

New research center to focus on family caregivers of elderly, disabled

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The University of Illinois at Chicago has received a five-year, \$4.3 million grant from the National Institute on Disability and Rehabilitation Research and the Administration for Community Living to establish a new, multi-institutional center to study the needs of families caring for people with disabilities. More than 65 million family caregivers in the U.S help 12 million seniors and people with disabilities to live at home. While family caregivers save the federal government billions each year in long-term care services, "these caregivers aren't getting much support in return," said principal investigator Sandy Magaña, professor of disability and human development at UIC. Family caregivers themselves often suffer health and stress-related problems, too, she said, due to the demands of providing care at home.

"By gaining a better understanding of the experiences of [family caregivers](#)—the services they use, and the needs and challenges they face—we can help set policy and research agendas that will lead to improvements in the health and well-being of individuals with disabilities of all ages, racial and ethnic backgrounds and the family members that help support them," Magaña said.

Currently, Magaña said, support services for caregivers of the elderly and caregivers of people with disabilities are isolated from each other.

"There are lots of good interventions and ideas within the aging and disability 'silos' that can and should be exchanged," Magaña said, which would help experts devise new, combined support programs that would

strengthen both.

The new Research and Training Center on Family Support will bring together experts on aging and on disabilities—to guide research, and to develop a national resource center. Co-principal investigators on the grant are Tamar Heller, professor and head of disability and [human development](#) at UIC, and Joe Caldwell, director of long-term services and support policy at the National Council on Aging.

The center will conduct several major research projects over the next five years and develop a strategic plan to prioritize research for federal funding. Interviews with family caregivers will inform the agenda the researchers set for policymakers, Magaña said.

Trends in caregiving—such as self-directed care, in which individuals remain in charge of deciding what services and supports they need—is another focus of the center. Researchers will also evaluate the experiences of families using managed care.

Collaborating institutions include the Lurie Institute for Disability Policy at Brandeis University, the National Resource Center for Participant-Directed Services at Boston College, the RTC on Community Living at the University of Minnesota, the National Alliance for Caregiving, and the National Council on Aging. Organizational partners include The Arc, Easter Seals, and the Sibling Leadership Network.

Provided by University of Illinois at Chicago

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