



## WISCONSIN LEGISLATIVE COUNCIL INFORMATION MEMORANDUM

### Family Caregiving for Elderly Persons

#### INTRODUCTION

Family caregiving is widespread in the United States. Family caregiving, also known by the broader term “informal caregiving,” is generally understood to mean unpaid care provided by relatives or close friends for a person who is no longer able to manage all aspects of his or her daily life or personal care.<sup>i</sup>

Estimates of the number of informal caregivers in the United States range from 24 million to 27.6 million people.<sup>ii</sup> These estimates encompass caregivers of persons with a chronic illness or disability, in addition to elderly persons. These caregivers are providing care for an estimated 12.8 million Americans of all ages needing long-term assistance to help carry out activities of daily living, such as eating, dressing and bathing.<sup>iii</sup> Of the persons being cared for by informal caregivers, 57% (7.3 million) are aged 65 and over; 40% (5.1 million) are aged 18 to 64, and 3% (400,000) are under age 18.<sup>iv</sup> A recent study showing the economic value of family caregiving estimates that, based on 1997 data, \$196 billion worth of informal caregiving was provided in that year. This compares with estimates of \$32 billion spent on home care and \$83 billion spent for nursing home care.<sup>v</sup>

Informal caregivers in the United States have the following characteristics:

- Approximately 72% of informal caregivers are female.<sup>vi</sup>

- The average age of a caregiver is 57 years of age.<sup>vii</sup>
- 85% of caregivers are family members.<sup>viii</sup>
- Caregivers provide, on the average, approximately 13 hours of care per week if the care recipient does not suffer from dementia and 19 hours per week if the recipient suffers from dementia.<sup>ix</sup>
- Approximately 31.7% of Asian households, 29.4% of African American households, 26.8% of Hispanic households, and 24% of Caucasian households are involved in caregiving.<sup>x</sup>
- 64% of caregivers are employed outside the home.<sup>xi</sup>

#### ISSUES RELATING TO FAMILY CAREGIVING

The following issues related to family caregiving have been identified as being of interest to policymakers:

- Family caregivers provide the majority of long-term care in the United States. A reduction in the amount of family caregiving may increase government long-term care costs for programs such as the MA program, which funds nursing

home care and other types of long-term care for low-income elderly persons and others.

- Caregiving is becoming increasingly complex and specialized, because of shorter hospital stays and patients being discharged to the home who need higher levels of care.
- More persons will require long-term care in the future, because of an increase in the percentage of the population which is elderly, and an increase in longevity.
- Family caregivers often face multiple roles of caregiving and employment. Caregiving can have an impact on career advancement, worker productivity and wage levels.

These considerations lead to calls for the provision and enhancement of caregiver supports, in the form of respite care, financial assistance for goods and services needed to provide care, employment supports, tax incentives and specialized caregiver training due to the increased complexity of caregiving.

### **CAREGIVER SUPPORTS**

Policymakers at both the state and federal levels have acknowledged the importance of providing supports for caregivers, in order to enable informal caregiving to continue. Since it forms the bulk of the long-term care provided in the United States, not having this care available would have financial and structural implications for the long-term care system. Programs at both the state and federal levels, ranging from leave benefits, tax credits or deductions, and specific support programs, have been established to provide support to the family caregivers.

### **FEDERAL PROGRAMS**

#### **National Family Caregiver Support Program**

At the federal level, the Administration on Aging (AOA), within the U.S. Department of Health and Human Services (DHHS), administers the aging network and programs which support elderly persons in the community. Some of these programs provide support to caregivers of elderly persons. The federal AOA distributes funds to states for programs such as congregate and homebound meal programs, transportation, and home care service programs. The state level agency (in Wisconsin, the Department of Health and Family Services (DHFS)), distributes federal as well as state funding to area agencies on aging, which administer the aging network at the local level. There are six area agencies on aging in Wisconsin.

A new program established within the aging network to provide support specifically to caregivers is the National Family Caregiver Support Program (NFCSP).

The NFCSP was signed into law on November 13, 2000, as part of the Older Americans Act Amendments of 2000 (P.L. 106-501). The NFCSP allocates \$113 million for grants to states to enable area agencies on aging to provide an array of support services to family caregivers of older adults, as well as grandparents and relative caregivers of children under age 18.

