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May 27, 2015 Joint Committee on Finance Paper #360

# Dementia Care Specialists
# (Health Services -- Medical Assistance -- Long-Term Care Services)

[LFB 2015-17 Budget Summary: Page 222, #4]

## CURRENT LAW

Dementia care specialists provide cognitive screening and programs that engage individuals with dementia in regular exercise and social activities, promote independence for individuals with dementia, and facilitate the participation of individuals with dementia in research studies to understand the causes of and explore treatment options for dementia. They also provide support for family caregivers, including assistance with care planning and connections to support groups. Finally, they provide community support, assisting in the development of dementia-friendly communities through increased civic awareness and dementia-capable emergency response.

## GOVERNOR

Provide one-time funding of $1,128,000 ($960,000 GPR and $168,000 FED) in 2016-17 to support dementia care specialist (DCS) positions in aging and disability resource centers (ADRCs).

## DISCUSSION POINTS

1. Dementia refers to a set of symptoms of cognitive decline resulting from brain cell death caused by disease and injury to the brain. Symptoms may include declines in memory, judgment, perception, and reasoning, as well as other cognitive abilities. Different causes of dementia symptoms exist, with the most prominent being Alzheimer's disease, for which there is currently no cure.

2. Prevalence of dementia-related diseases has increased in recent years due to the aging population. According to a RAND Corporation study published in the New England Journal of Medicine in 2013, the estimated prevalence of dementia among those ages 70 and older was 14.7% in 2010. Additionally, according to the Department of Health Services' (DHS) February, 2014 Wisconsin Dementia Care System Redesign plan, an estimated 120,000 individuals in Wisconsin have Alzheimer's disease or related dementia diseases. With the aging of the state's population, this number is expected to grow in coming years.

3. The costs associated with dementia care are significant, and are expected to increase in future years. The Alzheimer's Association estimates that, nationally, the cost of caring for individuals with Alzheimer's disease and other dementias was approximately $214 billion in 2014. Additionally, the 2013 RAND Corporation study estimates annual societal costs ranging from $41,000 to $56,000 per dementia case, including costs from out-of-pocket spending on healthcare, spending by Medicare on healthcare, net nursing home spending, and formal and informal home care that were considered attributable to dementia. This study notes that the cost of dementia care is comparable to the direct healthcare expenditures related to heart disease, and that costs related to dementia care are substantially higher than the direct healthcare expenditures related to cancer.

4. DHS is engaged in an initiative to redesign the state's dementia care delivery system. The goals of this initiative are to ensure that individuals with dementia receive appropriate, safe, and cost-effective care, that individuals with dementia are not unnecessarily or inappropriately placed in institutions, and that the burden on families and caretakers related to caring for those with dementia is reduced. The initiative is focused on providing improved services for individuals with dementia in the context of the state's aging population, as well as a recent Wisconsin Supreme Court decision that prevents individuals with dementia from being involuntarily committed under Chapter 51 of the statutes, unless they have an additional diagnosis of mental illness (*Fond du Lac County v. Helen E.F.*).

5. In recent years, the Department has provided funding for DCS positions in ADRCs. The Department indicates that there are three broad goals that DCS are intended to achieve: (a) making an ADRC "dementia capable"; (b) promoting "dementia friendly" communities; and (c) promoting opportunities for individuals with dementia to remain in their homes. The tasks related to each of these goals are described below.

- To make an ADRC "dementia capable," DCS positions are expected to provide consultation and technical assistance to all staff who interact with individuals with cognitive changes or dementia diagnoses, ensure that ADRC information and assistance specialists offer and administer cognitive screens and facilitate follow-up with health care providers, and establish referral relationships with health care providers so that screen results can be shared with providers.

- To promote dementia-friendly communities, DCS positions are expected to engage the community in developing strategies to recognize, communicate with, and support people with dementia, and to build relationships with health care and long-term care providers and systems to make them aware of local programs and supportive services.

• To promote opportunities for individuals with dementia to remain at home, DCS positions are expected to inform individuals and family caregivers of community and ADRC resources and the Alzheimer's Family and Caregiver Support program to help individuals stay in their homes as long as possible.

6. Each DCS is also required to become certified in the New York University Caregiver Intervention program, known as Memory Care Connections in Wisconsin, under which a DCS meets with a caregiver, family members, and others to assist them in better understanding the dementia and developing a plan of support for the caregiver. Additionally, the DCS is required to implement the Language Enriched Exercise Plus Socialization (LEEPS) program, in which trained volunteers work with individuals in the early stages of dementia on physical strengthening, as well as activities that allow the person to be a social and productive community member for as long as the individual can safely participate.

7. DHS awarded funds for DCS positions to ADRCs through a competitive application process in which ADRCs were required to demonstrate how the DCS would achieve the goals and accomplish the activities outlined above. The Department indicates that five of the nine applicants were awarded funding in 2013, and 11 of the 18 applicants were awarded funding in 2014. These positions provide services in ADRCs serving 26 counties. The following table shows the ADRCs that received funding awards and currently have a DCS.

**ADRCs with Dementia Care Specialists**

| | |
|---|---|
| Dane | Green, Grant, Iowa, Lafayette |
| Brown | Milwaukee |
| Waukesha | Kewanee, Manitowoc |
| Portage | St. Croix |
| Rock | Washburn, Barron, Rusk |
| Ashland, Bayfield, Price, Sawyer, Iron | Ozaukee |
| Kenosha | Dodge |
| Eau Claire | Jefferson |

8. The awards were made from funds available due to one-time underspending in ADRC contracts in the 2013-15 biennium. Selected ARDCs received $94,000 ($80,000 GPR and $14,000 FED) per DCS position. The Department notes that the ADRCs were aware that the grant funding was provided on a one-time basis, to be terminated at the end of calendar year 2015. The Department indicates that these funds were provided with the intention of introducing these positions in various ADRCs around the state and encouraging ADRCs to find alternative funding sources to maintain these positions in the future.

