## Chapter HSS 68

## SUPPORT FOR PERSONS WITH ALZHEIMER'S DISEASE AND THEIR CAREGIVERS

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HSS 68.01 Introduction. (1) AUTHORITY AND PURPOSE. This chapter is promulgated pursuant to ss. 46.87 and 227.11 (2) (a), Stats., and section 3023 (28m) of 1985 Wis. Act 29 to establish procedures and criteria for distributing funds to county boards and private nonprofit organizations for the provision of service payments, goods and services to persons with Alzheimer's disease and to their caregivers. The payments, goods and services provided in accordance with this chapter are intended to help make available a diverse array of community services directed at preventing or delaying institutionalization of persons who have Alzheimer's disease and enhancing the quality of their lives, and to provide assistance to family members and others who take care of persons with Alzheimer's disease without compensation.

(2) TO WHOM THE CHAPTER APPLIES. The chapter applies to the department, county boards, administering agencies designated by county boards under s. 46.87 (3) (c), Stats., and private nonprofit organizations selected by the department under s. HSS 68.04 (3).

History: Cr. Register, March, 1989, No. 399, eff. 4-1-89.

## HSS 68.02 Definitions. In this chapter:

- (1) "Administering agency" means a county agency or the private nonprofit organization selected by the department under s. HSS 68.04 (3) to receive and administer program funds.
  - (2) "Adult family home" means:
- (a) A home certified by a county department of social services established under s. 46.215 or 46.22, Stats., or a county department of human services established under s. 46.23, Stats., in which one or 2 adults unrelated to the operator reside and which provides a structured living arrangement for residents whose physical, developmental and emotional functioning is likely to be maximized in this family-type living arrangement; or
- (b) A home certified under s. 50.032, Stats., and ch.HSS 82.
- (3) "Alzheimer's disease" means a degenerative disease of the central nervous system characterized especially by premature mental deterioration, and includes any of the following related diagnoses which are similarly marked by irreversible deterioration of intellectual faculties with concomitant emotional disturbance resulting from organic brain disorder:
  - (a) Creutzfeldt-Jakob syndrome;

- (b) Friedreich's ataxia;
- (c) Huntington's chorea;
- (d) Irreversible multi-infarct disease;
- (e) Parkinson's disease;
- (f) Pick's disease;
- (g) Progressive supranuclear palsy;
- (h) Wilson's disease; or
- (i) An unspecified disease or condition resulting in irreversible dementia.
- (4) "Caregiver" has the meaning prescribed in s. 46.87 (1) (b), Stats., namely, any person other than a paid provider who provides care for a person with Alzheimer's disease.
- (5) "Community-based residential facility" or "CBRF" means a facility licensed under ch. HSS 3 in which 3 or more unrelated adults reside and receive care and treatment or services above the level of room and board but not including nursing care.
- (6) "County agency" means an agency designated by a county board under s. 46.87 (3) (c), Stats., to administer the program, namely, a county department of social services created under s. 46.215 or 46.22, Stats., a county department of community programs created under s. 51.42, Stats., a county department of developmental disabilities services created under s. 51.497, Stats., a county department of human services created under s. 46.23, Stats., or a county aging unit.
- (7) "Department" means the Wisconsin department of health and social services.
- (8) "Expand services" means to expand, after January 1, 1986, the staffing, size of physical plant or programming for an existing service offered by a service provider and included in a category listed under s. HSS 68.06 (2) (b) in order to increase by at least 10% over the number served prior to expansion the number of persons with Alzheimer's disease or their caregivers who are served by the provider, or to significantly improve, in the judgment of the administering agency contracting with the provider, the quality of services or service delivery for persons with Alzheimer's disease or for their caregivers. A service is no longer defined as "expanded" 3 years after the starting date of its expansion.

- (9) "Goods and services" means, unless otherwise qualified, goods and services purchased or provided under any of the categories listed under s. HSS 68.06 (2) (b).
- (10) "Household" means a person with Alzheimer's disease living alone or a person with Alzheimer's disease and the caregiver or caregivers with whom he or she lives, except that for purposes of determining financial eligibility under s. HSS 68.07 (3) and for purposes of determining ability to pay for the cost of program goods and services under s. HSS 68.08 (1) (c), "household" means only the person with Alzheimer's disease and his or her spouse.
- (11) "Income" means gross earnings including money, wages or salary, net income from non-farm self-employment and net income from farm self-employment, and unearned income including social security, dividends, interest on savings or on money loaned, income from estates or trusts, net rental income or royalties, public assistance, pensions or annuities, unemployment compensation, worker's compensation, maintenance payments under s. 767.26 Stats., child support, family support, veterans' pensions, and educational grants given for living expenses.