Basic support services which must be provided under the Act are as follows:

- Information to caregivers about available services.
- Assistance to caregivers in gaining access to support services.

- Individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decisions and solving problems relating to their caregiving roles.
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities.
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

Priority for services must be given to older individuals with the greatest social and economic needs, and older individuals providing care and support to persons with mental retardation and developmental disabilities.

Wisconsin received approximately \$2 million under this program in February 2001.

#### **Family and Medical Leave Act**

The federal Family and Medical Leave Act (FMLA) was enacted in 1993. The FMLA provides support to family caregivers by permitting eligible employees to take up to 12 weeks of unpaid, job-protected leave in each 12-month period for specified family or medical reasons. A permissible use of leave under the FMLA is leave to care for an immediate family member (spouse, child or parent) with a serious health condition. In some cases, care provided to elderly family members might qualify as a permissible use of leave, if the elderly family member has a "serious health condition," as defined in the FMLA.

Further information on the FMLA may be found in Wisconsin Legislative Council Information Memorandum 98-30, *Family and Medical Leave in Wisconsin*.

#### **Medical Assistance Program**

Low-income elderly persons who meet Medical Assistance (MA) eligibility standards may be eligible for MA-funded services. MA is a joint federal- and state-funded program which provides medical services to certain low-income persons. Some of these services may allow a care recipient living in the community to access needed supports to prevent institutional placement. In some cases, services such as respite care may be funded under MA to provide support to family caregivers. Under the MA program, programs known as home and community-based (HCB) waiver programs have been developed in order to prevent institutional placement or to relocate persons living in institutional placements. In Wisconsin, the Community Options Program (COP) and the Community Integration Programs (CIP) are examples of HCB waiver programs that provide these supports. Examples of services that can be provided to persons under HCB waiver programs include home modifications, adaptive equipment, communication aids, financial counseling, care management, housekeeping, and personal and home health care. These programs may also provide respite care to enable caregivers to take a break from caregiving responsibilities.

Personal care services under MA provide help with medically oriented activities to assist a recipient with activities of daily living necessary to maintain the recipient in his or her residence.<sup>xii</sup> In some cases, family members may be able to be paid to provide these services if they are not legally responsible relatives of the recipient.<sup>xiii</sup> Personal care workers must meet training and other requirements in order to be certified under MA.<sup>xiv</sup>

#### **Federal Tax Credit**

The federal Child and Dependent Care Tax Credit may, in some cases, be available for caregivers providing care for a dependent or a

spouse who is physically or mentally incapable of caring for himself or herself (a “qualifying individual”). The federal credit allows taxpayers to receive a tax credit for employment-related expenses which are expenses for household services and for the care of the qualifying individual to enable the caregiver to be gainfully employed. A qualifying individual is a person who is either a dependent under age 13, or a dependent age 13 or over or a spouse who is considered physically or mentally incapable of self care. A person is considered incapable of self care if, as the result of physical or mental defect, the person is incapable of caring for his or her hygienic or nutritional needs or requires the full-time attention of another person for his or her own safety or for the safety of others.<sup>xv</sup>

A number of state tax credits have been created which “piggyback” onto the federal credit. These are described in the section of this Information Memorandum entitled “Tax Credits and Deductions.”

### **WISCONSIN PROGRAMS**

#### **MA Programs**

Two MA HCB waiver services in Wisconsin may provide services to elderly persons living in the community who need supports to remain in the community: the COP HCB waiver program (COP waiver program) and the Community Integration Program II (CIP-II). These programs make available a wide array of supportive services to enable a person to remain in his or her home. In some cases, respite care and other services provide support to family caregivers. Both programs require that the individual meet a nursing home level of care. The COP waiver program diverts or relocates persons from nursing homes. CIP-II funds are available when a person is relocated from a nursing home and the bed is closed. Persons must meet both nonfinancial (age and disability-

related) criteria and financial eligibility criteria to be eligible for these HCB waiver programs.

In calendar year 1999, 2,516 persons were served in CIP-II in Wisconsin, and there were 9,840 funded slots in the COP waiver program.<sup>xvi</sup>

#### **COP-Regular**

The COP-“regular” (COP-R) program serves eligible persons living in the community who are not eligible for the COP waiver program and who are elderly, physically disabled, developmentally disabled, or chronically mentally ill. Almost 60% of the clients served under the COP-R program are elderly (over age 65).

