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Joint Committee on Finance

Paper #430

Alzheimer's Family and Caregiver Support Program, Alzheimer's Training and Information Grants, and Lifespan Respite Care Grants (Health Services -- Services for the Elderly and People with Disabilities)

[LFB 2023-25 Budget Summary: Page 268, #9, 10, & 11]

CURRENT LAW

The Department of Health Services (DHS) funds several programs and grants to address the needs of people with Alzheimer's disease, and programs that, while not targeted exclusively to the needs of people with Alzheimer's disease, may benefit these individuals and their caregivers.

Alzheimer's Family and Caregiver Support Program (AFCSP). Under AFCSP, DHS allocates funding to counties, tribes, and area agencies on aging (AAAs) to assist individuals to purchase services and goods related to the care of someone with Alzheimer's disease. In any calendar year, up to \$4,000 per person may be available, depending on the county's priorities and the person's need for services. In some instances, the funds are used to expand or develop new services related to Alzheimer's disease, such as respite care, adult day care, or support groups.

To be eligible for the program, a person must have a diagnosis of Alzheimer's disease or a related disorder, and be financially eligible. The program is administered by the DHS Bureau of Aging and Disability Resources, and is available in every county and tribe throughout the state. Under current law, DHS may provide up to \$2,808,900 annually, of which at least \$1,000,000 per year must be allocated for respite care under AFCSP.

Alzheimer's Training and Information Grants. Current law requires DHS to award a grant to at least one public agency or private non-profit agency that meets the following criteria: (a) provides training and technical assistance to the staff of county social and human service departments, to the staff of agencies administering the AFCSP, and to other providers of services to persons with Alzheimer's disease; (b) determines the need for and create appropriate services to

persons with Alzheimer's disease in coordination with local agencies and service providers; and (c) collects and disseminates information on Alzheimer's disease, coordinate public awareness activities related to the disease and advise the department on public policy issues concerning the disease.

Currently, \$131,400 GPR is available annually for this purpose, which DHS provides as a grant to the Wisconsin Alzheimer's Institute at the University of Wisconsin Madison.

Respite Care Grants. Under current law DHS is required to contract for the administration of life-span respite care projects with an organization that meets the following criteria: (a) the organization is a private, nonprofit organization, that is capable of operating on statewide basis and has expertise in respite care issues; (b) at least 51 percent of the members of the organization's governing board are consumers of respite care or caregivers; and (c) the membership of the organization's governing board includes providers and elected officials and represents the diverse geographical areas and cultural groups of the state.

Currently, \$350,000 GPR is available annually to fund the life-span respite care program operating under a contract between a nonprofit agency, Respite Care Association of Wisconsin (RCAW), and DHS. As part of the life-span respite care program, RCAW administers the caregiver respite grant program and the supplemental respite grant program, as well as a third grant program for recruitment, outreach, and education events. RCAW is also responsible for delivery of caregiver training, maintenance of the respite care provider registry, and other activities included in the contract with DHS.

DISCUSSION POINTS

Alzheimer's Family and Caregiver Support Program (AFCSP)

1. The Alzheimer's family and caregiver support program was created by the Wisconsin Legislature in 1985, in response to the stress and service needs of families caring at home for someone with irreversible dementia.

2. 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. There are several causes of dementia, the most prominent of which is Alzheimer's disease.

3. According to the Alzheimer's Association, it is estimated that approximately 5.3% of people ages 65 through 74, 13.8% of individuals ages 75 through 84, and 34.6% of individuals 85 and older have Alzheimer's disease. The Alzheimer's Association estimates that in 2020, 120,000 Wisconsin residents age 65 and older have dementia, with that number anticipated to reach 130,000 in 2025. The number of people with Alzheimer's disease and other dementias is expected to increase as the population continues to age.

4. There are two main eligibility criteria for AFCSP. First, the individual must be

diagnosed with Alzheimer's disease or any of the other irreversible dementias. Second, an individual or couple must have a joint annual income of \$48,000 or less. However, if the individual or couple's income is more than \$48,000, the costs related to Alzheimer's disease can be subtracted from the gross income. If, following this subtraction, the net income is then less than \$48,000, the individual or couple would be eligible.

5. Generally, the program funds services and items that are necessary to maintain a person with Alzheimer's disease in the community, including in-home help, respite care, adult day care, transportation, nutritional supplements, security systems, specialized clothing, home delivered meals, hobby equipment, and chair lifts. However, counties may limit the types of services covered by this program. Counties may also use program funding to start support groups, increase public awareness, purchase library books, start adult day care services, or to provide overnight or emergency respite care.

6. In calendar year 2021, 966 families received services funded by AFCSP. The program does not currently maintain a waiting list for services at the state level, although some families may need to wait until funding becomes available in their county.