Note: "Public assistance" includes but is not limited to programs such as aid to families with dependent children (AFDC), general relief, relief to needy Indian persons (RNIP) and supplemental security income (SSI).

- (12) "Medical assistance" means the assistance program operated by the department under ss. 49.43 to 49.497, Stats.
- (13) "New program" means any goods or services under one or more of the categories listed under s. HSS 68.06 (2) developed or offered for the first time on or after January 1, 1986, by a service provider under contract with an administering agency, to clients or beneficiaries, at least half of whom are persons with Alzheimer's disease or their caregivers. A program is no longer defined as "new" 3 years after its starting date.
- (14) "Private nonprofit organization" has the meaning prescribed for "nonprofit organization" in s. 108.02 (19), Stats.
- (15) "Program" means, unless otherwise qualified, the Alzheimer's family and caregiver support program under s. 46.87, Stats.
- (16) "Residential facility" means an adult family home or a community-based residential facility.

History: Cr. Register, March, 1989, No. 399, eff. 4-1-89.

- HSS 68.03 Allocation of funds. (1) The department shall allocate funds available under s. 20.435 (4) (b) and (o), Stats., for the program to each county by using the following equally weighted factors, except that no county may be allocated less than \$4,000 in any calendar year:
- (a) Each county's proportion of the state's monthly average medical assistance caseload for a 12 month period;
- (b) Each county's ranking on an urban-rural scale which shall be determined by the county's percentage of population living in cities, towns and villages with populations of 2,500 or more;
- (c) Each county's ranking as determined by the ratio of the full value of all taxable property in the county as defined in s. 70.57, Stats., to the county's population; and Register, June, 1995, No. 474

- (d) Each county's proportion of persons in the state who are 75 years of age or older.
- (2) For the purpose of determining allocations under sub.(1), the department shall use the same statistical and data sources that are used in distributing funds under s. 20.435 (4) (b), Stats., for the purchase and provision of community social, mental health, developmental disabilities and alcoholism and drug abuse services.

- HSS 68.04 Selection and reporting responsibilities of administering agencies. (1) PROGRAM ADMINISTRATION. The program shall be administered in each county by a county agency or, if the county board is not participating in the program, by a private nonprofit organization selected by the department under sub.(3).
- (2) COUNTY AGENCIES. A county board that wishes to participate in the program shall submit to the department a letter of intent to participate, except that a county board which submitted a letter of intent prior to the effective date of this chapter and which continues to participate in the program each year is not required to submit an additional letter. If the county board terminates participation in the program and in a subsequent year wishes to renew participation, it shall submit to the department another letter of intent to participate. The letter of intent shall include a statement signed by the county board chairperson indicating the county's intent to participate in the program, identifying the county agency, naming that agency's responsible contact person, estimating the number of households and residents of residential facilities to be enrolled and served in the next calendar year, identifying the maximum amount payable in a calendar year to or on behalf of any participating person with Alzheimer's disease, describing the goods and services related to Alzheimer's disease, describing the goods and services related to Alzheimer's disease which the county intends to develop or expand, and stating the policy which the county intends to use in placing applicants on and taking them off a waiting list. The categories of information required in the letter of intent shall constitute the criteria for the approval of a county board's proposed program pursuant to s. 46.87 (3) (b) and (4), Stats. The department may reject a county's participation in the program if it determines that the information provided by the county board in the letter of intent is insufficient or inconsistent with the purposes and procedures of the program as defined in s. 46.87, Stats., and this chapter.
- (3) PRIVATE NONPROFIT ORGANIZATION. If a county board does not submit a letter of intent or if it notifies the department of its decision to terminate participation in the program, the department shall:
- (a) Solicit applications from private nonprofit organizations to administer the program in the county for the calendar year; and
- (b) Select from the application or applications submitted under par. (a) a private nonprofit organization to be the administering agency for the county based on the adequacy of the organization's program budget submitted under s. HSS 68.05 (2), the organization's demonstrated knowledge of Alzheimer's disease, the organization's demonstrated ability to manage supportive service programs and the organization's experience in assessing and

meeting the needs of persons with Alzheimer's disease and their caregivers.

