

## **Family Living Programs**

### **Strengthening the Delivery of Family Caregiver Education through Partnerships**

#### **Situation**

There is a movement within Wisconsin, and nationally, to redesign the long-term care system. Family members are providing 80 percent of the care to someone who is older or ill. And for most, caregiving is a career they have not chosen, prepared for or planned for. These caregivers need education and training in order to handle their new roles and the responsibilities they will face over time as they work to provide consistent, quality care to a loved one.

Wisconsin is at the forefront of building partnerships to help communities address the challenges of family caregiving. Solutions to these daily challenges require the knowledge, skills and resources of many individuals and organizations. Community partnerships bring diverse stakeholders together to work toward a common goal, while engaging the individuals, families, and others who benefit from the work, in its planning and implementation. Research indicates that community collaborations can strengthen community health and resilience and foster coordination at the system and individual case levels. Coalitions enable spin off activities and initiatives, and studies are beginning to show long-term effects on policy change and individual well-being. The ability of coalitions and partnerships to mobilize and focus resources has contributed to these successes.

Partnerships are shaping the way caregiver education is delivered in Wisconsin. In an age when many families find themselves squeezed between taking care of children and older relatives, the Wisconsin Alliance for Family Caregiving serves a critical purpose—to educate and support a rapidly growing number of family caregivers.

#### **Response**

The Wisconsin Alliance for Family Caregiving fills the enormous need for family caregiving education and support by offering a single statewide resource for innovative hands-on training; a web site giving professional trainers access to all the promotional, education and evaluation materials they need to conduct classes; and opportunities to build caregiving partnerships.

The Wisconsin Alliance for Family Caregiving is in the business of educating professionals who work directly with family caregivers. It is not a professional organization for paid caregivers, rather, the Alliance has a statewide network of advanced instructors, or master trainers, who train individuals as class leaders in four research-based caregiving curricula. Class leaders go on to conduct classes for family caregivers throughout the state. The Alliance also organizes a biennial Family Caregiver Institute; offers resources for family caregivers on the web site (fact sheets, newsletters, university publications and web links to state and national organizations); supports local caregiving coalitions; and creates opportunities for professionals who work with family caregivers to network and learn from one another.

Partnerships form the foundation of the Alliance. Partners include 75 plus member organizations representing a diverse network of professional trainers; other caregiving organizations, alliances and coalitions; and most importantly, Wisconsin's family caregivers.

The Alliance offers four caregiving curricula: *Caregiving Relationships*, *Caregiving Near Life's End*, *Powerful Tools for Caregivers*, and *Elder Care and Work*. These curricula build on the knowledge and research of university researchers. For example, University of Illinois Extension staff developed *Caregiving Relationships*; University of Florida researchers developed the evaluation for *Caregiving Near Life's End*; a retired Oregon State University Extension gerontologist created *Powerful Tools*; and a University of Wisconsin-Extension specialist and county educator adapted *Elder Care and Work* to fit Wisconsin caregivers.

A patchwork of funds keeps the Alliance running. From its birth, Wisconsin AARP had been a major supporter. In 2005, the Alliance received a Wisconsin Partnership Program grant and recently, funds from two Area Agencies on Aging. Financial support was also provided by the Helen Bader Foundation, the University of Wisconsin-Extension, Wisconsin's six Area Agencies on Aging, county aging offices, and the State Bureau on Aging and Long Term Care Resources for underwriting training costs. University of Wisconsin-Extension provides the Alliance web site.

In 2006, The Wisconsin Alliance for Family Caregiving became a nonprofit organization and grew from the success of teaching the *Powerful Tools for Caregivers*. Caregiving professionals recognized the value of one organization providing leadership in the selection, training, dissemination and evaluation of family caregiver curricula statewide.

## Outcomes

The Wisconsin Alliance for Family Caregiving exists for one reason: to make life better for family caregivers who care for older, often ailing, family members. The vision of the Alliance is to give all Wisconsin family caregivers access to the education, resources and support they need to maintain their health and well-being. The Alliance's primary mission is training professionals to teach family caregivers. In six years of existence, the Alliance has trained some 400 individuals—educators, social workers, health-care providers, aging-network professionals and others—as class leaders in one or more of the four curricula. Class leaders have, in turn, reached more than 2,000 Wisconsin family caregivers through workshops, one-on-one consultations, support groups and other activities.

Class leaders are passionate about the changes they see in caregivers who attend family caregiving classes. *Powerful Tools* teachers tell Alliance members again and again: "These classes are life-changing. I'm amazed at the changes that occur immediately with individuals who take the class. They look better, are more confident, take control and feel as if they have options and choices. They're able to take charge of the caregiving situation."

The Alliance recognizes the need for training and education among Wisconsin family caregivers, and is dedicated to expanding the benefits of working at state and community level to these individuals throughout the state. Partner organizations express the benefits of working with The Wisconsin Alliance for Family Caregiving:

Lisa Wells, Eau Claire County Aging Director, says:

*"Working with the Alliance has been very beneficial to me and to Eau Claire County. I have been able to facilitate nine Powerful Tools for Caregiving classes, provide brochures from Caregiving Relationships and excellent handouts from the web site. I will also be providing training to caregivers in the workplace through the curriculum Elder Care and Work. The*

*trainings, web site and meetings with other Alliance members have expanded my knowledge about family caregiving and have allowed me to provide better access to education programs and resources. The Alliance has also been helpful in starting our own Chippewa Valley Family Caregiving Alliance.”*

Kathy Miller, Bayfield County UW-Extension Family Living Educator, says:

*“The Alliance has been very instrumental in extending family caregiver education to all corners of the state. In our northern rural counties, distance to travel for caregiving services and education is considerable. The Alliance has provided an avenue to train a variety of local professionals to teach family caregiving classes to residents right in the communities where they live and work. The Alliance web site is also a valuable resource for caregivers to pursue information on their own time. The web site posts program offerings throughout the state, and has a wealth of articles and references on caregiving topics and disease-related issues.”*

The Wisconsin Alliance for Family Caregiving has provided a prototype for the formation of local caregiver collaboratives in communities throughout Wisconsin.

For example, Kathy Miller reports that Ashland and Bayfield Counties have formed the *Ashland and Bayfield Counties Caregiver Support Network*, which consists of about a dozen agency representatives working hard to advocate for, and support the role of family caregivers providing care for others. Working as a team, they have implemented five successful annual conferences, organized a town hall meeting to raise public awareness of caregiving issues, served as a catalyst for the creation of a dementia diagnostic clinic in the local hospital, prepared educational displays for local libraries and county fairs, taught six *Powerful Tools for Caregiving* class series, and assisted in the staffing of caregiver support groups. The network utilizes regular monthly meetings to keep abreast of important family caregiver needs and resources as well as to plan and promote future collaborative educational programs. The organizations that serve in the collaborative include representatives from UW-Extension, County Aging Units, Hospice, Alzheimer’s Association, Cancer Society, Memorial Medical Center (local hospital), RSVP, and Lifespan Respite Care.

The Alliance prospers by listening to those it serves. In 2005, the Alliance conducted its own research, asking 168 social workers, health-care providers and others during 12 listening sessions how the Alliance can fill statewide gaps in education, resources and support for family caregivers. In response, caregiving professionals identified six major concerns. Issues included family caregivers not identifying themselves as caregivers and thus not participating in educational programs, and caregivers’ reluctance to accept help. The Alliance will use data gathered during these listening sessions to develop a strategic plan to meet the educational needs of family caregivers throughout Wisconsin. To see the “listening session” report, visit <http://www.uwex.edu/ces/flp/caregiving/alliance/news/index.cfm>

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