



Legislative Fiscal Bureau

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Joint Committee on Finance

Paper #368

Dementia Care Specialists (Health Services -- Mental Health, Public Health, and Other Programs)

CURRENT LAW

Aging and Disability Resource Centers. Aging and disability resource centers (ADRCs) provide services to individuals who need, or expect to need, long-term care services and their families. These services include: (a) providing information and assistance; (b) benefits counseling; (c) coordinating short-term services; (d) conducting functional screens; and (e) enrollment counseling and processing. In addition, physicians, hospital discharge planners, and other professionals who work with elderly and disabled individuals can also use the information services ADRCs provide. ADRCs provide all of their services at no cost to recipients.

The contract between an ADRC and the Department of Health Services (DHS) assigns responsibilities to each ADRC and allows the ADRC to be reimbursed for its costs in carrying out these required functions. Counties are not expected to contribute to the cost of operating ADRCs. State funding to support ADRCs is allocated based on the estimated size of the population served in each area and estimates of the amount of time required to carry out the ADRC functions. If actual costs exceed this limit, the ADRC is responsible for those costs.

In 2017, there are 40 ADRCs operating in Wisconsin, including 27 ADRCs that serve one county and 13 that serve multi-county regions. In addition, DHS allocates funding for tribes to support tribal aging and disability resource specialists (ADRS) and tribal disability benefits specialists. In calendar year 2017, DHS has contract commitments to these ADRCs and tribes totaling approximately \$67.8 million (\$41.1 million GPR and \$26.7 million FED).

Dementia Care Specialists. Dementia care specialists (DCSs) work at ADRCs and provide cognitive screenings, programs that engage individuals with dementia in regular exercise and social activities, and promote independence for individuals with 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 outreach events and professional consultations. Dementia care specialist positions are not state positions.

Funding to support DCS positions is not part of the ADRC base contracts. The program began as a DHS initiative in 2013, when DHS awarded funds for DCS positions to ADRCs through a competitive application process. Five of nine applicants were awarded funding in 2013, and an additional 11 of 18 applicants were awarded funding in 2014. Selected ADRCs received \$94,000 (\$80,000 GPR and \$14,000 FED) per DCS position. In the 2013-15 biennium, the program was funded entirely by reallocating funding that had been budgeted, but not expended, for ADRC contracts. The surplus funding available in the 2013-15 biennium was available because the state was able to claim more federal funds on base ADRC contract costs than had been budgeted. This surplus funding was used to continue the 16 DCS positions through June 30, 2016, and also to add three DCS positions in Wisconsin tribes to serve Native American communities in 2015.

In the 2015-17 biennial budget, one-time funding of \$1,128,000 (\$960,000 GPR and \$168,000 FED) was provided in 2016-17 to fund 12 one-year grants to support DCS positions at ADRCs, with each grant budgeted at \$94,000 (\$80,000 GPR and \$14,000 FED). DHS supplemented the funding budgeted in Act 55 to maintain funding for the existing 19 DCS positions through calendar year 2017. DHS extended the current grants, rather than fund grants to ADRCs that had not previously received grants, to avoid the time, training, and recruitment costs for one-year grants.

Currently there are 19 DCS positions serving 26 counties and three tribes in Wisconsin. These positions are funded through the end of calendar year 2017. Since the Act 55 funding for DCS was provided on a one-time basis, it is deleted from the agency's adjusted base budget as a standard budget adjustment.

The attachment identifies the ADRCs and tribes that currently have DCS positions.

GOVERNOR

No provision. Consequently, beginning January 1, 2018, no funding would be budgeted to support DCS positions at the ADRCs.

DISCUSSION POINTS

Background

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, the most prominent being Alzheimer's Disease, for which there is currently no cure.

2. In 2016, an estimated 115,000 individuals in Wisconsin were living with Alzheimer's disease or a related dementia. However, as the population continues to age, that number is expected to increase significantly. National projections from the Alzheimer's Association estimate Wisconsin's growth rate for individuals with Alzheimer's and related dementias to be 18.2% over the next ten years, and doubling by 2040.

