

CARIE

Executive Director
Diane A. Menio, MS

Board of Directors
Donna M. Hill, Esq.
Chair

Mary M. Austin, MSN
Vice-Chair

Jane Bonner Reitmeyer, MSW
Secretary

John A. Evans, Esq.
Treasurer

Emily Amerman, MSW
Ann Brennan, MBA
Willo Carey
Carolyn Cristofalo, MSW
Helen-Ann Comstock
Lynne Dant
Joan K. Davitt, PhD
Arthur De Leo
Antoinette R. Leatherberry, MBA
Timothy B. Monahan
Mabel Morris
Trudy Persky, MSW
Lisa Salley, MS
Ann J. Sholly, PA-C
Robert Warren, MD

Members Emeritus
Margaret Burns
Thomas W. Clark, MD*
Rev. Francis A. Shearer*
Bernice Soffer, MSW
Roger K. Stephens, MSW
Josephine Terrell
Margaret Yeakel, DSW*

National Advisory Council
Robert Applebaum, PhD
William F. Benson
Msgr. Charles J. Fahey, DDiv
Terry Fulmer, PhD
Iris Freeman, MSW
Elma Holder, MPH
Robert Hudson, PhD
Rosalie Kane, PhD
Brian Lindberg, MMHS
Karl Pillemer, PhD
Lori Rosenquist Griswold, PhD
Robyn Stone, DrPH

*Deceased

September 15, 2008

Arthur Coccodrilli, Chair
Independent Regulatory Review Commission
333 Market St, 14th Floor
Harrisburg, PA 17101

Dear Mr. Coccodrilli:

Attached please find a copy of the comments CARIE submitted to the Department of Public Welfare regarding the proposed Assisted Living Residences regulations, Regulation No. 14-514. Should you need any clarification or have questions, please do not hesitate to contact me at 267-546-3434 or menio@carie.org.

Respectfully submitted,



Diane A. Menio
Executive Director



Center for Advocacy for the Rights and Interests of the Elderly
T: 215.545.5728 F: 215.545.5372 W: www.carie.org



September 15, 2008

Gail Weidman
 Office of Long Term Care Living
 Bureau of Policy and Strategic Planning
 P.O. Box 2675
 Harrisburg, PA 17105

RE: Proposed Assisted Living
 Residences Regulations
 Regulation No. 14-514

Dear Ms. Weidman:

On behalf of CARIE, the Center for Advocacy for the Rights and Interests of the Elderly, I am submitting comments regarding the proposed Assisted Living Residences regulations, Regulation No. 14-514. 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 both consumers and providers 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), CARIE fully supports the detailed comments and recommendations submitted by PALCA. We encourage DPW to 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.

Executive Director
 Diane A. Menio, MS

Board of Directors
 Donna M. Hill, Esq.
 Chair

Mary M. Austin, MSN
 Vice-Chair

Jane Bonner Reitmeyer, MSW
 Secretary

John A. Evans, Esq.
 Treasurer

Emily Amerman, MSW
 Ann Brennan, MBA
 Willo Carey
 Carolyn Cristofalo, MSW
 Helen-Ann Comstock
 Lynne Dant
 Joan K. Davitt, PhD
 Arthur De Leo
 Antoinette R. Leatherberry, MBA
 Timothy B. Monahan
 Mabel Morris
 Trudy Persky, MSW
 Lisa Salley, MS
 Ann J. Sholly, PA-C
 Robert Warren, MD

Members Emeritus
 Margaret Burns
 Thomas W. Clark, MD*
 Rev. Francis A. Shearer*
 Bernice Soffer, MSW
 Roger K. Stephens, MSW
 Josephine Terrell
 Margaret Yeakel, DSW*

National Advisory Council
 Robert Applebaum, PhD
 William F. Benson
 Msgr. Charles J. Fahey, DDiv
 Terry Fulmer, PhD
 Iris Freeman, MSW
 Elma Holder, MPH
 Robert Hudson, PhD
 Rosalie Kane, PhD
 Brian Lindberg, MMHS
 Karl Pillemer, PhD
 Lori Rosenquist Griswold, PhD
 Robyn Stone, DrPH

*Deceased



Center for Advocacy for the Rights and Interests of the Elderly
 T: 215.545.5728 F: 215.545.5372 W: www.carie.org



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. CARIE has 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 for her mother, one of our staff was told that her mother would have a single room and was referred to the on-line tour. When she asked what would happen if her mother ran out of money, she was told that the facility does not "put anyone out" and that her 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.

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 didn't 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.

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.

There must be an independent advocate available for consumers to ensure they understand what signing an informed consent agreement means for them. The informed consent process described in the proposed regulations also raises a number of concerns for residents. 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 didn’t understand or agree with the contract. The contract has not resolved the underlying behavioral problems and in fact escalates problems when staff refers to the contract when 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. In addition, a facility should not be permitted to have a resident sign an agreement that includes a waiver of a service the facility does not even have the capacity to provide.

The use of the ombudsman is not appropriate as described in the section regarding informed consent agreements. The ombudsman is not trained to negotiate contracts nor do the federal rules governing the ombudsman program permit this function.

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 you will incorporate our recommendations and those of PALCA in the final form regulations. Should you need clarification or 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,

A handwritten signature in cursive script that reads "Diane A. Menio".

Diane A. Menio
Executive Director