LeadingAge™ Wisconsin

Better Services for Better Aging

January 13, 2014

Secretary Kitty Rhoades
Department of Health Services, Room 650
1 West Wilson St.
Madison, WI 53703

Subject: LeadingAge Wisconsin's Comments on the Wisconsin Dementia Care System Redesign

Dear Secretary Rhoades:

LeadingAge Wisconsin applauds the work of the Department of Health Services (DHS) to redesign the State's long term services and supports system as it relates to persons with dementia. Our Association also appreciates the opportunities provided to its staff and members to directly contribute to this important redesign effort and we look forward to continuing this dialogue with you and your staff.

As requested, the following provides the Association's initial comments on the DHS report, *Wisconsin Dementia Care System Redesign: A Plan for a Dementia-Capable Wisconsin.* In addition, we have submitted these comments via the DHS electronic survey provided to stakeholders on January 2, 2014. Our comments are centered on the Plan's **Section 5.0**, found on pages 13-38.

5.0 A Dementia Agenda for Wisconsin—LeadingAge Wisconsin's Comments and Observations

The Association generally supports efforts to strengthen and expand the resources and assistance available from the ADRCs, including creating greater access to the Dementia Care Specialist Program and consumer information via the ADRC web page. We suggest this section be further expanded to include efforts to better connect and educate persons/families about: (1) the public and private financial resources available to address the needs of persons with dementia and; (2) the level of personal responsibility that may be required to access certain care or service options.

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We do have immediate concerns regarding provisions found in **Section 5.1.1** on pages 14-15 calling for an increase in the capability and capacity of the Managed Care Organizations (MCO) to provide dementia-capable services. The Plan states, "The Department will work with the MCOs to develop dementia care skills, including skills needed to prevent situations involving challenging behaviors from escalating to a crisis level." Since the MCOs do not provide direct care and services to persons with dementia, the provider community is concerned that the MCOs will be compelled to add additional dementia-related requirements to their MCO-Provider contracts and these additional requirements will come without a concomitant increase in provider payments. We will address this concern below as we offer comments on the Plan's "voluntary training and certification requirements" discussed under **Section 5.4** on pages 31-36.

The Association makes special note and support of provisions found on page 15 calling for continued work on developing and testing enhancements to the Long Term Care Functional Screen. Our hope is that these efforts will lead to both recognition of the costs associated with caring for persons with dementia and higher payments to the provider community.

LeadingAge Wisconsin members wish to take exception with a provision found in **Section 5.1.3** on page 17: "In cases of degenerative diseases such as Alzheimer's, caregiver stress increases as the disease progresses. If a caregiver does not understand the disease trajectory, or has not been taught techniques to deal with their loved one's difficult behaviors, then caregiver depression and physical illness can result. It is not uncommon for a spousal caregiver to become seriously ill or die before the person with dementia dies, which leaves the person with dementia no alternative other than to be admitted to a nursing home. Programs to support family caregivers can significantly delay the need for institutional care and reduce costs to the Medicaid program."

While LeadingAge Wisconsin fully support efforts to serve people at the right time, right place and right cost, we submit that the above quoted paragraph unfairly depicts facility-based providers a part of the problem, not part of the solution. On behalf of the membership's nursing facilities, we suggest amending the report to state, "…..to become seriously ill or die before the person with dementia dies, <u>often resulting in a crisis as family and friends are forced to make sometimes uninformed and costly decisions regarding appropriate ongoing care and service options</u> ~~which leaves the person with dementia no alternative other than to be admitted to a nursing home. Programs to support family caregivers can significantly delay the need for institutional care and reduce costs to the Medicaid program.~~"

As one might expect, LeadingAge Wisconsin has a few comments to offer regarding **Section 5.2**, Facility-Based Long-Care. **Section 5.2.1** on pages 20-21 appears to be an attempt to address one of the top priorities indentified during the Dementia Care Stakeholder Summit in early October 2013. The Stakeholder report said the system should, "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." Instead of recognizing this priority as a legitimate concern, the Plan attempts to minimize the gravity of providers' regulatory concerns by suggesting the root of the problem is "the home did not properly assess the resident and implement the plan of care or did not re-evaluate the care plan after the resident became aggressive." This conclusion completely misses the mark.

The Plan's proposed limited review of nursing home immediate jeopardy (IJ) citations as a way to assess the need for safe harbors fails to account for a significant and growing number of "Level G -D citations" and, perhaps more significantly, the chilling effect the overall punitive nature of survey system has on providers' decision to admit or retain residents with behavioral challenges. It is well known that the Wisconsin nursing home regulatory environment and DQA's reliance on punitive measures imposes a standard unlike that in place for nearly all other States (This fact is documented by CMS citing statistics found at: www.leadingagewi.org/sites/default/files/reg5top10.pdf).

