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Written Testimony

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of the PA Public Policy Coalition of the Alzheimer's Association

House Aging & Older Adult Services Committee
Public Hearing on Assisted Living Regulations

Thursday, September 18, 2008 at 9:30am
Main Capitol, Room 418

INTRODUCTION

Good morning, ladies and gentlemen, and honorable members of the House Aging & Older Adult Services Committee. I extend sincere thanks to Chairwoman Phyllis Mundy and Chairman Tim Hennessey for convening this hearing on a very important subject, and for inviting our organization to represent consumers affected by Alzheimer's disease and related dementias on today's panel. My name is Michelle Seitzer, and I serve as the Public Policy Coordinator for the Pennsylvania Public Policy Coalition, representing the two state chapters of the Alzheimer's Association. Prior to serving in this capacity, I spent nine years as both a volunteer and an employee of several assisted living facilities in Pennsylvania and Maryland. As I reflect on those years and the people I served, I am honored to be here to speak on this issue today.

The Alzheimer's Association seeks to provide care, support, awareness, education, and advocacy for those afflicted by Alzheimer's disease and related dementias – which likely includes nearly 400,000 people currently living with these conditions in Pennsylvania and hundreds of thousands more who are caring for them, from spouses to adult children, neighbors and direct care staff.

Alzheimer's disease and related disorders are a complex and challenging spectrum of diseases, thereby requiring unique and detailed provisions both to protect consumers in residential facilities and to ensure that quality care is provided therein. Given this critical need, we would also like to recognize Representative Katharine Watson for championing the inclusion of her dementia-specific amendments into Senate Bill 704. Her amendments made passage of the legislation especially meaningful for our consumers and advocates and established a strong foundation for working through the regulatory process on these issues.

Thank you again for your leadership and for the opportunity to outline the priorities of the Pennsylvania Public Policy Coalition. We are grateful that the regulations "move the bar forward" for dementia-specific care in the state's long-term-care continuum.

BACKGROUND

Several national studies estimate that 60% or more of assisted living consumers have some type of dementia or cognitive impairment (of which Alzheimer's is the most common type).[1] This data, coupled with the high percentage of seniors living in the Commonwealth, strengthened our belief that dementia-capable services should be available in all units/levels of care in an assisted living residence.

As the disease progresses, so does the need for more specialized care. Therefore, if a facility markets itself as a provider of Alzheimer's care services, whether within the context of a Special Care Unit (SCU) or throughout the facility, we believe that clear standards for providing such care is crucial.

While the Personal Care Home regulations for Secured Dementia Units addressed some key components (i.e. admission requirements, staff training, and environmental protections), they do not go far enough for this newest license designation. Our appointment to the Assisted Living Regulations Workgroup allowed us to bring to the table what we believe the top priorities in caring for consumers with Alzheimer's or related dementias must be.

Those charged with crafting regulatory language have the unenviable task of creating standards that strike the difficult balance of providing quality care and ensuring access to that care. With so many complex issues on the table and an even broader range of opinions on those issues, we sought to keep that challenge of balance in mind throughout the entire process.

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[1] *People with Alzheimer's Disease & Dementia in Assisted Living*, Alzheimer's Association Advocacy & Public Policy Division, October 2004

PRIORITY 1: TRAINING

Adequately trained staff in adequate numbers continues to be our primary concern. It is also the concern addressed by most constituents with whom we interact. Therefore, we believe that **training should be augmented beyond the 2600 provisions**. Dementia often presents difficult and challenging behaviors and such conditions absolutely demand specialized, comprehensive, and continuing education. We believe that an investment in training will provide the skills, empowerment and support needed to maintain a higher retention rate of direct care workers, while ensuring the protection of and highest quality of care to vulnerable residents.

We affirm that basic **dementia training and awareness among all facility staff must be required**. The direct care worker may not always be the first or only staff member to interact with a resident inside/outside of the Special Care Unit (SCU). Dietary staff members who serve daily meals may witness changes in a resident's condition if trained to look for the warning signs. The housekeeper who cleans a resident's room on a weekly basis could be a valuable resource for revision of a resident's care plan/assessment (both for residents in the SCU or in the general population). Therefore, the following list highlights what we consider to be a necessary minimum standard for preparing a quality workforce:

Dementia-Specific Training Recommendations[2]

- At least 8 hours of training within 30 days of hire for all nurses, CNAs and direct care staff assigned to the SCU and a minimum of 8 additional hours of annual continuing education
- At least 4 hours of training within 30 days of hire for all other staff (including administrators) and 2 hours of annual continuing education
- New hire training topics must include: An Overview of Alzheimer's Disease & Related Dementias, Managing Challenging Behaviors, Effective Communication, Assistance with ADLs, and Creating a Safe Environment
- A monitoring mechanism to ensure compliance, such as a CNA registry
- Portability of completed training among employment sectors
- A formal certification of training programs by the lead state agency for licensing (or its designate, i.e. the Alzheimer's Association)

We will continue to advocate for increased educational opportunities for all staff, specifically those in the SCU, to meet the dynamic challenges that Alzheimer's disease presents. We also encourage assisted living residences to offer these opportunities in various formats (i.e. peer mentoring, workshops, and in-services) to effectively equip their employees in the delivery of exceptional care.

