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September 15, 2008

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

Reference Regulation No. 14-514

Dear Ms. Weidman:

The Pennsylvania Association of Rehabilitation Facilities (PARF) appreciates the opportunity to comment on regulations proposed by the Pennsylvania Department of Public Welfare on the licensing of assisted living residences.

In the August 16 Pennsylvania Bulletin, the PA Department of Public Welfare offered a correction to its proposed rulemaking on Assisted Living Residences. DPW added information to the public comment section of the preamble to the rulemaking which appeared at 38 Pennsylvania Bulletin 4459, 4460 (August 9, 2008). DPW invited interested persons to submit written comments, suggestions or objections regarding the proposed rulemaking to the Department.

PARF represents more than one hundred organizations in Pennsylvania providing medical and vocational services and community supports for people with disabilities. Many people are served by member organizations in programs that are operated as residential services programs.

Listed below are a series of comments and questions about proposed regulations that define and regulate residences that are defined as assisted living facilities.

We appreciate the opportunity to comment on the proposed regulations.

Sincerely,

Gene Bianco President/CEO

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Pennsylvania Association of Rehabilitation Facilities

Comments on Proposed Regulations by Pennsylvania Department of Public Welfare on Licensing of Assisted Living Residences

> Volume 38 Pennsylvania Bulletin August 9, 2008 August 16, 2008

> Reference Regulation No. 14-514

Comments Submitted September 15, 2008

SUMMARY

The Pennsylvania Association of Rehabilitation Facilities appreciates the opportunity to comment on regulations proposed by the Department of Public Welfare on the licensing of assisted living residences. PARF represents more than one hundred organizations in Pennsylvania providing medical and vocational services and community supports for people with disabilities. Many people are served by member organizations in programs that are operated as residential services programs.

Listed below are a series of comments and questions about proposed regulations that define and regulate residences that are defined as "assisted living facilities."

The proposed regulations should be revised. The proposed regulations present two (2) major problems for many facilities that are currently licensed as personal care homes and that offer head injury rehabilitation services as well as support services to people with cognitive disabilities.

First, the proposed regulations do not clearly state the circumstances under which a residence must apply for licensure as an assisted living facility. The proposed regulations are not clear as to which facilities must apply for licensure as assisted living residences. The regulations do not clearly indicate if a residence that is maintaining a licensure as a personal care home and offering home and community based services to people with disabilities to improve their functioning must obtain licensure as an assisted living residence. The regulations do not clearly state that all facilities providing housing and support services to people with enhancing or improving cognitive skills must apply for a license as an assisted living facility in order to continue providing services.

Without a clear statement, the intent of the Department is not clear. The specific terms that are utilized in the proposed regulations suggest that assisted living residences serve primarily those people with degenerative neurological conditions. The proposed regulations also state that people served in assisted living facilities receive services so that they may age in place. It seems that the regulations would not apply to those residences that are not serving aging people with degenerative conditions. However, the regulations also use general phrases and terms and state that people with cognitive disabilities other than dementia residing in the facility and receiving services are subject to the regulations.

Second, the assisted living regulations should not be applied to facilities that do not conform to the type of program that could be more properly and effectively regulated under the personal care home regulations. Such facilities should not be regulated under Act 56. If the Department maintains that regulations will be applied to residences offering head injury services, the Department will cause people with cognitive disabilities to be ill-served or harmed. This would run counter to the intent of Act 56.

Our comments below identify those provisions (a) that are unnecessary, (b) that present risk to the health and well-being of the resident, and (c) that misdirect the resources of the state.

Our concern is that the regulations would allow many people with cognitive disabilities to be placed in programs that will not serve them and may in fact diminish their capacity. This is contrary to the intention of the legislature in its passage of Act 56.

We are also concerned that the regulations applied to head injury programs offered in programs currently licensed as personal care home will cause public resources to be misapplied or squandered. In some cases, the proposed regulations would require facilities to incur costs that may cause facilities to fail and so reduce the number of community programs that stand as an alternative to institutional care.

The comments offered below address the specific provisions of the rules and our recommended changes.

REQUIREMENTS

COMMENT 1:

Regarding a residence that (a) is currently licensed as a personal care boarding home, (b) provides housing and support services, (c) serves people with cognitive disabilities, and (d) is not identified as an assisted living residence, the regulations do not clearly state whether or not such a residence is required to apply for licensure as an assisted living facility. In addition, the responsibility of facilities to apply for licensure is not clearly described.

The regulations should indicate clearly (a) if the application for licensure as an assisted living facility is voluntary (i.e., the facility elects to obtain a license in order to use the term "assisted living facility" in describing its services) or (b) if applying for licensure as an assisted living facility is mandatory (i.e., the facility must apply for licensure if it provides "a combination of housing and supportive services, as needed, and...designed to allow people to age in place, maintain their independence and exercise decision-making and personal choice.") Although certain statements in the discussion of requirements suggest that the application for licensure is mandatory, the statements on the fiscal impact of the proposed regulation suggests that application for licensure is voluntary: "It is assumed that those facilities that choose to apply for assisted living residence licensure will already comply with the facility structural requirements of the proposed regulations, so no costs are assumed for structural modifications." The regulations should also indicate clearly the duties of a facility if the facility serves people that qualify for home and community based services under Medicaid waivers. The regulations should clearly state the legal requirements that the facility must fulfill in assessing whether or not it must apply for licensure.

