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Better Services for Better Aging

October 6, 2015

To: Representative Mike Rohrkaste, Chair
Members, Speaker's Task Force on Alzheimer's and Dementia

From: John Sauer, President/CEO, LeadingAge Wisconsin

Subject: LeadingAge Wisconsin Testimony Regarding Dementia Redesign and Services

Thank you for today's opportunity to discuss Alzheimer's disease and other dementia-related issues. I have the honor of serving as the President/CEO of LeadingAge Wisconsin and in this capacity have been involved in policy and program issues for older adults and persons with a disability for over twenty-five years. LeadingAge Wisconsin is a statewide membership association of not-for-profit organizations principally serving older adults and persons with a disability. Membership is comprised of 190 religious, fraternal, private and governmental organizations which own, operate and/or sponsor 185 nursing homes, 6 intermediate care facilities for the intellectually disabled (ICF-ID), 182 assisted living facilities, 114 apartment complexes for seniors, and over 300 community service agencies which provide programs ranging from Alzheimer's support, adult and child day care, home health, home care, and hospice to Meals on Wheels. LeadingAge Wisconsin members employ over 38,000 individuals who provide compassionate care and service to over 48,000 residents/tenants/clients each day.

In October 2013, the Department of Health Services (DHS) convened a Dementia Care Stakeholder Summit that brought together thirty-three key stakeholders with diverse perspectives to identify concrete ways DHS and its partners could work together to make Wisconsin more "dementia capable" and to identify priorities.[1] As a participant of the Summit, I had the opportunity to learn from a field of experts and help build strategies to improve our care and service delivery system for older adults. Subsequent to the Summit, the DHS released its report, Wisconsin Dementia Care System Redesign Plan. It is this report that triggered intensive activities on the part of DHS, advocates, counties, law enforcement, the provider community and others to aid in the effort to

[1] "Redesigning Wisconsin's Dementia Care System: A Stakeholder's Report," DHS, October 1-2, 2013, www.dhs.wisconsin.gov/publications/p0/p00563.pdf.

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create a redesigned dementia care system. Through these efforts (and as noted in your Task Force meeting on September 16, 2015), much has been accomplished since the release of the *Redesign Plan*. Community forums have been held, educational programs developed, *Music and Memory* implemented (in over 250 nursing homes and countless assisted living facilities), training and certification (standard and advanced) programs launched and the number of dementia specialists expanded.[2]

Collectively, these efforts are making a difference and should be applauded.

I would like to focus my limited time today on two dementia care-related issues that desperately need further review and consideration by DHS, the Legislature and the Governor. They are: (1) The need for regional dementia crisis units; and, relatedly, (2) The need to address the legal aspects related to the *Helen E.F.* Wisconsin Supreme Court decision. These issues also will be addressed by the following speakers who served on the Legislative Council Special Committee on Legal Interventions for Persons With Alzheimer's Disease and Related Dementia.[3]

Regional Dementia Care Crisis Units

The aforementioned Dementia Care Stakeholder Summit produced the following "top priorities... to provide a starting point for further discussion, investigation, and planning that will lead to further actions by the Department of Health Services and its partners to make a 'dementia-capable' Wisconsin a reality."[4]

1. Increase community awareness of dementia issues and of the resources available to provide support to individuals with dementia and their family caregivers.
2. Expand the use of dementia care specialists and case managers to coordinate care, help with transitions, and work with individuals and their families throughout the disease process.
3. ***Revise state regulations to allow for "safe harbors" that let facilities care for residents who engage in challenging behaviors in place with less fear of liability or regulatory penalties.***
4. ***Create fiscal and systemic incentives for best practices.***

[2] LeadingAge Wisconsin has sponsored numerous dementia educational and training sessions before and after the Summit. The Association has been instrumental in the development of the Wisconsin Clinical Resource Center, https://wcrc.chsra.wisc.edu/, which includes modules on dementia and challenging behaviors. The Association and the WHCA has endorsed and sponsored the *CARES* online dementia care training programs and the Alzheimer's Association *essentiALZ* individual certification program, www.leadingagewi.org/media/28919/CARES-Online-Dementia-Care-Training.docx.