LeadingAge Wisconsin submits the DHS offer to seek federal regulatory flexibility regarding the imposition of IJ cites for incidents related to residents with behavioral challenges might be worth the effort although it is likely to be unsuccessful, particularly given CMS' history of unbending adherence to its historical positions (page 21). However, the Association also believes that DQA has significant regulatory flexibility in determining the level of both severity and scope of certain incidents and suggests a review of the DQA citing practices would be more productive than discussions with CMS. We also note the success of the WCCEAL program in promoting an effective assisted living quality improvement system over a punitive regulatory system. {Note: LeadingAge Wisconsin strongly endorses the Department's support of the WCRC and WCCEAL and recommends DHS work to sustain these efforts.}

In addition to the providers' regulatory concerns in serving persons with significant behavioral challenges, the Plan also needs to be amended to include references to the separate but related obstacles provides face when deciding to admit or retain residents with significant behavioral challenges. They include: Lack of adequate payments from the Medicaid fee-for-service and Family Care programs and the resulting impact on staffing levels (e.g., www.leadingagewi.org/sites/default/files/iplosses.pdf); The impact such residents may have on the quality of care and life for other residents; Lack of a readily available short and long-term placement options if the resident's behavioral challenges escalates to a level far beyond the facility's capabilities to address; and potential legal actions that may be brought against the provider community.

LeadingAge Wisconsin supports DHS efforts to promote best practices and resource tools developed by the provider community, consultants, educators and others. In doing so, we suggest DHS become familiar with the Wisconsin Clinical Resource Centers and other collaborative work being accomplished by MetaStar, the trade associations, advocates and others (e.g., efforts to reduce the use of antipsychotic medications in nursing homes and Interact training). As additional best practice resources and tools

are developed or refined, we recommend that DQA's nursing home and assisted living surveyors appropriately inform providers of this information.

Section 5.2.2 (pages 23-24) includes several strategies related to dementia training and certificate programs. However, it is worth noting that a highly regarded training program and toolkit already exists for nursing homes. Federal law requires CMS to ensure that nurse aides receive regular training on caring for residents with dementia and on preventing abuse. CMS, supported by a team of training developers and subject matters experts, created the *Hand in Hand* program to address the need for nurse aides' annual in-service training on these important topics. The mission of the *Hand in Hand* training is to provide nursing homes with a high-quality training program that emphasizes person-centered care in the care of persons with dementia and the prevention of abuse (see: www.cms-handinhandtoolkit.info/).

The majority of our comments on training and certificate programs will be included in our remarks on Section 5.4 (pages 31-36). ***As noted by our comments on Section 5.4, the Association does not support the morphing of best practice guidelines into mandated requirements.***

The Plan calls for an exploration of "incentives for facilities that adopt best or promising practices and show positive outcomes." LeadingAge Wisconsin fully supports the Plan's statements that:

> "Providing quality care cost money. This strategy looks to develop a closer relationship between the care provided and the reimbursement they receive through the State's Medicaid program." {**Section 5.22**, page 24}

Our hope is that the above DHS statement will be made applicable not only as it relates to serving persons with challenging behaviors, but to the overall Medicaid and Family Care programs. The current Medicaid nursing home fee-for-service formula severely limits direct care (RNs, LPNs and CNAs) funding. According to a March 2013 report (www.leadingagewi.org/sites/default/files/malossowner.pdf), over 96% of all Wisconsin nursing homes are not fully paid for their direct care staffing costs. Thus it is imperative that the reimbursement system begin to examine staffing costs necessary to serve persons with challenging behaviors. As noted during the deliberations by the Legislative Council Special Committee on Legal Interventions for Persons with Alzheimer's Disease and Related Dementias, residents needing one-on-one staffing attention generate costs 6 to 8 times higher than an average nursing home resident. To be clear, the current add-on for residents with Behavioral and Cognitive Impairment challenges 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.

The Association also has concerns with the Plan's call to, "Encourage MCOs to include dementia care expectations into contracts with nursing homes." (**Section 5.22**, page 24) It is our immediate fear that this intent would negate an earlier statement that the Plan seeks "to improve the quality of dementia care by building on current successes and relationships within the context of existing regulations." At the heart of our concern is the reality that MCOs do not provide direct care and services to Family Care recipients. Rather, the MCOs contract with the provider community for care and services required and desired by the recipient. Should DHS seek to "include dementia care expectations into contracts with nursing homes" it is reasonable for providers to assume that MCOs would translate these expectations into *requirements* when contracting with providers. We also are curious why nursing homes are singled out by DHS when imposing MCO contracting expectations.

Other LeadingAge Wisconsin members have concerns similar to those expressed by our nursing facilities. For example, in a recent in-person survey of fifty LeadingAge Wisconsin assisted living providers, 100% reported they have not received a rate increase from their MCO for at least three years (one AL provider last received an increase eight years ago). A number of providers have either capped Family Care participation or are opting out of the program altogether. Thus, new requirements imposed by the MCOs are not likely to be well received by the provider community and could negatively impact recipients' access to necessary care and services options.

