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Independent Regulatory Review Commission  
Public Meeting  
2800 Regulations for Assistive Living Facilities  
Testimony of Jennifer Strayer  
PA Chapters of the National MS Society  
June 3, 2010

Good morning. Members of the Independent Regulatory Review Commission, I am here today representing the PA Chapters of the National MS Society and the 25,000 individuals living with multiple sclerosis and their families. Thank you for giving me the opportunity to testify about the final-form Regulations for Assistive Living Facilities.

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 IRRRC 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 National MS Society has submitted written comments detailing our concerns on sections that we had hoped would have been addressed by the time the regulations reached final

form. Unfortunately these provisions were not addressed. The final form regulations do not go far enough in creating a home-like setting where individuals may age in place. The critical issues that are not addressed include:

- **Supplemental Health Care Services:** Resident's should be allowed to select their own supplemental health care providers. The regulations currently allow the residence to decide which neurologists, psychiatrists, physical therapists and a number of other medical specialists see patients. Every case of multiple sclerosis is different. The symptoms, frequency of the symptoms, and the severity of the disease all differ on a case by case basis. No case of MS is the same and it takes a specialist and a patient working together to pinpoint the best way to manage the symptoms. Individuals living with MS have built relationships with the physicians and specialists which should not be severed when they move from their home to a facility that is supposed to feel like home.
- **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 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.
- **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. Residents should be provided with the right and process to challenge a facilities decision to kick them out as well as with the process to excess their appeal rights.
- **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 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.

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

Thank you for the opportunity to address our concerns with you today.

Respectfully Submitted,

Jennifer Strayer

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PA Chapters of the National MS Society