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From: Cirka, Carol [ccirka@ursinus.edu]
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Subject: COMMENTS ON PROPOSED ASSISTED LIVING REGULATIONS #14-514

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INDEPENDENT REGULATORY
REVIEW COMMISSION

Attached please find comments related to the proposed assisted living regulations. I am attaching the file in PDF form. We look forward to your response to our comments.

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September 14, 2008

Gail Weidman
Department of Public Welfare
Office of Long Term Care Living
P.O. Box 2675
Harrisburg, PA 17105

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

Dear Ms. Weidman and Chairman Coccodrilli:

As independent scholars, we submit the following comments on the Proposed Assisted Living Regulations - # 14 – 514. Our perspective is intended to advance the quality of care provided to seniors in AL. We are observers of, not participants in, the assisted living industry, and we have no financial interest in it.

In the past five years, we have conducted research on everyday ethics in assisted living in Pennsylvania, and we are familiar with the academic literature in the field. As Pennsylvania residents with a scholarly and applied interest in gerontology, we have followed the development of the proposed regulations closely. Our remarks are based on our interpretation of the regulations, our knowledge of long term care and assisted living, and our research findings.

We support the comments and recommendations submitted by the Pennsylvania Assisted Living Consumer Alliance, and we submit these additional comments for your consideration. We, like PALCA, appreciate that the Department of Public Welfare has invested significant energy and time to take these first steps to improve the care provided to seniors who reside in assisted living; however, we also believe that the proposed regulations do not go far enough towards the promise of quality care and much work needs to be done to insure that consumers will have the information they need to make informed choices about the purchase of assisted living services for themselves or family members.

Although there are numerous issues we could raise, we are confining our comments in this letter to three major categories that we believe are critical to the future of safe, quality assisted living care in Pennsylvania:

- **Ethics in assisted living**
- **Marketing assisted living**
- **Training and credentials of assisted living staff**

Two of these are absent from the proposed regulations; the words “ethics” and “marketing” are never used. While the proposed regulations contain detailed language regarding training and credentials of assisted living staff, we believe they do not adequately insure the competent and safe delivery of care to frail Pennsylvania seniors. We support PALCA’s detailed analysis and suggestions for changes in this area. We offer more specific comments for each of these categories below.

ETHICS IN ASSISTED LIVING

FORMAL ATTENTION TO ETHICS IS ABSENT FROM THE PROPOSED REGULATIONS. We are concerned that the regulations do not address ethics in a systematic way and our research suggests that neither the industry nor providers have policies or procedures in place to manage ethically challenging situations that involve residents or staff. Because residents of AL facilities are a vulnerable population, there is even more reason to establish, by regulation, requirements for providers to incorporate ethics into their organizational structures and policies, initial and ongoing training, orientation programs, and facility handbooks. Formal mechanisms, such as codes of ethics and ethics committees can support decision making by residents, family members, and AL staff who encounter ethically problematic situations. Codes of ethics provide behavioral guidelines for action when an ethically challenging situation arises. Ethics committees allow for formal, careful consideration of these situations by individuals who bring diverse perspectives to the problem.

Formal attention to ethics is necessary in any organization; however, because AL cares for cognitively impaired clients through the “special care” designation, and as providers deliver complex health care services to increasingly needy residents when they receive waivers to provide “supplemental health care services,” it is incumbent upon Pennsylvania regulators to mandate added protections through formal attention to ethics. Sustained attention to ethics cannot be left to the individual administrator at a facility; rather, it must permeate the facility’s culture and achieving this requires formal policies and procedures that are explicit in the Department’s regulations. If the industry, providers, and regulators fail to address the question of ethics in assisted living, seniors residing in these facilities are placed at greater risk.

MARKETING ASSISTED LIVING

PROPOSED REGULATIONS DO NOT CONTAIN ANY LANGUAGE RELATED TO PROVIDER RESPONSIBILITIES TO EDUCATE CONSUMERS ABOUT ASSISTED LIVING OR TO ETHICAL MARKETING PRACTICES.

The regulations describe assisted living as a type of long term care; however, the industry continues to position itself as a residential living, rather than a long term care arrangement. A fundamental assumption of a consumer-driven market, such as assisted living, is that consumers can obtain needed information to make informed decisions about the purchase of the good or service. In long term care generally, and assisted living specifically, substantial evidence shows that consumers do not have the information they need to make informed buying decisions. In addition, consumers rely heavily on information provided by assisted living providers through advertising, facility brochures and other marketing materials, and industry trade associations. No consensus or data exist as to what constitutes “quality” in assisted living and consequently consumers cannot compare facility performance. There is no standardization in the industry due to differences in state regulations, and the decision by consumers to move to assisted living is typically made in a crisis situation with little time to investigate available options. In addition, the vast majority of consumers must pay for assisted living—where costs are substantial and rising—with private resources. Finally, the consumers of assisted living services are frail, vulnerable elders.

