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National Multiple Sclerosis Society Pennsylvania Chapter Advocacy Network

July 23, 2009

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INDEPENDENT REGULATORY REVIEW COMMISSION

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Office of Long Term Living Via email at: RA-assistedliving@state.pa.us

Central Pennsylvania Chapter 2040 Linglestown Rd. Suite 104 Harrisburg, PA 17110 tel+ 1 717 652 2108 nationalMSsociety.org/pac

To the Office of Long Term Living:

The Pennsylvania Chapters of the National MS Society are submitting our comments below on the interim draft 2800 Regulations for Assisted Living Facilities. The three Pennsylvania Chapters; Central Pennsylvania, Greater Delaware Valley, and Western Pennsylvania, represent more than 24,000 individuals living with multiple sclerosis throughout the state. Since multiple sclerosis is a disease that affects the entire family, we estimate the representation to be closer to 57,000 Pennsylvanians.

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The National MS 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 disease, approximately 20% of individuals living with multiple sclerosis require 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 alternatives for those who chose to live outside of their home. Assisted living, if properly regulated, can offer that quality alternative.

The original proposed regulations included provisions described in our earlier comments which would move us closer to a quality alternative. However, the National MS Society commented on portions of the regulations which fell short of protecting the consumer and needed to be improved to ensure the rights, quality of life and safety of the consumer were being preserved.

Having reviewed the interim draft of the regulations we again see a number of positive provisions which should be maintained in the final regulations. These include provisions which:

- Require assessments and support plans to be completed prior to admission, when possible, outlining the care needs of the new resident and plans for addressing them
Require the support plan to be included in the resident's contract
Define the core benefits package. This allows the consumer the opportunity to compare facilities and make an informed decision on which facility would better suit their needs.

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- Carefully explain dual licensure; when a facility can be both an assisted living facility and another type of facility.
- Adopt critical training topics for administrators and direct care staff.

Although there were some positive improvements to the interim regulations, some important areas still need to be revised to better protect the consumer. We encourage the Department to revisit the areas outlined below and consider the following changes:

- The facility should not be able to control all health care providers used by the resident. Those living with multiple sclerosis have built relationships with their physicians which should not be severed when a resident moves from their home to a facility that is to feel like their home. We urge the Department to seek amendment to the limiting statutory language at section 1057.3 (a)12 of Act 56 and in the interim to adopt in these regulations less restrictive language which is not inconsistent with the current law, such as amending section 2800.142(b)(i), to read "The residence shall permit a resident to select or retain his primary care physician. The resident has the right to choose all health care providers except 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 2800.142)
- All common areas and hallways in facilities must be accessible. The interim draft only requires that at least two indoor activity rooms and hallways be wheelchair accessible. Residents who require the use of a wheelchair should not be restricted to certain areas of the building. We urge the Department to require that all hallways and common areas in the facility be accessible for all residents. (Section 2800.98)
- The interim draft regulations require all new construction be at least 225 square feet, and existing construction be only 175 square feet. We feel the room size should be 225 square feet for all existing facilities as well. A room that is only 175 square feet would be inaccessible for a resident in a wheelchair. They would have difficulty maneuvering throughout the room, and would be forced to wait for assistance to transfer to and from the bed. We urge the Department to increase the room size to 225 square feet in both new and existing facilities. (Section 2800.101)
- In the original draft of the regulations and in the interim draft no provisions were made to allow service animals. Service animals give individuals an opportunity to maintain their independence. Federal law does require facilities to allow service animals, however the resident is responsible for challenging the facility. We urge the Department to require the acceptance of service animals and save consumers the difficulty of contesting this portion of the regulations upon the admission to a facility. (Section 2800.109)

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- The interim draft does not provide for an appeals process when a resident is being discharged. The facility is required to give the resident 30-days notice. However, we urge the Department to add an appeals process to the final regulations. Residents should be afforded the right to appeal the decision of the facility before being forced to leave their home. (Section 2800.228)

We recognize that there will be a cost to implement the regulations as amended. Yet 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.

We are supportive of the 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.

Sincerely,

Margie Adelman
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National MS Society

John Scott
Chapter President
Greater Delaware Valley Chapter
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Colleen McGuire
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