GENERAL PROVISIONS

COMMENT 2: The regulation (§ 2800.1. Purpose) indicates that the purpose of the assisted living facility is to allow individuals to age in place: (a). The purpose of this chapter is to protect the health, safety and well-being of assisted living residents. (b) Assisted living residences are a significant long-term care alternative to allow individuals to age in place. Residents who live in assisted living residences that meet the requirements in this chapter will receive the assistance they need to age in place and develop and maintain maximum independence, self-determination and personal choice. Many residences whose objective is to assist individuals to "return to community" may fit some of the terms of the general description of assisted living facilities but not other significant parts of the general description. The program of services that is provided in the residence may be accredited by national accrediting bodies as programs of rehabilitation and community support. The services that they offer may also be provided through state and federal programs focused on developing skills for independent living. These residences do not fit the terms used to describe assisted living facilities. The assisted living regulations should clearly establish that such programs are subject to personal care home regulations and not subject to assisted living regulations.

COMMENT 3: The regulations (§ 2800.2. Scope) do not refer to individuals with cognitive deficits other than dementia who are served efficiently by rehabilitation-focused programs providing education, training, and skills improvement. These facilities are currently served under personal care home regulations and offer services under contract with Pennsylvania state agencies. The assisted living regulations should clearly establish that such programs are subject to personal care home regulations and not subject to assisted living regulations.

- (a) This chapter applies to assisted living residences as defined in this chapter, and contains the minimum requirements that shall be met to obtain a license to operate an assisted living residence.
- (b) This chapter does not apply to personal care homes, domiciliary care homes, independent living communities or commercial boarding residences.

DEFINITIONS

In the section on Definitions, the definition of Assisted Living Residence states that premises in which those individuals requiring assistance in activities of daily living and receiving health care services reside are assisted living centers. In the definition below currently licensed personal care homes that are the site of brain injury programs certified by CARF and contracting with state agencies seem to be subject to the regulations.

Assisted living residence or residence--Any premises in which food, shelter, personal care, assistance or supervision and supplemental health care services are provided for a period exceeding 24-hours for four or more adults who are not relatives of the operator, who require assistance or supervision in matters such as dressing, bathing, diet, financial management, evacuation from the residence in the event of an emergency or medication prescribed for self-administration.

COMMENT 4: Cognitive Support Services. The definition of cognitive support services focuses the regulations upon dementia-related services as the target of the regulations. The regulations need to establish the boundaries of the regulations more clearly so that programs that are not related to dementia and degenerative neurological conditions are clearly exempt.

COMMENT 5: Dementia – The inclusion of a definition of dementia and the lack of a definition of acquired brain injury suggests that the assisted living regulations do not apply to brain injury rehabilitation programs currently operating in personal care homes.

Dementia--A clinical syndrome characterized by a decline of long duration in mental function in an alert individual. Symptoms of dementia may include memory loss, personality change, chronic wandering and the loss or diminishing of other cognitive abilities, such as learning ability, judgment, comprehension, attention and orientation to time and place and to oneself.

COMMENT 6: Informed Consent Agreement – Definition of the informed consent agreement requires further elaboration in order to clarify how the agreement would be crafted with individuals with brain injury.

COMMENT 7: Long Term Care Ombudsman – The inclusion of this definition and the protective services unit suggests that the scope of the regulation is limited to services for individuals defined by the need for care related to age and not to type of limitation/disability/handicap. The regulations should clearly establish how the application of the regulations is affected by the individuals served.

Long-term care ombudsman--A representative of the Office of the State Long-Term Care Ombudsman in the Department of Aging who investigates and seeks to resolve complaints made by or on behalf of individuals who are 60 years of age or older who are consumers of long-term care services. These complaints may relate to action, inaction or decisions of providers of long-term care services, of public agencies, of social service agencies or their representatives, which may adversely affect the health, safety, well-being or rights of these consumers.

Here the inclusion of this definition suggests that brain injury programs are to be subject of the regulations related to special care designation.

SECTIONS

COMMENT 8: 2800.20 - Financial Management. The regulation on financial management needs to be fine-tuned to the situation of individuals with brain injury in waiver programs providing assistance for cognitive limitations related to brain injury.

§ 2800.20 Financial Management (a) A resident may manage his personal finances unless he has a guardian of his estate.

COMMENT 9: § 2800.25. Resident-residence Contract (f) – The reference to long term care reinforces the focus on aging-related services.

(f) The residence may not require or permit a resident to assign assets to the residence in return for a life care contract/guarantee. A life care contract/guarantee is an agreement between the legal entity and the resident that the legal entity will provide care to the resident for the duration of the resident's life. Continuing care communities that have obtained a Certificate of Authority from the Insurance Department and have provided a copy of the certificate to the Department are exempt from this requirement.

