



Family Matters

A Newsletter for Wisconsin Policymakers

A Wisconsin Family Impact Seminars Publication



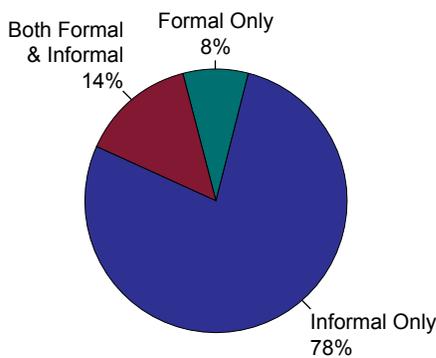
Families: The Backbone to Long-Term Care

Families are the backbone to long-term care. Families have always provided care to the aged and those with mental and physical disabilities, but historically family caregiving was short-lived. Given medical technologies that keep people alive longer, family caregiving now lasts longer and has become essential to our health and long-term care system.¹

How Much Informal Long-Term Care is Occurring?

Informal care, provided primarily by family and friends, is the only care received by almost 80% of adults with long-term care needs (see Figure 1).² These national statistics mirror what is happening in Wisconsin.³

Figure 1: Type of Care Received by Adults with Long-Term Care Needs Living in the Community 1994-1995



Source: Health Policy Institute, Georgetown University.

What is the Value of Long-Term Care in Wisconsin?

Without family caregivers, Medicaid and other health care costs would be much higher. In a recent study, one-half million caregivers in Wisconsin are providing almost 558 million hours each year caring for ill and disabled adults. The value of this informal family caregiving in Wisconsin is estimated at over \$4.9 billion—two to three times the amount spent by Medicaid.⁴

Given its economic value, it is no surprise that political observers have recommended reframing the long-term care debate to supplementing and strengthening family caregiving.

What Toll Does Long-Term Care Take on Family Caregivers?

Caregiving takes a financial and physical toll on caregivers. Out-of-pocket medical expenses are 2.5 times more for a family with a loved one with a disabling or chronic condition. Compared to non-caregivers, family caregivers providing 36 or more hours of care weekly experience more depression or anxiety and turn to prescription drugs 2 to 3 times more often.⁵

Without adequate financial and emotional support, family caregivers can put their own health and well-being in jeopardy. Respite, or occasional relief from the stresses of caregiving, has been shown to help avoid abuse, neglect, and costly out-of-home placements. In emerging evidence, respite care also reduces the likelihood of divorce.⁶

What Support Programs are Available for Family Caregivers in Wisconsin & Other States?

In Wisconsin, three main programs provide support to family caregivers for adults (excluding those with developmental disabilities): the Family Caregiving Support Program administered by the county aging offices; the Community Options Program-Waiver administered by the Area Agencies on Aging and county departments of human or social services; and the Alzheimer’s Family and Caregiver Support Programs administered by county health or aging departments. These programs are summarized in Table 1.

Table 1. Wisconsin Programs for Family Caregivers			
	Family Caregiver Support Program	Community Options Program-Waiver	Alzheimer’s Family/Caregiver Support
Funding	Local/county funds OAA, Title III-E	Medicaid HCBS waiver	State general fund
Expenditures (FY 2003)	\$2.7 million	\$144 million	\$1.9 million
Care Receiver Age	60+	18+	
Client	Family caregiver	Care receiver	Both caregiver and care receiver
Services provided (partial list)			
Education & training	•	•	•
Information & assistance	•	•	•
Respite care	•	•	•
Assistive technology	•		•
Care management	•		•
Counseling	•		•
Family consultation	•		•
Home modification/repairs	•		•
Homemaker/chore/personal care	•		•
Support groups	•		•
Respite cap	116 hours/year	no cap	\$4,000/year
Consumer-directed options			
Families have choice of respite providers	•	•	•
Voucher or budget for respite and/or supplemental services	•		•
Voucher or budget for respite only		•	
Direct payments to family members for purchase of goods or services	•		•
Menu of services from which caregivers can choose			•
Services families can be paid to provide			
Respite	•	•	•
Personal	•	•	•
Homemaker/chore		•	
Other		•	
Program Assesses	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver

Source: Family Caregiver Alliance study by Feinberg et al. (2004).⁷

How are States Responding to the Needs of Family Caregivers?

In 2004, the National Governors Association (NGA) released a report on strategies states are using to support family caregivers.⁸ We’ve added what Wisconsin is doing.