7. In calendar year 2021, a total of \$2,446,643 was expended through AFCSP. The following table shows 2021 expenditures under the program by service category.

2021 AFCSP Expenditures, by Service Category

<u>Respite Services</u>	
Adult day services	\$158,990
Caregiver self-care	5,523
Homemaker/chores	242,279
In-home general respite	1,012,820
In-home personal care	122,919
Overnight facility respite	54,037
Other respite	<u>46,902</u>
Subtotal respite services	\$1,643,470
 <u>Other</u>	
Other goods and services	\$238,074
Development of new or expanded services	3,997
Outreach activities and public awareness	143,283
Support group development or assistance	27,113
Case management	204,543
Staff training	5,668
Program administration	<u>180,495</u>
 Total	 \$2,446,643

8. In calendar year 2023, DHS allocated \$2,808,900 GPR for the program, including \$1,645,100 to 34 counties as an allocation under community aids, and \$1,163,800 to tribes and area agencies on aging as non-community aids allocations. By law, area agencies on aging are generally prohibited from providing direct services. As such, when funding is provided to area agencies on

aging the area agency on aging provides contract oversight and technical assistance but the program is still administered by the counties and tribes.

9. The amount each county or area agency on aging receives under this allocation is determined based on the state funding formula the DHS Office on Aging uses for distributing federal Older Americans Act funds. Counties are not required to contribute additional funding to the program, however, may choose to do so if they determine that additional funding is needed on occasion.

10. 2015 Act 273 established the current income eligibility limit of \$48,000. Further, 2015 Act 273 provided an additional \$1,000,000 GPR and increased the funding DHS is authorized to distribute under AFCSP to \$2,558,900, beginning in 2016-17. 2021 Act 58 increased the funding DHS is authorized to distribute under AFCSP to the current maximum of \$2,808,900, but did not change the income eligibility limit.

11. AB 43/SB 70 would modify AFCSP in two ways. First, financial eligibility would be expanded to allow an individual or couple to have a joint income of up to \$60,000, after any eligible deductions for Alzheimer's related care expenses, up from the current limit of \$48,000. Second, to ensure that benefits are not reduced or limited as a result of expanding eligibility, an additional \$500,000 would be provided annually for DHS to distribute to counties, tribes, and area agencies on aging under the program.

12. Based on ongoing demand for services, and the anticipated growth in the number of Wisconsinites aged 65 and older anticipated to live with Alzheimer's who could therefore benefit from AFCSP services, the Committee could provide an additional \$500,000 GPR annually to expand eligibility for AFCSP, as recommended by the Governor. [Alternative A1]

13. Alternatively, rather than expand the financial eligibility for the program, the Committee could instead provide \$500,000 GPR annually and increase the funding DHS is authorized to distribute under AFCSP to \$3,308,900 annually.

14. While the Department does not collect data on individual benefit payments, 27 counties and tribes have set maximum benefit limits below the statutory maximum of \$4,000 in order to serve more eligible individuals. The Administration indicates that funding limits set by local programs are a primary reason for the rise in requests for RCAW respite grants, as discussed later in this paper, since some families may seek assistance under the RCAW after they have exhausted their maximum annual AFSCP benefit.

15. By increasing the funding available, without changing eligibility limits, counties would be able to provide more aid to currently eligible individuals. [Alternative A2]

16. Finally, the Committee could take no action on this item and retain base funding for the program (\$2,808,900 GPR). [Alternative A3]

Alzheimer's Training and Information Grants

17. In addition to increasing funding for AFCSP, the bill would provide \$100,000 GPR

annually to increase funding available for Alzheimer's training and information grants.

18. As mentioned, the Wisconsin Alzheimer's Institute (WAI) currently receives the full amount available for training and information grants. According to WAI staff, the funding they currently receives supports faculty with expertise in dementia-related clinical, education and outreach endeavors who collaborate with a team to sustain and further develop programs that benefit Wisconsin residents and their families facing Alzheimer's disease and related disorders. The funding supports WAI staff with expertise in education of clinicians across a wide range of disciplines (including physicians, nurses, social workers, psychologists, occupational and physical therapists); program development and evaluation to improve access to quality dementia diagnostic and care services; and community-based dementia outreach and education in diverse communities across the state.

19. The Administration indicates that any eligible public agency or private nonprofit organization that meets the previously mentioned statutory requirements relating to training and the provision of information relating to Alzheimer's disease could apply in the next granting cycle.

20. The grant was established through 1995 Wisconsin Act 464 and was funded at \$132,700 GPR annually. Subsequently, the grant was reduced to its current annual amount of \$131,400 GPR through a one percent across the board reduction included in 2009 Wisconsin Act 28.