9. The Department requires all DCS positions and ADRCs to record and report data on results for dementia-related activities quarterly, including cognitive screens, presentations and consultations in support of dementia-friendly communities, Memory Care Connections interventions, participation in LEEPS programs, and one-on-one consultations with health professionals, county agencies, crisis teams, law enforcement, and adult protective services staff,

among others. The following table shows the number of DCS activities that were completed between December 1, 2014, through March 31, 2015, as reported by 15 of the 16 DCS positions.

**Activities of DCS Positions,**
**December, 2014 through March, 2015**

| Activity | Number |
|---|---|
| Referrals to Services or Support Programs | 1,037 |
| Consultations with Community Organizations, Employers, and Related Groups | 300 |
| Presentations or Events | 298 |
| Memory Screens | 129 |

10. Under this provision, the Department would allocate the one-time funding to support twelve DCS positions in 2016-17, with $94,000 ($80,000 GPR and $14,000 FED) allocated to fund salaries and benefits for each position. This estimate assumes that approximately 30% of the activities of a DCS would be Medicaid-related, and would qualify for 50% federal medical assistance administration matching funds. ADRCs would need to apply and compete for funding for these positions, under the same process the Department previously used to award funding for these positions.

11. Under the *National Plan to Address Alzheimer's Disease: 2014 Update*, published by the U.S. Department of Health and Human Services, several goals are identified that specifically relate to expanding and improving care and supports for individuals with Alzheimer's disease. In particular, the second goal relates to enhancing care quality and efficiency, and includes strategies such as building a workforce with the skills to provide high-quality care, ensuring timely and accurate diagnosis, educating and supporting people with Alzheimer's disease and their families upon diagnosis, ensuring that people with Alzheimer's disease experience safe and effective transitions between care settings and systems, and advancing coordinated and integrated health and long-term services and supports for individuals living with Alzheimer's disease. Additionally, the third goal involves expanding supports for people with Alzheimer's disease and their families, which includes strategies such as ensuring the receipt of culturally-sensitive education, training, and support materials, enabling family caregivers to continue to provide care while maintaining their own health and well-being, assisting families in planning for future care needs, and maintaining the dignity, safety, and rights of people with Alzheimer's disease. Finally, the fourth goal promotes enhanced public awareness and engagement, which includes educating the public about Alzheimer's disease and working with state, tribal, and local governments to improve coordination and identify model initiatives to advance Alzheimer's disease awareness and readiness across the government.

12. The DCS positions fulfill some of the goals and strategies targeted in the *National Plan to Address Alzheimer's Disease*, and providing funding for these positions could improve support and care for individuals with Alzheimer's disease and related dementias throughout the state. Because providing continued funding for DCS positions is consistent with the Department's dementia care redesign plan and nationally recognized goals related to expanding and improving

care for individuals with Alzheimer's disease and related dementias, the Committee may wish to approve the Governor's recommendation (Alternative 1). This alternative would allow the Committee to provide funding for these positions, while also avoiding a future ongoing financial commitment.

13. Instead, the Committee may wish to: (a) increase by one-third the amount of funding that would be provided in the bill to enable DHS to support 16, rather than 12, DCS positions annually, which reflects the number of DCS positions that are currently funded (Alternative 3 and Alternative 4); (b) reduce by one-half the amount of funding that would be provided in the bill to enable DHS to support six, rather than 12, DCS positions annually (Alternative 5 and Alternative 6); and (c) provide the funding on an ongoing, rather than one-time basis (Alternatives 2, 4, and 6).

14. However, in light of other GPR funding commitments, the Committee may decide not to increase funding for ADRCs for DCS positions. For this reason, the Committee could delete the Governor's recommendation (Alternative 7).

## ALTERNATIVES

1. Adopt the Governor's recommendation to provide one-time funding of $1,128,000 ($960,000 GPR and $168,000 FED) in 2016-17 to fund 12 grants to support DCS positions at ADRCs.

2. Modify the bill to provide the funding amount recommended by the Governor on an ongoing, rather than one-time, basis.

3. Increase funding in the bill by $376,000 ($320,000 GPR and $56,000 FED) in 2016-17 to fund 16 one-time grants in 2016-17, rather than 12 one-time grants.

| ALT 3 | Change to Bill |
|---|---|
| GPR | $320,000 |
| FED | 56,000 |
| Total | $376,000 |

4. Increase funding in the bill by $376,000 ($320,000 GPR and $56,000 FED) in 2016-17 to fund 16 grants in 2016-17, and provide the funding on an ongoing, rather than one-time, basis.

| ALT 4 | Change to Bill |
|---|---|
| GPR | $320,000 |
| FED | 56,000 |
| Total | $376,000 |

5. Reduce funding in bill by $564,000 (-$480,000 GPR and -$84,000 FED) in 2016-17 to fund six one-time grants in 2016-17, rather than 12 one-time grants.

| ALT 5 | Change to Bill |
|---|---|
| GPR | - $480,000 |
| FED | - 84,000 |
| Total | - $564,000 |

6. Reduce funding in bill by $564,000 (-$480,000 GPR and -$84,000 FED) in 2016-17 to fund six grants in 2016-17, and provide the funding on an ongoing, rather than one-time, basis.

| ALT 6 | Change to Bill |
|---|---|
| GPR | - $480,000 |
| FED | - 84,000 |
| Total | - $564,000 |

7. Delete provision.

| ALT 7 | Change to Bill |
|---|---|
| GPR | - $960,000 |
| FED | - 168,000 |
| Total | - $1,128,000 |

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