[3] Joint Legislative Council's Report of the Special Committee on Legal Interventions for Persons With Alzheimer's Disease and Related Dementias, January 10, 2014 http://lc.legis.wisconsin.gov/media/1175/jlcr_13_08.pdf

[4] "Redesigning Wisconsin's Dementia Care System: A Stakeholder's Report," DHS, October 1-2, 2013, www.dhs.wisconsin.gov/publications/p0/p00563.pdf, Page 1.

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5. Expand mobile crisis teams to assess and diffuse difficult situations and help avoid the need for restrictive placements.
6. ***Create placement facility capacity to care for people with complex and challenging behavior needs.*** (emphasis added)

Of the top priorities identified at the Stakeholder Summit, Priorities 3, 4, and 6 directly relate to the need for specialized facilities (dementia crisis units) to serve persons in need of intensive dementia-related care and for whom stabilization in a less intensive environment is no longer a viable option. The identification of these priorities likely was not a surprise to any of the Summit participants. Several months prior to the Summit, the Legislative Council Special Committee proposed legislation that, among other changes, would have required "each county department to designate at least one location as a dementia crisis unit for the purpose of emergency and temporary protective placement for behavioral or psychiatric evaluation, diagnosis, services, or treatment of individuals with dementia."[5]

Dementia crisis units would be highly staffed (often providing 1:1 staffing ratios[6]) and resourced facilities (likely nursing facility or community-based residential facilities, or CBRFs) specifically reserved for persons with dementia exhibiting unmanageable behaviors. Often these individuals are relatively young (55 to 79 years old) and present a significant danger to themselves or others. To be clear, persons in need of a dementia crisis unit are not representative of the vast majority of the population with Alzheimer's disease or other forms of dementia. We estimate that at any given time perhaps 1-3% of the persons with dementia who are nursing home eligible fit into this category. For these individuals, efforts to stabilize their situation at home or in long-term care facilities have not worked; frequently, encounters with injuries have occurred and strategies to counter the manifestations of their dementia have repeatedly failed.

How are persons with dementia who exhibit unmanageable behaviors addressed in the current system? The options are not well developed or uniformly available. In some regions, psychiatric facilities remain willing to accept short-term admissions. Several county nursing homes have stepped up and serve as the safety net for these individuals, incurring significant operating losses in doing so. In addition, local hospital representatives have noted, with obvious alarm, an increasing number of persons with dementia are living in the hospital for weeks or months at a time because no alternative, appropriate placement is available. In one community alone, we are aware of approximately 16 individuals living in hospitals due to lack of alternative placements.

Because regional dementia crisis units have not been established, other nursing homes and CBRFs remain reluctant to serve persons with significant behavioral challenges. As recognized by the Summit participants, the punitive nature of the nursing home survey

[5]Joint Legislative Council's Report of the Special Committee on Legal Interventions for Persons With Alzheimer's Disease and Related Dementias, January 10, 2014, http://lc.legis.wisconsin.gov/media/1175/jlcr_13_08.pdf, Page 3.

[6] Legislative Council Special Committee on Legal Interventions for Persons With Alzheimer's Disease and Related Dementias: Testimony of Mark Radmer, Administrator, Harbor Haven Health and Rehabilitation, July 31, 2012.

system has a chilling effect on providers' decision to admit or retain residents with behavioral challenges. The lack of a regulatory "safe harbor" and the absence of a care and services safety net that would be provided by dementia crisis units mean most facilities are unwilling to assume added safety and liability risks associated with serving this population. These facilities have an obligation to protect their residents and staff and are often unwilling to "take a chance" by admitting or retaining a resident with extreme behavioral challenges.

In addition, the current system does not provide any true fiscal incentives for providers to serve persons with extreme behavioral challenges. In 2013-14, nursing facilities incurred Medicaid losses of over $329,151,095; facilities, on average, lost $52.11* per day for each Medicaid resident they serve. For the average Wisconsin nursing home, that results in an annual loss of $1,074,400* to provide care to its Medicaid residents.[7] Further, this year's Medicaid nursing home rates will be cut by $1.26 per resident day because the State Budget failed to fund the projected increase in resident acuity.