We are gratified that the current proposed regulations include our training recommendations, which enhance the levels outlined in the current personal care home regulations. However, it is important to note that the proposed Pennsylvania requirements are still less robust than such diverse states as Illinois, Arkansas, and North Carolina, where up to 40 hours of annual dementia-specific training is required.

PRIORITY 2: STAFFING LEVELS

Preventing staff burnout is another key component of providing quality dementia-specific care. No matter how much training a direct care worker has completed, a high level of patience is required in the care of individuals with AD/dementia. For example, many who suffer from the disease will repeat themselves numerous times throughout an employee's 8-hour shift. While specialized training will provide the direct care worker with strategies and tools for redirection and dealing with these and other trying manifestations of the disease, there may be times when an employee needs to step away from the situation and take a few minutes to regroup. It is crucial that adequate levels of staffing are in place so that the direct care worker can take this needed break.

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[2] *Quality Care Campaign Review* , Alzheimer's Association Advocacy & Public Policy Division, 2006

Since Alzheimer's progresses in different timeframes for different people, there may be a distinction in a Special Care Unit between "higher-functioning" residents and those who have more limited capabilities. Therefore, **staffing patterns must appropriately meet the varying levels of care needed** by the consumers as they move through the stages of dementia. Continual (and well-documented) revision of the care plan assessment is a key measure that supports aging in place and affirms that the individual is receiving the care he/she needs.

Research and practice models also indicate that **ADLs often take longer for a person with AD/dementia**, and individuals will need various levels of cueing and support to complete their daily tasks in a way that maintains their independence and dignity. The spouse of a consumer in a Northwestern PA dementia unit shared that 2 staff members are assigned to feed 30 residents. Because a person with dementia often needs constant cueing and assistance in order to eat, this coverage is likely not sufficient to meet that need.

PRIORITY 3: DISCLOSURE

As Alzheimer's advances, the individual's **care needs intensify, requiring more complex strategies for intervention**. A husband and wife residing in a dementia unit in South-central PA were separated when his Alzheimer's advanced beyond the facility's ability to meet his care needs. Another consumer with Alzheimer's in the same region had been labeled combative during a hospital stay; as a result, the family had difficulty placing her in an appropriate care facility.

We are sensitive to the difficult balancing acts that providers must face daily, weighing risk/liability factors with the goal of providing quality service to all residents. However, in both of the above cases, there seemed to be a lack of clarity regarding what symptoms of AD the care facility was prepared to address. Education/training, continual assessment of the care plan in regards to the resident's needs, and more detailed disclosure requirements might have been helpful in discerning whether a different approach to care could have met the need (or avoided a harmful label), rather than recommending a new level of care be provided in a completely different setting.

We also believe that cognitive support services that would be provided in the general population as part of the core/supplemental services package should include at least the following:

1. *Appropriate cueing where needed as it relates to hygiene, meals and ADLs/IADLs*
2. *Assistance with self-administration of medication or medication administration*
3. *Measures to address wandering*
4. *Dementia-specific activity programming (There is a directive in the statute to provide dementia-specific activity programming as part of "cognitive support services" for the entire facility.)*
5. *Specialized communication techniques*

The proposed regulations do provide for more detailed disclosure for special care designation, for which we are grateful. Some clarification is still needed in regards to what services are offered to consumers in the general population. However, we affirm it is absolutely critical that consumers of assisted living facilities, particularly pursuing residence in a Special Care Unit, to have a clear understanding of what specialized services will be provided there.

CONCLUSION

Thank you again for this opportunity to speak on behalf of the nearly 400,000 Pennsylvanians with Alzheimer's or related dementias, many of whom are currently living in these facilities. We hope that the Commonwealth will move forward with these regulations and ensure that they are properly and adequately enforced. In a rapidly aging state such as ours, this is indeed a step forward that is long overdue. We offer our support to agency officials and members of the Legislature, and we are always available to advise on any issues pertaining to constituents affected by Alzheimer's and related dementias in the Commonwealth.