- (4) CHANGE OF ADMINISTERING AGENCY. If a county board that is not participating in the program submits a letter of intent to participate under sub.(2), the private nonprofit organization selected to administer the program under sub.(3) shall continue as the administering agency for the remainder of the calendar year.
- (5) NOTIFICATION TO THE DEPARTMENT OF CHANGES. Pursuant to s. 46.87 (7), Stats., the county board or the private nonprofit organization selected under sub.(3) to administer the program shall notify the department in writing within 15 working days after any of the following occurs:
  - (a) The county board designates a new county agency;
- (b) The county board or private nonprofit organization selected under sub.(3) to administer the program decides to terminate participation in the program; or
- (c) The county board or private nonprofit organization selected under sub.(3) to administer the program decides to make a change in the program or services which would result in a substantial difference from the description of the county's program and services contained in the letter of intent most recently submitted by a county board or in the application most recently submitted by the private nonprofit organization. The county board or private nonprofit organization selected under sub.(3) shall notify the department when it decides to:
- Contract with a service provider to develop a new program or expand services;
- 2. Discontinue providing, purchasing, or making payments for goods and services under one or more categories listed in s. HSS 68.06 (2) (b);
  - 3. Change its waiting list policy;
- 4. Establish a maximum payment of less than \$4,000 in a calendar year for each person with Alzheimer's disease who is participating in the program; or
- 5. Change the agency it contracts with to provide goods and services under any of the categories listed under s. HSS 68.06 (2) (b).
- (6) NOTICE TO PARTICIPANTS OF CHANGES. The administering agency shall notify each affected caregiver in writing of any change identified under sub. (5) (b) or (c) 2 or 5 at least 10 working days prior to implementing that change
- (7) RECORDS AND REPORTS. The administering agency shall maintain program records and submit reports as required by the department.

History: Cr. Register, March, 1989, No. 399, eff. 4-1-89.

HSS 68.05 Program budget requirement. (1) COUNTY AGENCY. (a) A county agency shall annually prepare a distinct budget for this program and shall submit the budget to the department each year by September 30. This distinct budget shall be part of either the proposed budget required under s. 46.031, Stats., or the plan for older people required by the department and prepared by

the county aging unit under s. 46.87 (3) (c) 4, Stats. The budget shall include at least the following information:

- 1. The total amount of allocated funds anticipated for the program for the calendar year;
- 2. The number of households anticipated to be enrolled and served for the calendar year;
- 3. The planned distribution of allocated funds by purpose under s. HSS 68.06 (1);
- 4. The method or methods for paying for goods and services under s. HSS 68.09;
- 5. The maximum amount payable in a calendar year to or on behalf of any participating person with Alzheimer's disease, if that amount is less than \$4,000;
- A brief description of any limitations on goods and services that are to be provided, purchased or contracted for:
- 7. Brief descriptions of any new programs or expanded services:
  - 8. A summary of the waiting list policy; and
- 9. The name and phone number of the principal contact person at the county agency for the program.
- (b) The department may terminate a county's participation in the program if it determines that the information provided by a county agency in the distinct budget is insufficient or inconsistent with the purposes and procedures of the program as defined in s. 46.87, Stats., and this chapter, or the county agency does not submit the distinct budget by September 30.
- (c) The county's contract with the department under s. 46.031 (2g) (a), Stats., shall include the name of the county agency and the amount of the allocation for the contract year.
- (2) PRIVATE NONPROFIT ORGANIZATION. (a) A private nonprofit organization applying to be an administering agency shall submit with its application and annually thereafter a program budget that includes:
- 1. The total amount of allocated funds anticipated for the program for the calendar year;
- The number of households anticipated to be enrolled and served for the calendar year;
- 3. The planned distribution of allocated funds by purpose under s. HSS 68.06 (1);
- 4. The method or methods for paying for goods and services under s. HSS 68.09;
- 5. The maximum amount payable in a calendar year to or on behalf of any participating person with Alzheimer's disease, if that amount is less than \$4,000;
- A brief description of any limitations on goods and services that are to be provided, purchased or contracted for;
- Brief descriptions of any new programs or expanded services;
  - 8. A summary of the waiting list policy; and

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- 9. The name and phone number of the principal contact person for the program at the private nonprofit organization.
- (b) The department may terminate an organization's participation in the program if it determines that the information provided by the organization in the budget is insufficient or inconsistent with the purposes and procedures of the program as defined in s. 46.87, Stats., and this chapter or the organization does not submit the budget by the required date or the county board of the county in which the organization is operating the program submits a letter of intent to participate for the subsequent calendar year.