COMMENT 10: The section § 2800.27 – SSI Recipients does not reflect fiscal circumstances of individuals supported by the Department of Health and Department of Public Welfare programs. The section needs to address the terms of support under DOH and DPW programs supporting residential services.

COMMENT 11: The regulations § 2800.30 – Informed Consent Process should address the role of the supports personnel that may be provided through public programs. The regulations should also indicate if updates are affected only by the change in the resident's condition.

COMMENT 12: The regulations (d) – Informed Consent Meeting should indicate what types of measures will be used to evaluate the capacity of the individual to enter into informed consent agreements.

COMMENT 13: In § 2800.53 – Qualifications and Responsibilities of Administrators, there are no requirements that administrators obtain specific education or training in the behavior and needs of people with cognitive limitations other than education and training related to credentials required to qualify.

COMMENT 14: The rule on administrator staffing - § 2800.56. Administrator Staffing related to on-site presence of the administrator is expected to result in an average of 40 hours a week. The time required in satisfying the new off-site training requirements and the time that would be required to provide for vacation, holiday and sick time of personnel would make it necessary for a residence to employ and train an individual to serve as an additional administrator. The purpose of the additional staffing is not clear. The individual's administrative service would only be needed intermittently and would add to costs unnecessarily.

COMMENT 15: The section § 2800.57. - Direct Care Staffing describes the key provisions for staffing. The regulations on age of personnel should conform to the Medicaid waiver requirements. Staffing requirements should conform to accreditation standards when facilities maintain accreditation.

COMMENT 16: The requirement for an on-call nurse at all times - § 2800.60. Additional Staffing Based on the Needs of the Residents - is for a high acuity setting, but residences serving higher functioning individuals with less pressing medical needs will be required to assume the cost with little to no benefit to the individual. Additional staffing should be based on the acuity of the need.

COMMENT 17: Regulations on Direct Care Staff Person Training - § 2800.65. Direct Care Staff Person Training and Orientation - should be developed in accord with the experience of the assisted living programs to recruit and maintain staff.

COMMENT 18: The proposed regulations - § 2800.101 Resident living units — establish structure requirements that existing personal care residences may not be able to satisfy. The minimum square footage for floor space (2800.101b) and the individual kitchen and hardware requirements (2800.101d) for residential units are greater than the size of living area space currently needed in offering rehabilitative care. The requirement for notification devices (2800.101r) (2800.1021n) in the living units and bathrooms may be beneficial to the high acuity or aged population. However, residences in which individuals are involved in a rehabilitation program may not require this amount of space.

(a) A residence shall provide a resident with the resident's own living unit unless the conditions of subsection (c) are met.
(b)(1) For new construction of residences after (Editor's Note: The blank refers to the effective date of adoption of this proposed rulemaking.), each living unit for a single resident must have at least 250 square feet of floor space measured wall-to-wall, excluding bathrooms and closet space. If two residents share a living unit, there must be an additional 80 square feet in the living unit.
(2) For residences in existence prior to (Editor's Note: The blank refers to the effective date of adoption of this proposed rulemaking.), each living unit must have at least 175 square feet measured wall to wall, excluding bathrooms and closet space. If two residents share a living unit, there must be an additional 80 square feet in the living unit.
(d) Kitchen capacity requirements are as follows:
(1) New construction. For new construction of residences after (Editor's Note: The blank refers to the effective date of adoption of this proposed rulemaking.), the kitchen capacity, at a minimum, must contain a small refrigerator with a freezer compartment, a cabinet for food storage, a small bar-type sink with hot and cold running water and space with electrical outlets suitable for small cooking appliances such as a microwave oven. The cooking appliances shall be designed so that they can be disconnected and removed for resident safety or if the resident chooses not to have cooking capability in his living unit.
(2) Existing facilities. Facilities that convert to residences after (Editor's Note: The blank refers to the effective date of adoption of this proposed rulemaking.), must meet the following requirements related to kitchen capacity:
(r) Each living unit must be equipped with an emergency notification system to

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notify staff in the event of an emergency.

COMMENT 19: The regulations regarding special care units are designed for care of individuals with dementia. However, the terminology used in the section on special care units would allow individuals with cognitive disabilities other than dementia to be served within the dementia program. See Section 2800.231.g. This provision seems to conflict with 2800.231.d. The participation of an individual without dementia in the dementia program should be justified through documentation. Regulations should require that individuals are to be served according to specific needs. The regulations should support provisions of § 2800.234 - Resident care.

COMMENT 20: The proposed regulation § 2800.236. Training requires specific trainings on dementia. However individuals with dementia may or may not be served by a residence. Under both the Chapter 2600 regulations and under the new proposed regulations there is a stipulation for trainings to be delivered any time a new population is served. This regulation should suffice. It seems that the regulation is already in place requiring training and orientation on the new population to be served.

COMMENT 21: In § 2800.237 – Program the description of the program does not reflect many aspects of cognitive therapy rehabilitation services. The regulations are not appropriate to those existing programs operating under personal care home licensure that offer head injury services to people with cognitive disabilities who are progressing and improving cognitive function for living in the community – with or without supports.