



**National  
Multiple Sclerosis  
Society**  
Pennsylvania Chapter  
Advocacy Network

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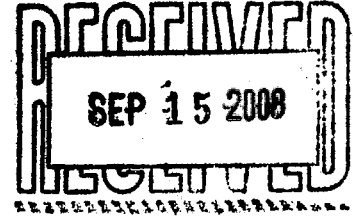
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INDEPENDENT REGULATORY  
REVIEW COMMISSION



September 15, 2008

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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 St, 14th Floor  
Harrisburg, PA 17101

**Central Pennsylvania  
Chapter**  
2040 Linglestown Rd.  
Suite 104  
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Re: Comments on Proposed Assisted Living Regulations #14-514

Dear Ms. Weidman and Chairman Coccodrilli:

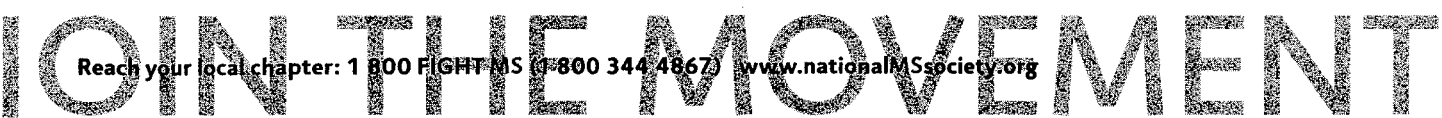
**Greater Delaware  
Valley Chapter**  
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I am writing on behalf of the Pennsylvania chapters of the National Multiple Sclerosis Society to comment on proposed Assisted Living regulations # 14-514. The three chapters, Allegheny District, Central Pennsylvania and Greater Delaware Valley, represent more than 19,000 people living with MS throughout the state. Since MS is a disease that affects the entire family, however, we estimate the representation to be several times that.

The National Multiple Sclerosis Society has long been concerned about the needs of people with multiple sclerosis for quality, accessible, affordable, and comprehensive long-term living services. Due to the chronic, often disabling nature of the disease, approximately 20% to 25% of individuals with MS need long-term care at some point during the course of their illness. As a result, we support the rebalancing of the long term living system to provide more in-home services as well as the development of quality long term living residential alternatives for those who choose to live outside their homes. Assisted living, if properly regulated, can offer that quality alternative.

A number of provisions in the proposed regulations offer the promise of a quality alternative and must serve as a minimum for regulating assisted living facilities. Others fall short and must be improved.

Specifically, the following sections of the regulations are positive. The sections which must, at a minimum be maintained are those which:





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- Establish licensure fees that are meaningful and potentially sufficient to fund the licensure and oversight and relocation efforts of the Department, as required by Act 56. 2800.11
- Require fire safety approval to be renewed every 3 years. 2800.14
- Limit the number of regulatory provisions that a facility could seek to have waived. 2800.19
- Provide for some important pre-admission disclosures that facilities will have to make to potential residents. 2800.22(b)
- Add a requirement that the person who manages and controls the operations of the facility have prior experience in the health or human services field. 2800.53
- Require the facility to at all times be under the supervision of a person who is trained in how to operate and manage the facility. 2800.56
- Require a nurse to be on call 24 hours a day and a dietician to be involved in meal planning for residents whose support plans call for special diets. 2800.60
- Call for air conditioning for the entire facility. This is particularly important to people, like those with MS, who are heat-sensitive. 2800.83
- Require all stairs to have strips to help ensure safe evacuation for those with vision impairments. Again, this is important to those with MS who have low vision. 2800.94
- Require facilities to have 250 square feet of living space for new construction. We do not, however, believe that the 175 square foot minimum for existing facilities is sufficient. It is difficult to see how 175 square feet can provide sufficient space for those who use wheelchairs. 2800.101
- Require living units to have kitchenettes with counter space, cabinet, microwave, fridge, and access to a sink. 2800.101
- Require facilities to disclose their policies about pets and whether pets are already in the facility. We would, however, recommend that the allowance for service animals be explicitly included. 2800.109
- Require smoke detectors in each living unit. 2800.129
- Require that access to all exits be marked with readily visible signs indicating the direction to travel. 2800.133
- Require assistance with meals and cueing for meals for residents who need it. 2800.162.
- Require vehicles which transport residents to be accessible to those who use wheelchairs and other devices. 2800.171
- Require facilities to obtain medications prescribed for residents and to maintain an adequate supply of the residents' medications on site. 2800.185
- Require residences to provide cognitive support services to all of those who need it, not only those in special care units. 2800.220



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- Require a written explanation for denial of residency and referral to an agency which can assess the person for appropriate services. 2800.224
- Require a nurse to review and approve the support plan. 2800.227
- Mandate that a facility must ensure that residents who are discharged will have their medications, durable medical equipment, and personal belongings go with them. 2800.228
- Require tracking of admissions and discharges and transfers by the facility – including those involving excludable conditions. 2800.228 and 2800.229
- Adopt a good standard for when an exception to the excludable conditions prohibitions should be granted. 2800.229

The sections noted above represent improvements over the current personal care home regulations which serve as a base for these assisted living regulations. These improvements are crucial in light of the fact that assisted living facilities can serve those with more severe disabilities and conditions. The following provisions fail to provide adequate standards in compliance with Act 56 and must be improved.

- As previously noted, the provision (2800.101) on bedroom size for existing facilities—175 square feet—is inadequate. Someone in a wheelchair could not negotiate that space. 225 square feet should be the minimum size. Similarly a provision must be added requiring that all hallways and common areas be wheelchair accessible.
- Section 2800.142 is far too restrictive in terms of choice of provider. It should not limit choice of pharmacy or physician. To the extent possible, it should allow people to continue with providers with whom they have a history. At a minimum, the section must be rewritten to provide, “The resident has the right to choose all healthcare providers. To the extent prominently displayed in the written admission agreement, a residence may require residents to use providers of supplemental health care services approved or designated by the residence.”
- Section 2800.225 fails to provide for assessments until 15 days after the person is admitted to the facility. This should be amended to require that the assessment be completed prior to admission, except in specified circumstances, such as in urgent cases of hospital discharges.
- Language must be added providing for appeal rights, particularly in cases of discharge and also for marketing protections. We also would recommend that the regulations include a process—a public process-- for obtaining waivers of the regulations.

We recognize that there will be a cost to implement the regulations as amended. Yet the failure to provide the needed protections and quality of care will be far costlier in human terms. No facility is forced to get into the business of assisted living and thus to comply with these regulations. By setting the bar where it should be we offer vulnerable Pennsylvanians the quality, home-like environment that they deserve.



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We are supportive of more detailed concerns and recommendations in the comments filed by the Pennsylvania Assisted Living Consumer Alliance (PALCA).

Thank you for considering our comments on this important matter.

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Sincerely,

Jennifer Strayer  
National Multiple Sclerosis Society  
Public Policy Manger

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