History: Cr. Register, March, 1989, No. 399, eff. 4-1-89.

HSS 68.06 Allowable use of funds. (1) PURPOSES. As permitted by s. 46.87 (5), Stats., the administering agency in each county may use allocated funds for the following purposes:

- (a) To pay for the cost of goods and services provided to or purchased for or by households and for or by persons living in residential facilities who are found eligible to participate in the program under s. HSS 68.07;
- (b) To contract with service providers to develop new programs or expand services;
- (c) To provide outreach, that is, to search out persons in need of support by the program, or to provide activities designed to develop or enhance public awareness of Alzheimer's disease;
- (d) To develop or assist support groups for persons with Alzheimer's disease or their caregivers; or
- (e) To pay for program administration, except that no more than 10% of funds allocated for the program may be used for this purpose.
- (2) GOODS AND SERVICES. (a) A household or a person living in a residential facility who is participating in the program may not be restricted from purchasing goods and services listed under this subsection and identified under s. HSS 68.08 (1) (a) from providers who are located outside of the county to which application is made.
- (b) The administering agency at the time of need determination under s. HSS 68.08 (1) (a) shall enumerate to households and individuals participating in the program the goods or services that may be purchased or provided to accomplish the purposes listed under sub. (1), which shall be limited to goods and services that can be provided under the following categories:
  - 1. Adult family home;
  - 2. Advocacy and legal assistance;
  - 3. Case management or service coordination;
  - 4. Community-based care or treatment facility;
- Community organization and awareness, including all activities designed to start or support Alzheimer's support groups;
  - 6. Community support;
- Congregate meals;
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- 8. Counseling and therapeutic resources;
- 9. Crisis intervention;
- 10. Daily living skills training;
- 11. Day center services or treatment;
- 12. Health screening and accessibility;
- 13. Home-delivered meals;
- 14. Housing and energy assistance;
- 15. Information and referral;
- 16. Inpatient treatment;
  - 17. Intake and assessment;
  - 18. Interpreter services and adaptive equipment;
  - 19. Outreach:
  - 20. Protective payment or guardianship;
  - 21. Recreation and alternative activities;
  - 22. Respite care;
  - 23. Shelter care;
  - 24. Specialized transportation and escort;
  - 25. Supportive home care;
  - 26. Work-related services; and
- 27. Any other goods and services that are necessary to maintain the person with Alzheimer's disease as a member of the household.
- (3) ADMINISTRATION. Administering agencies may use program funds to pay for the cost of administering the program only if the costs are incurred under one or both of the following categories:
  - (a) Training and development; or
  - (b) Agency and systems management.

Note: For descriptions of the categories listed under subs.(2) and (3), write the Division of Community Services, Bureau of Management and Budget, P.O. Box 7851, Madison, Wisconsin 53707.

- HSS 68.07 Client eligibility. In accordance with s. 46.87 (5), Stats., the administering agency in each county shall determine the eligibility of each household or person living in a residential facility in that county who applies to participate in that county's program by establishing that the household or person meets all of the following conditions:
- (1) DIAGNOSIS OF CONDITION. At least one member of the household or the person who lives in a residential facility has received a final, tentative or preliminary written diagnosis of Alzheimer's disease from a physician;
- (2) COUNTY OF RESIDENCE. (a) The person in the household who has Alzheimer's disease or that person's caregiver resides in the county; or
- (b) The person with Alzheimer's disease lives in a residential facility located in the county; and

(3) HOUSEHOLD INCOME. The person with Alzheimer's disease and that person's spouse are expected to have a joint income of no more than \$40,000 for the 12-month period immediately following application for the program, except that in determining the income of a household with a joint gross income of more than \$40,000, the administering agency shall subtract any expenses attributable to the Alzheimer's-related needs of the person with Alzheimer's disease or of the person's caregiver. If the net income determined by subtracting Alzheimer's-related expenses for a household is \$40,000 or less, the household shall be considered as having met the household income eligibility condition.

History: Cr. Register, March, 1989, No. 399, eff. 4-1-89.

