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August 13, 2008

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

RE: Comments on Proposed Assisted Living Regulations

Dear Ms. Weidman,

Thank you for this opportunity to comment on the Proposed Assisted Living Regulations.

I am pleased that the proposed regulations for assisted living facilities include a designation for severe cognitive impairment and I am interested in confirmation that this designation can be used to create specific facilities for those with severe cognitive impairment due to brain injury. Currently, there are only two alternatives for this population - jail/prison or a mental/forensic unit - neither of which are designed to provide brain injury rehabilitation or support designed for this condition. Judges, parents, and guardians have nowhere to send these individuals so that they can receive the care that they need - so this is a marvellous opportunity, if I am understanding the proposed regulations properly. [**DEPARTMENT OF PUBLIC WELFARE [55 PA. CODE CH. 2800] Assisted Living Residences § 2800.4. Definitions. The following words and terms, when used in this chapter, have the following meanings, unless the context clearly indicates otherwise:** ***page 4464 Special care designation*—A licensed assisted living residence or a distinct part of the residence which is specifically designated by the Department as capable of providing cognitive support services to residents with severe cognitive impairments, including dementia or Alzheimer's disease, in the least restrictive manner to ensure the safety of the resident and others in the residence while maintaining the resident's ability to age in place.]**

Unfortunately, Section 2800.231 Admission regarding facilities with special care designation is not congruent with the definition of special care designation. The definition includes those with severe cognitive impairments, including dementia or Alzheimer's - rather than restricting the units to those with Alzheimer's disease or other dementia. Brain injury may result in severe cognitive impairment, but it is not a form of dementia (though it predisposes to Alzheimer's and dementia) because it is due to an injury and there is generally improvement, even after severe impairment. Clearly the state has every incentive to include and rehabilitate those with severe cognitive impairment due to brain injury as they will otherwise be served elsewhere at public expense with perhaps less access to federal reimbursement (prison, homeless services). **[§2800.231. Admission. (a) This section and §§ 2800.232—2800.239 apply to special care units. These provisions are in addition to the other provisions of this chapter. A special care unit is a residence or portion of a residence that provides specialized care and services for residents with Alzheimer's disease or other dementia in the least restrictive manner consistent with the resident's support plan to ensure the PROPOSED RULEMAKING 4489 PENNSYLVANIA BULLETIN, VOL. 38, NO. 32, AUGUST 9, 2008 safety of the resident and others in the residence while maintaining the resident's ability to age in place. Admission of a resident to a special care unit shall be in consultation with the resident's family or designated person. Prior to admission into a special care unit, other service options that may be available to a resident shall be considered.]**

I am very happy that resident services will include cognitive support services **[§ 2800.220. Assisted living residence services. (d) *Cognitive support services.* The residence shall provide cognitive support services to residents who require such services, whether in a special care unit or elsewhere in the residence.]** - because the deficits of those with brain injury lie along a continuum of mildly noticeable to severely incapacitating. Those with mild or moderate problems will need cognitive assistance for some activities while only those with severe problems will need a facility with a special care designation. HOWEVER - while all facilities are require to provide cognitive support, cognitive support services are later described as including dementia-capable programing and crisis management, while not being clear whether this is for all facilities or those with a special care designation. **[*Cognitive support services*—(i) Services provided to an individual who has memory impairments and other cognitive problems which significantly interfere with his ability to carry out ADLs without assistance and who requires that supervision, monitoring and programming be available 24 hours per day, 7 days per week, in order to reside safely in the setting of his choice. (ii) The term includes assessment, health support services and a full range of dementia-capable activity programming and crisis management.]**

I am hoping that the initial training for staff in all facilities will include brain injury - as those over 85 are at a peak age for brain injury events, and they have a higher mortality rate from brain injury than those in the other two peaks. I was glad to see that staff in a facility with the special care designation will be properly trained to meet the needs of the residents depending on their diagnosis. If they accept individuals with brain injury, there must be requirements for training as brain injury is very different from any other condition. **[§ 2800.65. Direct care staff person training and orientation. (3) Initial direct care staff person training to include the following: (i) Safe management techniques. (ii) Assisting with ADLs and IADLs. (iii)**

Personal hygiene. (iv) Care of residents with mental illness, neurological impairments, mental retardation and other mental disabilities. (v) The normal aging-cognitive (f) Training topics for the annual training for direct care staff persons must include the following: (1) Medication self-administration training. (2) Instruction on meeting the needs of the residents as described in the preadmission screening ....assessment tool, medical evaluation and support plan. (3) Care for residents with dementia and cognitive impairments. (4) Infection control]