The Association applauds the Plan's recognition of the development of dementia-friendly facility designs as discussed under **Section 5.2.3** (pages 24-25). We wholeheartedly agree that the "cost neutrality" requirements of the DHS Modernization Program severely limits the Program's effectiveness in offering incentives to organizations wishing to undertake significant renovation or replacement projects. Since the need to modernize the physical plants of aging facilities is not limited to facilities that predominantly serve persons with dementia, LeadingAge Wisconsin encourages DHS to offer a budget proposal intended to increase the overall number of qualifying projects.

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.

In addition to addressing the need for each county to designate at least one facility for emergency placements (**Section 5.3.3**, page 29), the Department should consider how certain facilities might also serve, on an on-going, non-emergency basis, dementia residents who nonetheless present considerable programmatic, staffing and safety concerns. This could be accomplished either by dedicated facilities or by specialty units within a facility. Several of our county home members have expressed interest in serving as placements for both short-term and longer-stay residents. LeadingAge Wisconsin concurs with DHS that much work needs be done to establish appropriate payment and programmatic incentives in order for facilities to serve these roles.

Section 5.4 of the Plan (pages 32-36) was not well received by LeadingAge Wisconsin members. Many of our concerns already have been covered in the above remarks, so please forgive a certain amount of redundancy. Members fully support promotion and recognition of available voluntary training and education programs designed to make our long term services and supports system more dementia capable. Publicizing and making available resources (i.e., best practices, toolkits, educational programs and related information) would likely prove helpful to both consumers and providers. Yet, it is our strong belief that creation of a "Voluntary Assurance Program for facilities and Home Health Agencies" (page 33), replete with standards, training provisions, staffing ratios and other recommendations, would quickly transform into mandated requirements by either DHS or MCOs, or both. (The Association is reviewing its position on a truly voluntary certificate program and will provide feedback to DHS separate from these remarks. We do have concerns about the use of limited additional funds necessary to create the program and a registry.)

A glimpse into why our fear isn't unfounded can be found in the verbiage used in the DHS plan calling for this "voluntary" program. For example, providers would be required "to attest to their *compliance*" (emphasis added), and the standards may include "staffing ratios…and criteria for admission, transfer and discharge." (page 33) More directly, **Section 5.4** (page 35) notes the Department's intent to "Create Incentives for **Compliance** with Staff Training and Other Standards." (Page 36; emphasis added) This Section goes on to say DHS will "encourage MCOs to contract with providers that follow the dementia care standards…. MCOs will also be encouraged to include provider contact *requirements* to *comply* with state-approved dementia care standards, including staff that have completed and obtained certificates of training." (emphasis added)

How could these standards not become mandates?

The Plan also says the DHS strategy would involve, "Encouraging MCOs to build dementia care expectations and incentives into their contracts with the nursing home, assisted living facilities and community-based providers in the MCO's provider networks." (Page 36) Providers expect the MCOs would impose the DHS-directed expectations/standards, but are predictably skeptical the MCOs would increase provider rates to reflect these new mandates. To be blunt, most providers are simply asking the

MCOs to provide cost of living increases so caregivers can receive wage increases and/or maintenance of fringe benefits. Given this state of affairs, expecting the MCOs to suddenly provide higher payments related to newly created dementia standards and training mandates would be spectacularly optimistic on the part of the provider community.

Section 5.5 (pages 36-38) includes several recommendations related to research and data collection. The need to learn more about the quality and cost of serving persons with dementia is not isolated to facility-based providers. LeadingAge Wisconsin suggests **Section 5.5** gives far too great of emphasis on the 25% of the dementia population that is receiving facility-based care, while largely ignoring the majority of persons living at home or in an unregulated setting.

The Plan calls for the development of "provider classifications relating to the dementia care services provided and acuity of the population served….A stakeholder workgroup will be convened to assist the Department in developing a classification system that can be related to service standards and caregiver training needs. A classification system could differentiate those providers or facilities delivering a basic level of care from those that are equipped to provide crisis stabilization and response, address co-occurring medical or psychiatric conditions, or manage challenging behaviors on a long-term basis." LeadingAge Wisconsin believes many of the issues embedded in this DHS recommendation could be addressed by identifying facilities serving as emergency protective placement facilities, and by designating facilities as special care facilities as an appropriate option to serve longer-stay residents with serious behavioral challenges. The Association would be concerned that further subdividing facilities beyond what we have suggested could lead to an unnecessary differentiation among the general nursing home provider community. For many facilities, revisions to the current Behavioral and Cognitive Impairment add-on could help better relate resident conditions to payment levels and provide recognition that all nursing facilities are likely to serve a significant number of persons with Alzheimer's Disease or related conditions. Following this approach, and not creating separate classification systems within the provider community, would avoid creating provider "silos" and reinforce that future long term care populations are most likely to include a dementia-related condition.

In closing, LeadingAge Wisconsin appreciates the opportunity to participate in the redesign of the Wisconsin dementia care system. The Association and its members are available to further assist the Department and stakeholders in this endeavor and we look forward to continued and ongoing dialogue on this important topic.

Respectfully,

John Sauer, President/CEO
LeadingAge Wisconsin