Like the COP waiver program, persons in COP must meet nonfinancial eligibility criteria, such as requiring a nursing home level of care. Persons may also be eligible for COP if they suffer from Alzheimer’s Disease or a related illness and need supervision, personal assistance and other services.

Financial eligibility criteria also applies under COP-R. However, these criteria are more generous than the criteria for the COP waiver program. In addition, if the person exceeds the financial limits, they may still receive services if they pay for them.

As of calendar year 1999, there were 10,954 funded slots under the COP-R program.<sup>xvii</sup>

#### **Alzheimer’s Family and Caregiver Support Program**

The Wisconsin Alzheimer’s Family and Caregiver Support Program (AFCSP) was established in 1985. The program provides services to persons with the diagnosis of Alzheimer’s Disease or related dementias to enable them to remain in their homes, and to provide support to their caregivers. This AFCSP is completely state funded in the

amount of \$2,342,800 in each fiscal year. The person serves approximately 1,000 persons.

Under the program, DHFS allocates funds to counties on a formula basis that takes into account such factors as the county's MA caseload, value of taxable property, number of residents age 75 or older and the county's degree of urbanization.

A person may receive up to \$4,000 per year in services under the AFCSP. Individuals or couples with incomes of up to \$40,000 may qualify for assistance. Some of the services that may be provided to assist a recipient and the recipient's caregiver include in-home health care services, respite care, adult day care and transportation. Goods provided include nutritional supplements, security systems, specialized clothing, home-delivered meals, and adaptive equipment.<sup>xviii</sup>

### **Lifespan Respite Care**

Lifespan Respite Care program, authorized under s. 48.986, Stats., provides \$225,000 general purpose revenue (GPR) in each fiscal year for respite care projects.

Under the program, DHFS contracts with the Respite Care Association of Wisconsin to administer a lifespan respite care project in each of five geographic regions across the state. The projects provide an array of services, which are focused on coordinating and developing resources available for respite care, recruiting and screening respite care providers and facilitating access to respite care options.

Under the program, "respite care" is care that is provided to a person with special needs or a person at risk of abuse or neglect, in order to provide temporary relief to the caregiver of that person or when the caregiver is unable to provide care. Eligibility for the program is not limited to caregivers of elderly persons. A caregiver is an individual who lives in the home

of a person with special needs and provides care or supervision for that person. A special need that qualifies a person for respite care is a need resulting from an emotional, behavioral, cognitive, physical or personal condition that necessitates receipt of care or supervision in order to meet the person's basic needs or prevent harm from occurring to the person.

### **OTHER STATES' PROGRAMS**

Two states that are frequently cited as having innovative family caregiver support programs are Pennsylvania and California.

#### **Pennsylvania Family Caregiver Support Program**

The Pennsylvania Family Caregiver Support program has operated on a statewide basis since 1990. It serves family caregivers for elderly persons, but also serves caregivers of adults with chronic dementia who may not be elderly. The family caregiver must reside in the same home as the care recipient.

The program is 100% state-funded, providing approximately \$11.5 million per year for up to \$200 per month in reimbursement for the following services: information and referral; needs assessment; care planning; care management; legal consultation; respite care; home modifications; support groups; emergency response; education and training; counseling; and financial assistance to purchase goods and supplies. Families with incomes less than 380% of the federal poverty level are eligible for the program.<sup>xix</sup>

#### **California Caregiver Resource Centers**

California's Caregiver Resource Centers were established in 1984 and operate 11 regional sites serving over 10,000 clients. The program is 100% state-funded. The 11 caregiver resource centers provide services to unpaid family members and individuals who assume the

responsibility for care of persons with adult-onset cognitive impairments, such as traumatic brain injury, Alzheimer's and other dementias, Parkinson's Disease, Huntington's Disease, epilepsy, multiple sclerosis, and many other conditions.

Services are consumer-directed, and include: specialized information and referral; comprehensive assessment; family consultation and care planning; counseling; support groups; legal consultation; caregiver education and training; respite care; and psychoeducational groups.