21. In light of the anticipated increase in the number of Wisconsinites diagnosed with Alzheimer's disease as the population continues to age, as well as the absence of additional funding for this purpose since the creation of the grant in the 1995 legislative session, the Committee could choose to provide \$100,000 annually to increase funding available for Alzheimer's training and information grants. [Alternative B1]

22. Alternatively, the Committee could take no action on this item, which would retain base funding for the program (\$131,400 GPR). [Alternative B2]

Respite Care Grants

23. The respite care grant program provides respite care services for caregivers, but unlike AFCSP, not exclusively to persons who care for individuals with Alzheimer's disease.

24. DHS is budgeted \$350,000 GPR annually to fund the life-span respite care program, which currently operates under a contract between a non-profit agency, Respite Care Association of Wisconsin (RCAW), and DHS. AB 43/SB 70 would provide \$200,000 GPR annually to increase funding for this contract.

25. As part of the life-span respite care program, RCAW administers the caregiver respite grant program (CRGP) and the supplemental respite grant program (SRGP), as well as a third grant program for recruitment, outreach, and education events.

26. CRGP offers respite care not covered by Medicaid or other programs that provide respite services, for example AFCSP, or once respite services under those programs have been exhausted. Applicants may hire family, friends, respite agency providers, or neighbors since RCAW does not

dictate who the primary caregiver hires to provide respite care. Applicants can reapply for CRGP within a timeframe set by RCAW as funds allow.

27. As with CRGP, RCAW's SRGP is the payer of last resort for primary caregivers or care recipients who cannot be served by other caregiver support programs or those who do not qualify for other caregiver support programs that assist with respite care. Applicants can receive up to \$250 for supplemental supports such as emergency response systems, grab bars, home-delivered meals, housekeeping, laundry services, lawn care, snow removal, or transportation to meaningful or respite activities or medical appointments.

28. From the \$350,000 contract, RCAW budgeted \$57,000 for grant awards (consisting of the CRGP and SRGP discussed above and a third grant program for recruitment, outreach, and education events), \$240,600 for staff salary and fringe, and the remaining \$52,400 for a variety of other business expenses. The staff and business expenses support not only the administration of the three grant programs, but also the delivery of caregiver training, the maintenance of the respite care provider registry, and other activities included in the contract with DHS, as well as the activities conducted under the federal grant.

29. Despite an annual increase of \$125,000 in the 2019-21 budget, funding has not kept pace with demand for respite grant services. Specifically, by early November, 2021, RCAW temporarily suspended new applications for both CRGP and SRGP grants as they had reached or exceeded the amounts the organization had budgeted for each program. At that time RCAW had awarded 43 CRGP grants in 2021-22 totaling \$40,700 and awarded the full \$6,000 budgeted for the SRGP.

30. Since both programs are relatively new, with CRGP created in 2019 and SRGP in 2021, it is likely that demand for services will continue to increase as more people become familiar with the programs and the services offered by RCAW. As such the Committee may choose to increase funding available for the life-span respite care program contract by \$200,000 annually. [Alternative C1]

31. Alternatively, due to the relative newness of some of the grants funded by RCAW, the Committee could provide a smaller funding increase of \$100,000 annually to ensure that demand for the programs exist prior to committing additional resources. [Alternative C2]

32. Finally, the Committee could take no action on this item, which would retain base funding for the program (\$350,000 GPR). [Alternative C3]

ALTERNATIVES

A. Alzheimer's Family and Caregiver Support Program (AFCSP)

1. Provide \$500,000 GPR annually and increase the maximum amount of funding the Department may provide under the Alzheimer's family and caregiver support program from \$2,808,900 to \$3,308,900 annually. Increase the maximum income eligibility limit for the program to \$60,000 per year.

ALT A1	Change to Base
GPR	\$1,000,000

2. Provide \$500,000 GPR annually and increase the maximum amount of funding the Department may provide under the Alzheimer's family and caregiver support program from \$2,808,900 to \$3,308,900 annually.

ALT A2	Change to Base
GPR	\$1,000,000

3. Take no action.

B. Alzheimer's Training and Information Grants

1. Provide \$100,000 GPR annually to increase funding available for Alzheimer's training and information grants.

ALT B1	Change to Base
GPR	\$200,000

2. Take no action.

C. Respite Care Grants

1. Provide \$200,000 GPR annually to increase funding available for the life-span respite care program.

ALT C1	Change to Base
GPR	\$400,000

2. Provide \$100,000 GPR annually to increase funding available for the life-span respite care program.

ALT C2	Change to Base
GPR	\$200,000

3. Take no action.

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