

Wisconsin

Help for Caregivers

Cuts, rural challenges strain service

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Christina Fox of Milwaukee, Wisconsin, is a member of the "sandwich generation," caring for both her live-in mother and two teenage sons. — Kevin j. Miyazaki/Redux

Christina Fox describes her life as a caregiver as being torn between two generations.

See also: Caregiving Resource Center

"Calling it the 'sandwich generation' is just a nice way of saying you're caught between your parents and your own children," said Fox, 43, of Milwaukee, who took in her ailing mother two years ago while parenting two teenagers.

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Although her mother, Sara Muhammad, 66, does not drive and has difficulty walking, Fox never considered rejecting the caregiver role.

"I did it out of not wanting my mother in a nursing home or around strangers," she said.

Her experience reflects the difficulties caregivers face and she is just one of the half a million caregivers in Wisconsin.

'One-stop' resource centers

Wisconsin has long prided itself on above-average services for older people, people with disabilities and their caregivers, although recent budget cuts have stalled key programs, including the Family Care Partnership program for in-home caregivers.

Government programs are boosted by nonprofit organizations, skilled at spreading information and recruiting volunteers.

For example, the Alzheimer's Association has several branches in Wisconsin offering support groups, advice and help in tapping community resources.

"Wisconsin is aging, and more people will be caregivers for a parent or other family member," said Krista Scheel, program director for the Alzheimer's Association Southeastern Wisconsin chapter.

Wisconsin's larger cities have significant <u>Hispanic and African American</u> populations. Providing support services for those populations has unique challenges because there can be a greater stigma and reluctance to seek help for dementia, Scheel said.

"The word 'dementia' translated into Spanish means 'crazy,' so we use the phrase 'pérdida de memoria,' or 'memory loss,' " she said.

Maria Isabel Valdes, who immigrated with her mother and siblings from Cuba in 1961, a few months after their father, appreciates the help she received to line up aides to change, bathe and dress her father, Manuel, 88, who had dementia. Valdes, 52, also got help negotiating with Medicare to pay for a wheelchair and lift her father, who died in September.

"Older people like my mom don't fully understand everything and what's covered and what's not covered," said Valdes. Although Valdes called it "heart-wrenching" to witness her father's dementia, being able to remain in his home enabled him to recognize and enjoy familiar things like his favorite Cuban coffee. "For some reason that stuck in his brain," she said. "He knew 'Isa' was coming on Saturdays to make his coffee and get him shaved."

Next: Connecting caregivers to services. »

Pearlean Cannon, 74, whose spouse, Charles, 81, has dementia, lives in a predominantly African American Milwaukee neighborhood. She started a support group at her church to get the word out that there's help for caregivers. For many of her neighbors, having dementia is considered shameful, Cannon said. "I try to neutralize that by bringing in speakers," she said. "I refer them to the 24-7 line that they can call to ask questions."

Thirty-seven Aging and Disability Resource Centers (ADRC) have been set up in 68 of Wisconsin's 72 counties to offer a one-stop resource that can connect caregivers to services. Staffed with social services professionals, stocked with libraries of information and bolstered by connections to nonprofit groups and corps of volunteers, the ADRCs have replaced the old system of dividing services among county offices.

The private, nonprofit Greater Wisconsin Agency on Aging Resources provides technical services at ADRCs and offers a statewide toll-free number (866-843-9810) and a website to help people find local resources.

AARP Wisconsin is taking a lead in advocating for caregivers and helping more of them access community services, said state director Sam Wilson. AARP Wisconsin offers presentations on caregiving, such as "Powerful Tools for Caregivers," maintains a website and toll-free help line (866-448-3611) and lobbies for legislation and public funding to provide home care services and respite care.

"These are resources that would be pennywise and pound foolish to cut as a way to reduce deficits," said Wilson, noting that failure to support family caregivers forces more people into nursing homes—at far greater financial cost to society.

While most support services are provided in southern Wisconsin's urban areas, the percentage of older people is growing fastest in rural areas where services such as home-delivered meals and transportation to doctor's appointments are harder to provide.

Retiree influx up north

Lynn Gall of the Wisconsin Department of Health Services estimates that the percentage of residents 65 and older in most northern counties could surpass 30 percent by 2035.

"The phone's been ringing off the hook," said Geri Heppe, a gerontologist hired as a program specialist for the newly formed ADRC of the Northwoods, which serves four rural counties and three Indian tribes. An influx of retirees in the popular vacation area has already boosted the over-60 population to 34 percent in Vilas County and 29 percent in Oneida County, she said.

Although the state plans to set up more rural ADRCs, they often have little money, have a smaller pool of volunteers and face transportation hurdles, particularly on wintry rural roads.

Kay Nolan is a writer and editor living in Pewaukee, Wisc.