3. DHS estimates that 25% of Wisconsin residents with dementia are enrolled in Medicaid (approximately 28,800 individuals). Of the estimated total number of Wisconsin residents with dementia, approximately 11% (12,700) receive Medicaid-funded long-term care services, 9% (10,400) receive Medicaid supported institutional services, and 5% (5,800) receive other Medicaid services.

DCS Services

4. The four main goals of the 19 DCS positions are to: (a) support individuals with dementia to remain active and able to stay in their own homes in the community; (b) support family caregivers so that they can continue to help family members with dementia remain in the least restrictive setting for as long as possible; (c) increase the dementia capability of the local ADRC as well as other county and tribal agencies; and (d) facilitate local efforts to build dementia-friendly communities.

5. The DCS positions connect individuals with dementia and their caregivers with other community resources. According to DHS Dementia Care Specialist 2016 Activity Report, in 2016, DCSs made 4,031 referrals. Of these referrals, 63% were to one of the following: (a) caregiver support programs (21%); (b) county or tribal agencies (15%); (c) Alzheimer's or dementia agencies (11%); (d) memory cafés (9%); and (e) and health care professionals (7%). ADRCs, DCSs, and referral agencies help connect people with dementia and their caregivers to a wide range of services, including, home-delivered meals, family caregiver training and support, legal advice and services, information and assistance, options counseling, intergenerational volunteer programs, transportation services, chronic disease self-management programs, long-term care programs, and independent living services.

6. In addition to providing general referrals, DCSs are trained to perform memory screens for individuals in the community to determine the need for clinical follow-up with a primary physician or other health care professional. Beyond administering their own screens DCSs also train other ADRC and tribal staff to use the memory screen tools. The exercises administered by the DCSs do not provide a reason for the memory issue, if one is indicated, and do not constitute a medical diagnosis. However, these free screens indicate whether clinical follow-up is warranted, which may help reduce the need for an individual to seek further medical services. Between April and December, 2016, DCSs performed a total of 620 memory screens and other ADRC staff performed 1,332 memory screens, for a total of 1,952 memory screens. Of these memory screens, 27% were referred to a doctor for clinical follow-up.

7. Early detection of dementia allows individuals to work with their doctors to determine what lifestyle changes they can make or what treatment options may be available to address the progression of the disease or ease symptoms; and participate in making health care and financial

decisions and plans for the future, which may help avoid potentially costly, crisis situations.

8. One way to address the progression of the disease or ease symptoms is the Language Enriched Exercise Plus Socialization (LEEPS) program. Led by the DCSs, the LEEPS program provides opportunities for people in the early stages of Alzheimer's Disease or mild dementia to engage in exercise and social opportunities with trained volunteers. One study found that LEEPS participants improved their physical fitness and mood, and maintained functional ability.

9. Caregiver support is another significant part of DCS services. The Alzheimer's Association reports that 83% of care provided to people with dementia who live in the community is provided by unpaid caregivers, most of whom are family members. Of the 2,800 contacts DCSs received for services between April and December, 2016, 43% were caregivers seeking help for themselves in their caregiving roles. In The Dementia Care Specialist 2016 Activity Report, DHS estimates that family caregivers provided 219 million hours of unpaid care for people with dementia, valued at \$2.7 billion, in Wisconsin in 2015.

10. DCSs provide training and referrals for family caregivers to better support the person with dementia in the community. Specifically, caregivers are offered the opportunity to participate in the Memory Care Connections program (also known as the New York University Caregiver Intervention program), which is an evidenced-based program that provides family caregivers with education about dementia and Alzheimer's Disease, as well as an individualized support plan. One review found that program participants were able to care for individuals with dementia at home an average of 18 months longer than those who did not have the support of the program.

