

January 10, 2014

Dementia Subcommittee preliminary comments to the Dementia Capable Wisconsin Plan (the Plan)

Overall comments

We are very excited and pleased that the State is taking these positive and much needed steps to prepare Wisconsin to meet the needs of people with dementia now and moving into the future. The leadership on this is admirable, timely, and greatly appreciated.

We are pleased also that the plan has been on a fast-track since the Dementia Summit, but need to express some concern that the community had such a short time to make comments. We want to be sure there is a balance of moving quickly toward implementation, but also gathering the best ideas and most comprehensive input in the process.

Considering this is at present a high-level plan, our comments are intended to be high-level as well. They are not intended to be an exhaustive list.

Initial recommendations – broad level

The Dementia Subcommittee of the Long Term Care Council will provide input from a diverse group of volunteers and professionals who represent many different networks, populations and interests. This subcommittee should be continued into the foreseeable future to provide further input and assistance to the Department. A further discussion of the specific charge to the subcommittee should take place.

We need to be sure we do not duplicate efforts under the Plan with initiatives underway elsewhere. It's better to incorporate good work than to reinvent the wheel. One example: WALA has been developing dementia standards for some time.

{Statement added by LeadingAge Wisconsin separate from the Dementia Subcommittee comments: The LeadingAge Wisconsin's WCCEAL- approved RCAC QI Network has a Quality Initiative for Dementia, and the CBRF QI Network has a Quality Initiative and a Quality Module on Cognitive Impairment, plus additional tools that are applicable for dementia care.}

We need to foster broad and shared ownership of the Plan so it is not seen as being solely State-developed and State-run. One example: how can we engage the Legislature in a way that gives them a stake in the success of the plan?

The Plan development and implementation should be done in ways that bring together constituencies such as facility-based and community-based providers, and does not foster divisiveness.

There is a great deal of interrelatedness between Plan components that needs to be taken into consideration. Two examples: there is relationship between expanding mobile crisis response and developing placement facilities; there is a relationship between expanding Dementia Specialists and AFCSP modifications.

Even at this early point, it is not too soon to be thinking about continuation funding for new initiatives, as well as possible areas for enhanced funding in order to truly accomplish this robust agenda. This is another good reason to engage the legislature. We agree that "quality care costs money" and recommend a review of payment systems to assess payments for residents with behavioral challenges and how enhanced or new payment incentives might serve to create a more dementia capable system.

Specific recommendations

We need a broader discussion on the role and scope of the Dementia Specialists. While these positions are very promising and much needed, there are concerns about the broad range of activities they are expected to focus on, and questions about why there is such a reliance on only certain programs such as LEEPS when other evidence-based programs may be available. There is a separate concern about the capacity for this position to successfully accomplish needed tasks of volunteer recruitment, training, and management to meet the needs of the potential volume of individuals and families.

We also need a discussion about data and metrics. While we are in agreement that they are lacking and much needed, we need to reach consensus on what data will be gathered and why, along with what metrics will be developed and tracked.

We would like greater clarification (or perhaps more discussion) about the words “ensure” and “encourage” when used in regard to developing dementia capacity in MCO provider networks.

We recommend a careful study be initiated of AFCSP programs statewide. We enthusiastically support the expansion of AFCSP and agree it is due for some analysis. We also see AFCSP as being a cornerstone for developing dementia capable communities across the State. Some areas worthy of study in AFCSP would include:

- How can the money be made to go further?
- Are income limits a barrier to getting people identified and into supportive resources sooner?
- What is AFCSP data telling us about affordable day care and respite?
- Are there model dementia-specific uses of AFCSP that could be replicated?

We also recommend that where possible, a “do no harm” approach is taken to people already relying on AFCSP funding as the program is being modified or reviewed.

We repeat that there is a clear inter-relation between AFCSP, the use of volunteers, and the Dementia Specialist program that should be examined.

We recommend that the topic of respite be considered as a separate issue. While respite can be and is funded through both AFCSP and Family Care, it is a pivotally important component of the spectrum of care that is not otherwise addressed in the Plan.

In the development of standards and certification programs, we encourage the use of already-existing standards and training methodologies instead of creating new ones, since so much good work has already been done in these important areas. We are concerned that the pursuit of “voluntary standards and certification options” might soon transform into mandatory requirements, especially as the Departments works to “ensure or encourage” MCOs to contract with providers meeting these standards.

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 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.

Submitted by Subcommittee chair Tom Hlavacek and members Carol Eschner, Devon Christianson, Bob Kellerman, Heather Bruemmer, and John Sauer