair and walker users throughout the facility and meet federal ADA standards.*** Many providers are voicing concerns about the costs associated with making facilities accessible for residents and describe costs as too prohibitive in meeting the current proposed standards for fire safety and accessibility. Since the purpose of the assisted living regulations is to create a long term care alternative to "allow people to age in place" and "maintain their independence," the Department should not weaken these standards. Providers are not being forced to transition to assisted living and could certainly continue to operate under current regulations as personal care homes. In fact, the proposed regulations do not go far enough to ensure that residents who may need to use walkers or wheelchairs, perhaps even temporarily, the opportunity to age in place.

***We have serious concerns about the informed consent provisions of the law.***

While we do believe that it is important that consumers be informed and educated, we do not see any advantage to consumers in signing a contract that might limit their individual rights. By signing, consumers are relinquishing the rights they have under law to refuse medical treatment and to make decisions about their care. The support planning process is a wonderful vehicle for discussing concerns about whether those decisions are placing the resident at risk and to arrive at mutually-agreeable methods of addressing them. If agreement is not possible and the consumer continues to wish to exercise her rights, the residence has other remedies available. They can document their efforts to educate the consumer about potential harm or risk and in some circumstances can even discharge the resident for legal reasons. We know that facilities are quite concerned about liability. However, we are concerned that the informed consent process could be abused in order to limit liability of the facility. We also believe that there are too many unanswered questions about how this process will work. For example, a residence can initiate the informed consent process when a consumer's behavior is placing other residents at risk. But, the process cannot result in an agreement which places other residents at risk. This is understandable, but what then is the point of using an informed consent process in this situation?

***There must be an independent advocate available for consumers to ensure they understand what signing an informed consent agreement means for them. However, the use of the ombudsman is not appropriate.*** The ombudsman is not trained to negotiate contracts nor do the federal rules governing the ombudsman program permit this function. The very nature of the informed consent process puts the resident at a

disadvantage with the provider. The resident will probably be an older adult with multiple health problems. The provider benefits from legal counsel and other support and experience. There is one particular nursing facility in our area that essentially requires certain residents to sign a “behavioral contract.” When ombudsman speak to residents about the contract, they respond by stating they believed they had to sign it or face being discharged even though they did not understand or agree with the contract. The contract does not resolve the underlying behavioral problems and in fact is more likely to escalate problems when staff refers to the contract at the time residents are acting out. While the proposed regulations state that “a licensee may not require execution of an informed consent agreement as a standard [emphasis added] condition for admission,” an applicant should not be denied admission for refusal to sign an informed consent agreement under any circumstances particularly without the right to appeal. Section 2800.43 (c) states that, “waiver of any resident’s right shall be void.” This seems to be in conflict with the signing of an informed consent agreement that specifically waives residents’ rights. With so much potential for confusion and abuse, it is imperative that an independent advocate be available to help consumers and families navigate this challenging new provision.

***The regulations should better reflect a higher standard in terms of staffing levels and training.*** The proposed regulations do not ensure an adequate number of staff or enough training to meet the needs of residents. We have witnessed and it is well documented that serious problems occur in long term care settings when there is not an adequate number of staff to care for vulnerable residents with multiple medical problems. These problems are exacerbated when staff is not fully trained. Residents could experience an adverse impact on their health and functioning if needs are not recognized

and addressed. CARIE Ombudsman frequently hear from residents that staff yells at them but they do not want to make a formal complaint out of fear of being discharged. The result is that residents are not treated with dignity or respect and staff is not getting the support or training needed to cope with challenging situations. Due to the prevalence of Alzheimer's Disease and other dementias, it is imperative that all staff including Administrators receive training about caring for cognitively impaired residents. Since assisted living is supposed to have the capacity to provide a higher level of care than personal care homes and residents should have the opportunity to "age in place," the training should be enhanced.

***Vulnerable assisted living residents deserve the best possible standards of care and effective enforcement of these standards.*** We hope we can count on your support to help ensure the final regulations will ensure the health, safety and well-being of older Pennsylvanians who will reside in assisted living residences in Pennsylvania and that the final form regulations will include our recommendations as well as those of PALCA. Thank you again for providing the opportunity to testify today.