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Office of Long Term Living Bureau of Policy and Strategic Planning Via email at RA-asstdliving@state.pa.us

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INDEPENDENT REGULATORY RE: Assisted Living Residences Interim Draft 2800 Regulations COMMISSION

To Whom It May Concern:

On behalf of CARIE, the Center for Advocacy for the Rights and Interests of the Elderly, I am submitting comments regarding the interim draft Assisted Living Residences 2800 regulations. 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. We appreciate the effort made to review and consider the many public comments and recommendations. Hopefully, the final regulations will provide needed protections for assisted living residents, create policies to foster quality care and quality of life as well as ensure strong standards for oversight. The interim draft includes critical improvements that we hope will be retained in the final regulations.

As a member of the Pennsylvania Assisted Living Consumer Alliance (PALCA), CARIE fully supports the comments and recommendations on the interim draft 2800 Regulations for Assisted Living facilities submitted by **PALCA.** We encourage the Office of Long Term Living to support these recommendations by incorporating them into the final regulations.

Our experience serving as a long term care ombudsman compels us to emphasize the need for the regulations to expand resident rights as well as include the process to appeal or challenge decisions made by facilities related to cost, care, and discharge. Since Act 2007-56 states that the "regulations for assisted living residences shall: meet or exceed standards established in 55 PA. Code §2600 (Relating to Personal Care Homes)" and the proposed regulations state "A resident has the right to use both the residence's procedures and external procedures to appeal involuntary discharge," we believe appeal procedures can be included in the regulations. We appreciate Representative Mundy's commitment to introduce new legislation to address this critical issue. If new legislation is the only alternative to address this gap, the legislative process needs to be expedited without further delay. We recommend that sections 2800.41, 2800.42, and/or 2800.228 of the draft regulations be amended accordingly. The requirements for a 30 day notice and an "appropriate" discharge in section 2800.228 should be amended to include specific appeal rights and 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

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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 information given upon admission is often forgotten when a discharge notice is issued. As ombudsman, we routinely deal with issues related to inappropriate discharges from personal care homes. 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. Residents need clear rights and procedures to protect them from threats, retaliation and inappropriate discharges.

We strongly recommend adding the following rights to section 2800.42:

- 1. A resident has the right to choose healthcare providers.
- 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.
- 5. Residents may organize Resident Councils and meet in the facility in a private space without the presence of staff unless invited by the group. The same rights shall be granted to family members wishing to organize Family Councils and meet about the care and services provided in a facility. While we appreciate the addition of the word "privately" to the right granted residents to "freely associate, organize and communicate privately with friends, family, physician, attorney, and other persons," it should be clear that Resident Councils and Family Councils are permitted to organize and function. The facility should designate a staff person to assist the groups and respond to any written requests from the meetings. The facility should respond to any complaints or recommendations made by the councils. Resident Councils and Family Councils have proven to be an 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.

Sections 2800.56, 2800.57, 2800.64 and 2800.65 must include higher standards 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. CARIE Ombudsman hear from residents, and it is well documented, the serious problems that occur in long term care settings when there is not adequate numbers 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, functioning, and well-being if needs are not recognized and addressed in an appropriate manner. Many problems can be avoided with adequate numbers of well trained staff. Staffing is critical and the regulations must assure that there is adequate staffing and staff are trained to meet the needs of residents.

Finally, the enforcement sections need to be strengthened. The penalties proposed in section 2800.262 are too limited to deter poor performance or noncompliance with the regulations. Additional alternatives should also be permitted such as monitors, temporary management, and receivership.

Vulnerable assisted living residents deserve the best possible standards of care and effective enforcement of these standards. We hope you will incorporate our recommendations and those of PALCA in the final form regulations. Should you have any questions, please do not hesitate to contact me at 267-546-3434 or menio@carie.org. Thank you for the opportunity to provide comments.

Respectfully Submitted,

Diane A. Menio Executive Director