We should acknowledge the Medicaid nursing home payment system does include a "Behavioral and Cognitive Impairment Challenges Incentive" add-on to a facility's daily resident rate. To be clear, however, the current add-on for residents with dementia and behavioral challenges, representing about $0.28 per resident day, does not begin to constitute an incentive payment; it merely offers an extremely modest add-on payment based on certain resident characteristics and diagnoses. LeadingAge Wisconsin supports the recommendation to make this add-on payment an actual incentive payment and examine ways to more effectively recognize the costs associated with caring for persons with complex medical and behavioral needs.

To be succinct, we agree with this statement included in the DHS Dementia Redesign Plan:

> "Providing quality care costs money. This strategy looks to develop a closer relationship between the care provided and the reimbursement they receive through the State's Medicaid program." [8]

This leads to my brief comments on proposed statutory changes.

Legal Considerations/Chapter 51 and 55 Changes

Within many of the provider and advocacy communities, the need to establish and fund dementia crisis units is clear. In responding to the DHS Dementia Redesign Plan, the Dementia Subcommittee of the State Long-Term Care Council noted, "We believe more attention must be given to potential statutory changes necessary to ensure persons in immediate crisis have access to providers capable of addressing the behavioral

[7] Fact Sheet: The Underfunding of Nursing Facility Resident Care, LeadingAge Wisconsin, www.leadingagewi.org/media/21824/2014-MALossFactLAW.pdf, February 23, 2015.
[8] "Wisconsin Dementia Care System Redesign Plan: A Plan for a Dementia Capable System," DHS, www.dhs.wisconsin.gov/publications/p0/p00586.pdf, February 2014, page 23.

challenges sometimes exhibited by persons with dementia. These changes likely involve revisions to Chapters 51 and /or 55. We believe further discussion of the concept of 'safe harbors' for nursing facilities or assisted living facilities will be needed as the Plan progresses."[9]

As you know, the Legislative Special Committee recommended amending current law to enable persons with dementia and behavioral challenges to receive the necessary care and services in an appropriate setting. As noted above, one of the top priorities indentified at the Stakeholder Summit was to create placement facility capacity to care for people with complex and challenging behavior needs. My observation is that this placement capacity will not be created unless additional funding is provided and the statutes are clarified as to how persons with dementia and behavioral challenges should appropriately enter the system.

For the most part, the Association's position on the need for a funding and statutory solution remains unchanged since it commented on the DHS Redesign Plan in January 2014:

> "LeadingAge Wisconsin supports many of the strategies identified under Section 5.3 (pages 28-30), particularly as they related to crisis intervention and mobile response capabilities. However, we believe the Plan lacks a clear focus on the designation and role of facilities intended to serve persons with behavioral challenges. LeadingAge Wisconsin urges DHS to reexamine its position on the legislation (2013 Assembly Bill 575) proposed by Legislative Council Special Committee on Legal Interventions for Persons with Alzheimer's Disease and Related Dementias. From our members' perspective, the need for this legislation will not be negated by the recommendations advanced by the DHS Plan, even if parties work to 'clarify Chapter 55 provisions' or 'address inconsistencies among counties.' In short, the Plan must directly address situations that can only be described as an immediate and certain crisis for which no amount of training, certification or education can negate."[10]

Thank you for the opportunity to offer testimony on this important issue.

[9] Dementia Subcommittee Input on DHS Dementia Capable Plan, Dementia Subcommittee of the State Long-Term Care Council, www.leadingagewi.org/files/demsubcom.pdf, January 10, 2014.
[10] LeadingAge Wisconsin Comments on 2014 DHS Dementia Capable Plan, Submitted to DHS Secretary Kitty Rhoades, January 13, 2014, www.leadingagewi.org/files/dhsdementia.pdf, page 5.