11. Finally, in keeping with the goals of the positions, DCSs conduct a number of outreach activities and consultations with other professionals. Between April and December, 2016, DCSs contributed to and participated in 1,900 outreach events, with a total of approximately 40,400 attendees. These outreach events worked to foster dementia-friendly communities by working with businesses; employers; local organizations, such as law enforcement, adult protective services crisis response teams, and medical providers; and the general public. Between May and December, 2016, DCSs documented approximately 1,200 consultations with professionals such as adult protective staff, medical professionals, law enforcement, educators, social service workers, residential care providers, and attorneys.

12. During the public hearings on the 2017-19 biennial budget, the Committee heard testimony in support of maintaining the DCS positions at the ADRCs. Several funding options are available to the Committee. First, the Committee could provide ongoing funding for all of the current DCS positions through the 2017-19 biennium. Under this option, the Committee could increase funding in the bill by \$893,000 (\$759,100 GPR and \$133,900 FED) in 2017-18 and by \$1,786,000 (\$1,518,100 GPR and \$267,900 FED) in 2018-19 for this purpose. The amount of funding in 2017-18 reflects one half of the annualized cost of these positions, since the current positions are funded through December, 2017 [Alternative 1a]. Alternatively the Committee could maintain the current positions for another two- year period, though June 30, 2019, by providing the funding budgeted in the 2017-19 biennium as one-time funding [Alternative 1b]

13. A second set of options would be to maintain funding for some, but not all, of the

current DCS positions. For example, the Committee could maintain funding for eight, rather than 19, DCS positions at the ADRCs. This funding could be provided either on an ongoing basis [Alternative 2a] or on a one-time basis [Alternative 2b].

14. If the Committee decides to fund these grants on an ongoing basis, as provided under Alternative 1A or 2A, it may wish to provide ADRCs that have not, to date, received grants the opportunity to compete for these grants. The bill could be modified to direct DHS to solicit new grant applications for the contract period beginning January 1, 2018 [Alternative 3]. Under this option, current grantees could compete, but would not necessarily be selected, for future grants.

15. Finally, in light of other GPR funding commitments, the Committee could choose to take no action on this item by adopting the Governor's recommendation to not provide funding to maintain DCS positions in the 2017-19 biennium [Alternative 4].

ALTERNATIVES

1A. Increase funding in the bill by \$893,000 (\$759,100 GPR and \$133,900 FED) in 2017-18 and by \$1,786,000 (\$1,518,100 GPR and \$267,900 FED) in 2018-19 to maintain funding for 19 dementia specialist positions on a permanent basis.

ALT 1A	Change to	
	Base	Bill
GPR	\$2,280,000	\$2,280,000
FED	<u>399,000</u>	<u>399,000</u>
Total	\$2,679,000	\$2,679,000

1B. Increase funding in the bill by \$893,000 (\$759,100 GPR and \$133,900 FED) in 2017-18 and by \$1,786,000 (\$1,518,100 GPR and \$267,900 FED) in 2018-19 on a one-time basis to maintain funding for 19 dementia specialist positions through June 30, 2019. This funding would be deleted from the base as a standard budget adjustment as part of the 2019-21 budget bill.

ALT 1B	Change to	
	Base	Bill
GPR	\$2,280,000	\$2,280,000
FED	<u>399,000</u>	<u>399,000</u>
Total	\$2,679,000	\$2,679,000

2A. Increase funding in the bill by \$376,000 (\$320,000 GPR and \$56,000 FED) in 2017-18 and by \$752,000 (\$640,000 GPR and \$112,000 FED) in 2018-19 to fund eight dementia specialist positions on a permanent basis.

ALT 2A	Change to	
	Base	Bill
GPR	\$960,000	\$960,000
FED	<u>168,000</u>	<u>168,000</u>
Total	\$1,128,000	\$1,128,000

2B. Increase funding in the bill by \$376,000 (\$320,000 GPR and \$56,000 FED) in 2017-18 and by \$752,000 (\$640,000 GPR and \$112,000 FED) in 2018-19 on a one-time basis to fund eight dementia specialist positions through June 30, 2019. This funding would be deleted from the base as a standard budget adjustment as part of the 2019-21 budget bill.