(1) Using state and federal funds to support respite care and family caregivers

All states provide the service that family caregivers say they need most—respite and day care to provide time away from the stresses of caregiving.⁹ However, the amount of respite varies from state to state and from program to program. A March 2006 report highlighted two innovations.¹⁰





The Value of Families in Long-Term Care! A Brief for Policymakers



Family Matters is a newsletter for state policymakers published by the Wisconsin Family Impact Seminars (WISFIS). WISFIS connects research and policymaking, and examines the impact of policies on families. The seminars provide objective, state-of-the-art information on a range of policy options. WISFIS is a joint effort of University of Wisconsin-Extension and the Center for Excellence in Family Studies in the School of Human Ecology at the University of Wisconsin-Madison.

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Family Matters is on the web at:
<http://www.familyimpactseminars.org/newsletters.htm>

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First, states are taking a more “family-centered” approach to long-term care by considering as the client both the person receiving care and the caregiver. When family and friends are physically and mentally healthy, they are more able to care for their loved one and to provide better care. One new direction states are taking is to uniformly assess the needs of caregivers in their home and community-based services programs. To date, only 5 states that conduct uniform assessments (not Wisconsin) include a caregiver component.¹¹

Second, states are building collaborations between the aging network and health care providers. Because health care providers are often the first entry into the long-term care system, they can (a) identify when caregiving may be impairing the health of caregivers, and (b) connect caregivers with support services.¹²

(2) Maximizing choice for consumers and caregivers

States are moving toward giving care recipients more choices and greater control of their long-term care by offering options such as vouchers for purchasing services, paying family members to provide care, and offering a variety of respite care arrangements. *Cash and Counseling*, perhaps the most well-known of these efforts, was piloted by **Arkansas, Florida, and New Jersey**. With the passage of the 2005 Deficit Reduction Act in February 2006, states now can offer these “individual budget” programs without a federal waiver.¹³

Wisconsin is one of 10 states that already had an individual budget program in place before February. Wisconsin offers some aspects of consumer direction in all three of its main family caregiver support programs (See Table 1). In addition, Family Care offers Self Directed Supports (SDS), a voluntary program for Family Care beneficiaries. Most (91%) of the expenditures have been used for personal care, supportive home care, or other home health care.¹⁴ The average SDS expenditure per member is \$700 per month. In February 2005, there were 2,087 Family Care beneficiaries participating in some form of SDS; most were in Milwaukee.

- In 2002, Wisconsin ranked 8th in the nation for the percent of people aged 85 and older.
- In 2004-2005, Wisconsin’s Medicaid program spent nearly \$2.2 billion on long-term care, about half on home and community-based care (48%) and half for institutionalized care (52%).
- In 2003, Wisconsin ranked 11th highest in the nation for the percent of elderly in a nursing home.
- The elderly without family caregivers are 7 times more likely to be in a nursing home.
- In Wisconsin, one-half million citizens are providing almost 558 million hours each year caring for ill and disabled adults—at an estimated value of over \$4.9 billion.

(3) Expanding Family and Medical Leave

The federal Family and Medical Leave Act guarantees employees of businesses with at least 50 employees 12 weeks of unpaid leave each year to care for a newborn, newly adopted child, or seriously ill family member. States have expanded their laws in several ways.¹⁵ Listed below are provisions that Wisconsin does not currently provide:

- **Oregon** and **Vermont** expanded leave provisions to workplaces with fewer than 50 employees.
- **California, Connecticut, Louisiana, Oregon, Rhode Island, and Tennessee** extended the 12-week leave period.
- **Washington** allows public and private sector employees to use family leave to care for a seriously ill grandparent. **Wisconsin** does not, unless the grandparent is raising a child.
- No state covers leave for a caregiver whose child or elder is not seriously ill, but is too sick to go to child care or day care.

(4) Improving tax treatment of caregiver expenses

In Wisconsin, caregivers can count the care recipient as a dependent if they provide more than half of the care. However, Wisconsin citizens cannot deduct caregiver expenses on their state income taxes.

References are at <http://www.familyimpactseminars.org/newsletters.htm>.

To read the entire National Governors Association report, visit <http://www.nga.org/Files/pdf/0406AgingCaregivers.pdf>.

To read *A Policymakers Guide to Long-Term Care in Wisconsin: Public, Private, and Family Perspectives*, from the recent Wisconsin Family Impact Seminar report on long-term care reform, visit <http://www.familyimpactseminars.org/fis23.htm>.

To read the *Family Caregiver Alliance 50-state study*, visit http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1220.



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Source: Wisconsin Legislative Fiscal Bureau (December, 2005), based on information from the Wisconsin Department of Health and Family Services.

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