The proposed regulations do not address providers’ responsibilities to fully disclose to consumers all of the information they need to make an informed choice. Although residents are required to be given a resident handbook at the time of application for admission, essential content of that handbook is not specified. A handbook could provide a convenient and useful mechanism for educating consumers and disclosing to them, in easy-to-understand language, the information that they need to make informed choices. If such a handbook were available online in a searchable format, it would be easily accessible to consumers. We offer the following additional comments related to marketing practices in assisted living:

- Eliminating this consumer information gap is even more important because the proposed regulations do not include a clear or standardized definition of “assisted living.” Further, the regulations do not include precise definitions that distinguish assisted living from personal care or even from skilled nursing facilities. Confusion about these terms is likely to further increase because both PCHs and ALs are administered by the Department of Public Welfare and PCHs are the historical root of assisted living in Pennsylvania.
- One of the intentions of Senate Bill 704 was to reduce consumer confusion and help seniors and their families to make educated decisions about their own care. We do not believe that the proposed regulations achieve this goal, and in fact consumers are likely to be even more confused if the regulations are implemented in their present form.

- The original model of assisted living was not intended to care for frail or sick elders. As the industry has evolved, delivery of health care services has been increasingly demanded and delivered and the regulations pursuant to SB 704 reflect this reality. However, the regulations fail to explicitly acknowledge that assisted living providers have become and will continue to be health care providers, and as such, should be subject to the oversight and requirements of other health care providers. Consumers must understand how (or if) assisted living providers differ from other health care providers, including skilled nursing facilities. They must also understand how care in assisted living will differ from care received in other health care settings.
- Consumers will not be able to make meaningful comparisons and informed choices about the differences among facilities and their service offerings and capabilities. The following are but a few of the areas where consumer confusion will continue, and even increase, unless the regulations include guidelines for marketing practices by assisted living providers.
 - ✓ What does self administration of medication mean?
 - ✓ Will consumers understand their rights regarding choices about the sources and costs of medication?
 - ✓ Will consumers understand the meaning of the “special care designation” and what that licensing designation means in terms of what facilities can and cannot offer, and how and in what physical arrangement services to cognitively impaired residents will be delivered?
 - ✓ How will consumers be educated about informed consent – what it is and how it will be implemented? The imbalance of power between the facility and the resident results in fertile ground for ethical violations. The language of the regulations currently suggests that cognitively impaired residents are more protected than non-cognitively impaired residents, yet both categories of residents are in need of advocacy.
 - ✓ What must facilities disclose in their marketing materials (before a prospective resident reaches the contract stage) about products, services, policies, and procedures? Proposed regulations stipulate the potential residents or their designated person be provided with specific written disclosures; however, this list is limited and disclosures will only occur upon the potential resident’s application for residency.
 - ✓ The potential for consumer confusion is high in many areas, but especially informed consent, financial management, pricing structures and changes, transfer and discharge, third party providers, timetable for assessments and support plan development and modifications, and contracts. Consumers should have access to

easy-to-understand materials that help them make an informed choice before they apply for residency at a specific facility, especially because having such information is likely to influence the choice of the facility where they actually submit an application.

- ✓ How will the Department insure that the term “assisted living” will not be used by any person, organization, or program that does not meet the requirements for an assisted living license, and what are the sanctions for using this term when the provider is not a licensed assisted living facility?

TRAINING AND CREDENTIALS OF ASSISTED LIVING STAFF

THOSE WHO DELIVER CARE AND HEALTH CARE IN ASSISTED LIVING MUST HAVE APPROPRIATE TRAINING AND CREDENTIALS TO INSURE COMPETENCE AND RESIDENT SAFETY.

If the primary distinguishing characteristic of assisted living facilities is the availability of health care and their ability to deliver it (either directly or via a contractual arrangement), then staff training and credentials must be equivalent to those required in other health care facilities where such care is delivered in order to insure competent delivery of care and resident and staff safety.

- The proposed regulations confer significant discretion on the provider to make decisions about quantity and quality of staff, and adopt the direct care staff qualifications and training required currently of personal care home staff despite differences between assisted living and personal care homes, and the greater care needs that are often characteristic of assisted living residents. In addition, providers retain discretion in the area of annual training for direct care staff and the Department requires no periodic reporting or assessment of learning beyond internal record keeping by the provider.
- Qualifications of administrators remain largely at the discretion of the provider due to the “menu” approach of possible ways to satisfy requirements to be an AL administrator. No requirements are stated for the qualifications of third party providers.
- Given the persuasive often-referenced evidence from the Institute of Medicine, medication errors should be of significant concern to the Department and providers; however, proposed regulations do little to minimize the probability of medication errors in assisted living, and make no provision for reporting of errors to the Department.
- The authorization for delivery of “supplemental health care services” makes assisted living facilities in effect medical facilities; however, regulations do not adequately address policies and procedures related to regular reporting requirements, procedures, and medical records in the areas of incident reports, training, oversight of supplemental health care delivery, admission decisions, assessments, screening, care and support plans, medication errors, etc.

We join the Department of Public Welfare as advocates of current and future residents of assisted living. We believe that the proposed regulations represent a first step because they establish a separate licensure category for assisted living. With the modifications we propose, along with those recommended by the Pennsylvania Assisted Living Consumer Alliance, Pennsylvania has a unique opportunity to take the lead among states in proactive oversight of this important sector in the long term care marketplace.

Finally, we hope that, once approved, the Department of Public Welfare and the Office of Long Term Living will develop and implement a comprehensive, state-wide education program that informs consumers about the changes that will result from these regulations.

We encourage you to reflect on these comments and those of PALCA and other advocates of quality care and consumer protection as you work toward making assisted living in Pennsylvania a model of ethical, quality care. We look forward to your response.

Respectfully submitted,

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