ALT 2B	Change to	
	Base	Bill
GPR	\$960,000	\$960,000
FED	<u>168,000</u>	<u>168,000</u>
Total	\$1,128,000	\$1,128,000

3. In addition to either 1A or 2A, both of which would provide ongoing funding for DCS positions, direct DHS to solicit grant applications for the contract period beginning with calendar year 2018, to enable ADRCs that have not had DCS positions to compete for grant funding.

4. Take no action.

Prepared by: Alexandra Bentzen
Attachment

ATTACHMENT

Aging and Disability Resource Centers and Dementia Specialist Positions Calendar Year 2017

<u>ADRC</u>	<u>Funded DCS</u>
ADRC of Adams, Green Lake, Marquette, and Waushara Counties	No
ADRC of Barron, Rusk, and Washburn Counties	Yes
ADRC of Brown County	Yes
ADRC of Buffalo and Pepin Counties	No
ADRC of Calumet, Outagamie, and Waupaca Counties	No
ADRC of Central Wisconsin (Serving Langlade, Lincoln, Marathon, and Wood Counties)	No
ADRC of Chippewa County	No
ADRC of Clark County	No
ADRC of Columbia County	No
ADRC of Dane County	Yes
ADRC of Dodge County	Yes
ADRC of Door County	No
ADRC of Douglas County	No
ADRC of Dunn County	No
ADRC of Eagle Country (Serving Crawford, Juneau, Richland, and Sauk Counties)	No
ADRC of Eau Claire County	Yes
ADRC of Florence County	No
ADRC of Fond du Lac County	No
ADRC of Jefferson County	Yes*
ADRC of Kenosha County	Yes*
ADRC of Marinette County	No
ADRC of Northwest Wisconsin (Serving Burnett and Polk Co. and St. Croix Chippewa Indians of WI)	Tribal DCS
ADRC of Ozaukee County	Yes
ADRC of Pierce County	No
ADRC of Portage County	Yes*
ADRC of Racine County	No
ADRC of Rock County	Yes
ADRC of Sheboygan County	No
ADRC of Southwest Wisconsin (Serving Grant, Green, Iowa, and Lafayette Counties)	Yes
ADRC of St. Croix County	Yes
ADRC of the Lakeshore (Serving Kewaunee and Manitowoc Counties)	Yes*
ADRC of the North (Serving Ashland, Bayfield, Iron, Price, and Sawyer Counties)	Yes*
ADRC of the Northwoods (Serving Forest, Oneida, Taylor, and Vilas Counties, Forest County Potawatomi, Lac du Flambeau, and Sokaogon Chippewa Tribes)	No
ADRC of the Wolf River Region (Serving Menominee, Oconto, and Shawano Counties and Stockbridge Munsee Tribe)	No
ADRC of Trempealeau County	No
ADRC of Walworth County	No
ADRC of Washington County	No
ADRC of Waukesha County	Yes
ADRC of Western Wisconsin (Serving Jackson, La Crosse, Monroe, and Vernon Counties)	No
ADRC of Winnebago County	No

ADRC

Funded DCS

Aging Resource Center (ARC) of Milwaukee County
Disability Resource Center of Milwaukee County

Yes
No

ADRS

Bad River Band of Lake Superior Tribe of Chippewa Indians
Ho Chunk Nation
Lac Courte Oreilles Band of Lake Superior Chippewa Indians

No
No
No

Menominee Indian Tribe of Wisconsin
Oneida Nation
Red Cliff Band of Lake Superior Chippewa

Tribal DCS
Tribal DCS
No

Total

16 ADRC Grants
3 Tribal Grants

*Five Original Pilot ADRCs