As of 1999, the appropriation for this program was approximately \$9.2 million.<sup>xx</sup>

#### **STATE TAX CREDITS AND DEDUCTIONS**

Several states have adopted tax credits or deductions that alleviate the financial impact of caregiving. These credits and deductions can be summarized as follows:

- Employment-related dependent care tax credits that are a percentage of the federal credit: Arkansas, Delaware, District of Columbia, Hawaii, Iowa, Kansas, Kentucky, Maine, Minnesota, Nebraska, New Jersey, New York, North Carolina, Ohio and South Carolina.
- Caregiving-related tax credits which provide a credit for expenses related to caregiving for an elderly family member: Georgia, Montana, North Dakota and Oregon.
- Employment-related dependent care tax deduction: Idaho, Maryland, Massachusetts and Virginia.
- Caregiving-related tax deduction: Iowa.
- Employer tax credits for dependent care assistance provided to employees:

Illinois, Mississippi, Montana and Rhode Island.<sup>xxi</sup>

The following websites provide additional information on informal or family caregiving:

#### **Family Caregiver Alliance:**

<http://www.caregiver.org>

#### **Alzheimer's Association:**

<http://www.alz.org>

#### **United States Administration on Aging:**

<http://www.aoa.gov>

#### **Wisconsin Department of Health and Family Services:**

<http://www.dhfs.state.wi.us/aging/index.htm>

#### **American Society on Aging:**

<http://www.asaging.org>

#### **National Alliance for Caregiving:**

<http://www.caregiving.org>

This memorandum was prepared on September 24, 2001 by Laura Rose, Deputy Director, Legislative Council Staff. The information memorandum is not a policy statement of the Joint Legislative Council or its staff.

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<sup>i</sup> National Alliance for Caregiving and the American Association of Retired Persons, *Family Caregiving in the U.S.: Findings From a National Survey*, June 1997, p. 6.

<sup>ii</sup> Arno P., Levine, C. and Merriott, M., "The Economic Value of Informal Caregiving," *Health Affairs*, v. 18, no. 2, pp. 182-188.

<sup>iii</sup> Family Caregiver Alliance, *Fact Sheet: Selected Caregiver Statistics*, August 1999, p. 1.

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<sup>iv</sup> *Id.*

<sup>v</sup> Tennstedt, Sharon, *Family Caregiving in an Aging Society*, presented at the U.S. Administration on Aging Symposium: “Longevity in the New American Century,” March 29, 1999.

<sup>vi</sup> National Alliance for Caregiving, *supra.*, note i., p. 9.

<sup>vii</sup> *Id.*, p. 8.

<sup>viii</sup> *Id.*, p. 12.

<sup>ix</sup> National Alliance for Caregiving, *supra.*, note i, p. 8.

<sup>x</sup> *Id.*

<sup>xi</sup> Tennstedt, *supra.*, note v, p. 5.

<sup>xii</sup> Section HFS 107.112 (1), Wis. Adm. Code.

<sup>xiii</sup> Legally responsible relatives are defined under s. 49.90 (1), Stats., and are the parent of a child under age 18; a spouse; and a grandparent, if the grandparent’s dependent child under age 18 has a child.

<sup>xiv</sup> Section HFS 105.17 (3), Wis. Adm. Code.

<sup>xv</sup> Devore, Elizabeth, *State Tax Incentives for Caregivers and Other Related Provisions*, Alzheimer’s Association, July 1999, p. 3.

<sup>xvi</sup> Wisconsin Department of Health and Family Services website.

<sup>xvii</sup> *Id.*

<sup>xviii</sup> Chapter HFS 68, Wis. Adm. Code.

<sup>xix</sup> Family Caregiver Alliance, *Survey of Fifteen States’ Caregiver Support Programs: Final Report*, October 1999, p. 139.

<sup>xx</sup> *Id.*, p. 89.

<sup>xxi</sup> Devore, *supra.*, note xvii, pp. 4-12.

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**WISCONSIN LEGISLATIVE COUNCIL**

One East Main Street, Suite 401 • P.O. Box 2536 • Madison, WI 53701-2536

Telephone: (608) 266-1304 • Fax: (608) 266-3830

Email: [leg.council@legis.state.wi.us](mailto:leg.council@legis.state.wi.us)

<http://www.legis.state.wi.us/lc>