Because of the high incidence of brain injury among seniors, the initial and annual assessment must include questions about brain injury (a validated screening instrument to assure accurate and complete information). Seniors are at high risk but are often ignored and the changes in function are labeled as the normal effects of aging, thus preventing rehabilitation. Where there is evidence of a brain injury, a neuropsychological evaluation and treatment planning must occur. This treatment plan would be incorporated into the support plan of the resident. If needed, services could be provided at the residence or in a day program to promote recovery. Seniors are eligible for the CommCare Waiver and the Head Injury Program, neither of which specify a treatment location or contain a residential requirement. This is an important issue because of the high rate of brain injury in seniors and because there is generally no other source of funding for brain injury rehabilitation - currently brain injury rehabilitation is not provided under Medicare or Medicaid. **[§ 2800.225. Initial and annual assessment. (a) A resident shall have a written initial assessment that is documented on the Department's assessment form within 15 days of admission. The administrator or designee, or licensed practical nurse, under the supervision of a registered nurse, may complete the initial assessment.]**

While special arrangements are required for more than one resident of a room, two residents per room are permitted without any special arrangements in a facility with a special care designation. I am very concerned about the safety risk of two per room. Those with dementia or Alzheimer's or brain injury must be carefully evaluated for the risk to a roommate - and generally the rule should be single rooms unless there are special circumstances which are documented. **[§ 2800.232. Environmental protection. (b) No more than two residents may occupy a living unit regardless of its size. A living unit shall meet the requirement in § 2800.101 (relating to resident living units), as applicable.]**

Along the same lines, the provisions for kitchen equipment must be modified for special care designated facilities, as microwaves, stove tops, and other heating applicances should not be accessible. **[(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: (i) The residence shall provide a small refrigerator in each living unit. (ii) The residence shall provide a microwave oven in each living unit. (iii) The residence shall provide access to a sink for dishes, a stovetop for hot food preparation and a food preparation area in a common area. A common resident kitchen may not include the kitchen used by the residence staff for the preparation of resident or employee meals, or the storage of goods.]

Safety concerns in facilities with a special care designation would also exclude firearms **[§ 2800.108. Firearms and weapons. (a) A residence shall have a written policy regarding firearms.]**, heating stoves **[(c) Wood and coal burning stoves must be securely screened or equipped with protective guards while in use.]** and fireplaces **[§ 2800.129. Fireplaces. (a) A fireplace must be securely screened or equipped with protective guards while in use.]**

While the regulations mention advocates and guardians, many with brain injury have no one interested in filling this role for them or their relatives do not have the money to pay for a guardianship. Since those with significant impairment due to brain injury are not competent to make any decisions themselves, the regulations should include measures to more easily secure a guardianship, including a set of standards for an organization to contract with the state to provide guardianship for individuals in this situation. Those with brain injury are commonly taken advantage of and also lack the capacity to pursue rehabilitative options on their own.

There are also a few general issues.

The regulation on indoor activity space is contradictory and/or not clear. While the combined areas must accommodate all residents, this clearly will not happen when 50 units would require 15 square feet per living area or 750 square feet, and 51 units or more are limited to a combined total of 750 square feet of living/lounge areas. **[§ 2800.98. Indoor activity space. (b) The residence shall have at least one furnished living room or lounge area for residents, their families and visitors. The combined living room or lounge areas must accommodate all residents at one time. There must be at least 15 square feet per living unit for up to 50 living units. There must be a total of 750 square feet if there are more than 50 living units. These rooms or areas must contain tables, chairs and lighting to accommodate the residents, their families and visitors.]**

Regarding Exit signs in case of fire, smoke rises. Smoke will obscure common Exit signs which are up in the air - so additional signs are needed at floor level. In addition, large topographically raised letters specifying EXIT should be located on the interior side of the actual doors that are to be used, at both eye level and floor level. Within three days, I participated in three live evacuations from the fifth floor of the same hotel and signage led to a great deal of confusion. **[§ 2800.133. Exit signs.The following requirements apply for a residence serving nine or more residents: (1) Signs bearing the word "EXIT" in plain legible letters shall be placed at all exits. (2) Access to exits shall be marked with readily visible signs**

indicating the direction to travel. (3) Exit sign letters must be at least 6 inches in height with the principal strokes of letters at least 3/4 inch wide.]

And, finally, since New York City considers trans fats/hydrogenated oils too dangerous for human consumption, it is appropriate for Pennsylvania to protect those in assisted living by prohibiting the inclusion of this non-food consumable in edibles supplied by assisted living facilities. **[§ 2800.162. Meals].**

Thank you for this opportunity to comment on these proposed regulations.

Regards,

Barbara A. Dively
Executive Director

cc: Arthur Coccodrilli, Chairman
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