HSS 68.08 Payment calculation. (1) Determination of NEED. For the purpose of calculating the funds to be paid to or expended for a household or individual participating in the program, the administering agency in the county shall determine:

- (a) The goods and services needed by the household to enable it to maintain the person with Alzheimer's disease as a member of the household, or the goods and services needed by a person with Alzheimer's disease living in a residential facility;
  - (b) The cost of each good and service that is needed; and
- (c) The ability of the household to pay for the goods and services identified under par. (a), using as the basis for this determination the uniform system of fees for services established by the department under s. 46.03 (18), Stats., and ch. HSS 1, except that in determining income of eligible households with gross incomes of more than \$40,000 the administering agency shall use gross income and not net income as the basis for determining ability to pay.
- (2) COST SHARING. If the administering agency determines under sub.(1) (c) that an applicant household or person with Alzheimer's disease is able to pay for goods and services identified under sub.(1) (a), the administering agency:
- (a) Shall require as a condition of participation that the household or person pay for all or a portion of the costs of goods and services to accomplish the purposes under s. HSS 68.06 (1) (a). The amount of payment shall be determined according to the uniform system of fees for services established by the department under s. 46.03 (18), Stats., and ch. HSS 1; and
- (b) May require the household or person to pay for all or a portion of the costs of goods and services to accomplish the purposes under s. HSS 68.06 (1) (b). The amount of payment shall be determined according to the uniform system of fees for services established by the department under s. 46.03 (18), Stats., and ch. HSS 1.
- (3) APPLICATION OF REVENUES. If revenues are received by an administering agency from cost-sharing payments, these revenues may only be used for the non-administrative purposes under s. HSS 68.06 (1) (a) to (d) and only for the goods and services under s. HSS 68.06 (2).
- (4) LIMIT. The administering agency in each county may pay to or expend on behalf of a participating household or on behalf of a person with Alzheimer's disease living in a residential facility the costs of any goods and services

identified under sub.(1) (a) minus the amount the household or person with Alzheimer's disease is able to pay, as determined under sub.(1) (c), except that the amount paid or expended may not exceed \$4,000 in any calendar year for each person with Alzheimer's disease in the household or for each person with Alzheimer's disease living in a residential facility.

History: Cr. Register, March, 1989, No. 399, eff. 4-1-89.

HSS 68.09 Method of payment. The payment by an administering agency for goods and services shall be made using one or more of the following methods:

- (1) Payment made to a service provider on behalf of the person with Alzheimer's disease or of the person's caregiver;
- (2) Payment made to a service provider under contract with the administering agency to develop new programs or to expand services;
- (3) Payment made to the household of a person with Alzheimer's disease pursuant to accounting requirements set forth by the administering agency; or
- (4) Payment made to the manager of a residential facility in which a person with Alzheimer's disease resides for the purchase of goods or services, or both, pursuant to accounting requirements set forth by the administering agency.

- HSS 68.10 Hearing. (1) JURISDICTION. Any household or individual participating in the program or caregiver may appeal the following actions by an administering agency:
- (a) Denial of an application to participate in a county's program;
- (b) The calculation of funds to be paid to or expended for a household or a person with Alzheimer's disease living in a residential facility and participating in the program;
- (c) Reduction, suspension, limitation or termination of goods and services provided under this chapter;
- (d) Change of provider of goods and services provided under this chapter;
- (e) Change of method of payment for goods and services provided under this chapter; and
- (f) Change of the maximum amount payable in a calendar year to or on behalf of any participating person with Alzheimer's disease.
- (2) NOTIFICATION OF APPEAL RIGHTS. At the time an administering agency takes any of the actions under sub. (1), it shall inform the household, individual participating in the program, any caregiver, and any guardian or protective payee, in writing, of the right to a hearing under this chapter and of the procedure for requesting a hearing.
- (3) REQUEST FOR HEARING. A household or individual participating in the program or caregiver wishing to contest an action under sub.(1) shall file a written request for a hearing with the department's office of administrative hearings within 45 days after the date of the action for which review is sought. A hearing request shall be consid-

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ered filed on the date of receipt by the office of administrative hearings.

Note: The mailing address of the Office of Administrative Hearings is P.O. Box 7875, Madison, Wisconsin 53707-7875.

(4) Arrangements for a hearing. In response to a request for a hearing under this section, the director of the office of administrative hearings shall appoint a hearing examiner, set a date for the hearing and notify the parties at least 10 days before the hearing of the date, time and place of the hearing and of the procedures to be followed.

History: Cr. Register, March, 1989, No. 399, eff. 4-1-89.

HSS 68.11 Exceptions to requirements. The department may grant an exception to an administering agency of any requirement made of the administering agency under this chapter, except a requirement under s. HSS 68.03 or 68.10 (2), if the department is convinced that an alternative to the requirement meets the intent of and is in compliance with s. 46.87, Stats. The department shall respond in writing to a written request for an exception within 30 days after receiving the request.