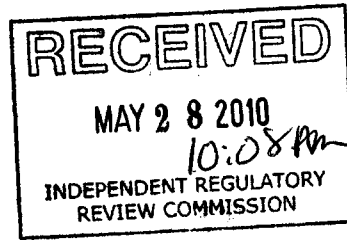




**National  
Multiple Sclerosis  
Society**  
Pennsylvania Chapter  
Advocacy Network

2712



May 27, 2010

**Western Pennsylvania  
Chapter**  
1501 Reedsdale Street  
Suite 105  
Pittsburgh, PA 15233  
tel+ 1 412 261 6347  
nationalMSsociety.org/pax

Independent Regulatory Review Commission  
333 Market Street, 14<sup>th</sup> Floor  
Harrisburg, PA, 17101

RE: Regulation ID # 12-514 (IRRC #2712)  
Department of Public Welfare  
Assistive Living Residences

**Central Pennsylvania  
Chapter**  
2040 Linglestown Rd.  
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Harrisburg, PA 17110  
tel+ 1 717 652 2108  
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We are writing on behalf of the Pennsylvania chapters of the National MS Society to comment on the final-form 2800 Regulations for Assistive Living Facilities. The three chapters, Western Pennsylvania, Central Pennsylvania and Greater Delaware Valley, represent more than 25,000 individuals living with MS throughout the state. Since MS is a disease that affects the entire family, we estimate our actual representation to be several times that number.

**Greater Delaware  
Valley Chapter**  
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The National MS Society has long been concerned about people with multiple sclerosis' need for high-quality, accessible, affordable and comprehensive long-term living services. Due to the chronic, often-disabling nature of this disease, approximately 20% of individuals living with MS 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 high-quality long-term living alternatives for those who choose to live outside of their homes. Assisted living, if properly regulated, can offer that quality alternative.

After careful review of the final-form 2800 Regulations for Assistive Living Facilities, we ask the IRRC to reject the regulations as they stand. The Office of Long Term Living has made some improvements to the regulations and we applaud them for their efforts. However, we feel that we cannot support the regulations in their final form. We believe that several provisions will be harmful to consumers who choose assisted living in order to age in place, as the statute intends.

The following provisions fail to provide adequate standards and are the reasons that we ask the IRRC to reject the regulations as they currently stand.

- **Section 2800.142: Supplemental Health Care Services**  
This section of the regulations currently allows a residence to limit a resident's choice of supplemental health care providers. The residence would be allowed to decide which neurologists, psychiatrists, physical therapists and a number of other medical specialists see patients. Those living with multiple sclerosis have built relationships with their physicians and specialists which should not be severed when they move from their home to a facility that is supposed to feel like home.
- **Section 2800.101: Resident Living Units**  
The room size requirements are inadequate. The final-form regulations reduced the size of rooms in existing facilities from 175 to 160 square feet. An individual in a



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wheelchair will not be able to negotiate that space properly, causing them to be confined to their chair or bed until a direct-care worker can help them transfer.

Similarly new construction was reduced from 250 to 225 square feet. Furthermore the regulations provide for exceptions to room size minimums for new and existing facilities, so the rooms could wind up being even smaller. The regulations also fail to articulate grounds on which the department will consider exceptions. The possibility of confining people in impassable space is of great concern to us.

- Section 2800.228: Transfer Discharge  
Currently, a 30-day written notice must be provided to the residents when they are being involuntarily discharged. However, there is no appeals process included in the final-form regulations. The resident should have the opportunity to appeal the decision that is removing them from their home-like setting.
- Section 2800.30 Informed Consent Process  
The final-form regulations remove the “imminent risk” and “substantial harm” tests for informed consent, allowing the residence to start the process whenever they perceive that there is a risk for harm to a competent resident, other residents or staff. This test is too expansive. An individual living with MS could have only temporary difficulty walking due to an exacerbation of their disease, and this could force them to pay for extensive and expensive care that they may not need.
- Section 2800.131 Fire Safety  
The every-room requirement for fire extinguishers was replaced with one on each floor and every 3,000 square feet in walkways and common areas. This change is a safety concern because residents are now permitted to have kitchens in their units. This change makes it essential that all units have a fire extinguisher for safety reasons.
- Section 2800.98 Indoor Activity Space  
The regulations only require two wheelchair-accessible indoor activity rooms and hallways. Residents who require the use of a wheelchair should not be restricted to certain areas of the building. A provision should have been included to require that all common areas be wheelchair accessible in new and existing construction.

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. By setting the bar where it should be, we offer vulnerable Pennsylvanians the quality, home-like environment that they deserve.

Thank you for considering our comments and our recommendation to reject the final-form regulations as they currently stand. If you require any additional information, please do not hesitate to contact Jennifer Strayer, State-Wide Public Policy Manger for the National MS Society. She can be reached at (717) 652-2108 or by e-mail at [Jennifer.Strayer@nmss.org](mailto:Jennifer.Strayer@nmss.org).



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Sincerely,

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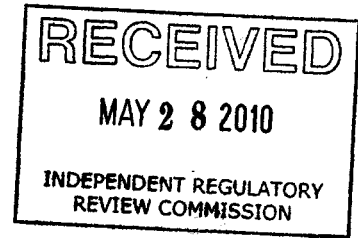
Tami Caesar  
President  
Greater Delaware Valley Chapter  
National MS Society

CC: Representative Phyllis Mundy, Chair, House Aging and Older Adult Services Committee  
Members of the House Aging and Older Adult Services Committee  
Senator Pat Vance, Chair, Senate Health and Public Welfare Committee  
Members of the Senate Health and Public Welfare Committee  
Honorable Harriet Dichter, Secretary, Department of Public Welfare  
Honorable Michael Hall, Secretary, Department of Aging

Cooper, Kathy

2712

**From:** Jennifer Strayer [Jennifer.Strayer@nmss.org]  
**Sent:** Friday, May 28, 2010 9:57 AM  
**To:** IRRC  
**Cc:** Smith, James M.; Jewett, John H.  
**Subject:** 2800 Regulations for Assistive Living Facilities  
**Attachments:** 2800 Final Form AL Regulations\_Comments.pdf  
  
**Importance:** High



Hello,

Attached you will find the comments from the PA Chapters of the National MS Society. If you require any additional information or have any questions please feel free to contact me.

Thank you.

Sincerely,  
Jennifer

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**Jennifer Strayer**  
Public Policy Manager

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