Family Caregiver Support Project Update

As part of a three-year, inter-agency collaboration with the California Department of Aging (CDA), the Center continues to work on the implementation and evaluation of the National Family Caregiver Support Program (NFCSP). Most recently the Center completed a report culminating its work on interrelated caregiver projects over the past two years – California’s Family Caregiver Support System: Findings and Recommendations. The report provides guidance and specific recommendations for family caregiver support policy and program development efforts and includes: (1) a profile of family caregiver and care recipient needs and characteristics; (2) a summary of the strengths and deficiencies of California’s caregiver support system; and (3) a model information system. The report concludes that the basic building blocks upon which to develop a more comprehensive system of support for family caregivers in California appear to be in place. However, developing a more effective system will require collaboration and coordination among formal and informal networks, including public and private entities, as well as leadership from local and state governments. The report includes 14 specific recommendations for building a comprehensive caregiver support system in California (see side bar).

The Center’s remaining tasks under the inter-agency agreement include caregiver focus groups (see page 2 for summary) and pilot testing an Area Agency on Aging (AAA) caregiver information system. The pilot test of the information system will build on the profile of caregivers and care receivers from the telephone survey (see page 2) and will include two additional components: (1) a PSA-based client data set incorporating client-specific information on caregiver and care receiver characteristics with unduplicated counts of service utilization for caregiver support services; and (2) a PSA-based service effectiveness profile, including client satisfaction and outcome information from a representative sample of clients using caregiver support services. The Center is currently finalizing the selection of the data elements and the pilot sites and will provide a preliminary report to CDA on this process in June.

Recommendations

1. Public education
2. Universal information & referral
3. Staff training in caregiver identification and assessment
4. Caregiver education and training
5. Support for vulnerable caregivers
6. Education for service providers
7. Collaboration with employers
8. Collaboration with health care providers & other organizations
9. Integrated information systems
10. Expanded target population(s)
11. Local and state level coordination
12. Increased funding
13. Advocacy by and for caregivers
14. Quality assurance systems
The California Statewide Survey of Caregivers

The Center has recently completed a profile of California’s caregivers and care receivers from a statewide telephone survey of 1,643 randomly-selected caregivers. The survey results not only characterize caregivers and the impact of caregiving on their lives, but also capture their current use of support services, satisfaction with services, and reasons for non-use of services. Furthermore, care recipients’ characteristics are described, including their current health status and care requirements. Several of the survey’s notable results are highlighted below.

It is estimated that 16% of all California households contain at least one caregiver for an ill or disabled individual age 50 or over; this translates to a minimum of 1,803,995 caregiver households out of 11,502,870 total California households. Surveyed caregivers are 51 years old on average, predominantly female, and often married; about half are employed, and the majority report that they are in good to excellent health. Whites/Caucasians comprise 61% of the caregivers, followed by 25% Hispanic/Latino, 6% Black/African American, and 5% Asian/Pacific Islander. Care recipients have an average age of 77 years, are frequently widowed or married women, and most often live either with their caregiver, or alone. Care recipients with severe memory problems or dementia were 36% of the sample, 44% have mental health, emotional, or behavior problems, and 56% have more than two physical health problems.

While caregiving can be a positive experience, it can also have negative impacts on caregivers’ health and well-being. Particular types of caregivers are more likely to experience the highest levels of emotional stress, physical strain, and financial hardship as a result of their caregiving responsibilities. The California caregivers that are disproportionately affected by deleterious caregiving impacts include those who are female, low-income, and in poor health.

The subset of vulnerable caregivers includes those who are assisting someone with mental health, emotional, or behavioral problems, caring for a person with more than two physical health problems, or assisting someone with severe memory problems or dementia. These caregivers spend significantly more time in an average week providing help, and are more likely to adjust their work schedules (missing work, reducing hours) to accommodate these caregiving situations. The results also show that 70% of caregivers use support services. However, Latinos & Asian/Pacific Islanders are only one-half as likely to use such services as are White non-Hispanic and African Americans.

The California Statewide Survey of Caregivers is the most comprehensive statewide survey of caregivers to date, providing a better understanding of the nuances of the caregiving experience. In an effort to further enrich the initial survey’s results, focus groups representing distinct ethnic, cultural, and geographical segments also will be conducted to help understand the service use and other decision making processes of caregivers. Participant recruitment is currently underway for groups to held in March and April at community groups/agencies across the state.

Recent Publications Available on Center’s Website

California’s Grandparents Raising Children: What the Aging Network Needs to Know as it Implements the National Family Caregiver Support Program (December 2001).
Local Caregiver Needs Assessment Under California’s Family Caregiver Support Program (June 2002).
Major Caregiver Resources in California: An Inventory Analysis (June 2002).
A Profile of California Grandparents Raising Grandchildren (January 2003).
A Profile of Family Caregivers: Results of the California Statewide Survey of Caregivers (January 2003).
2002-2003 Kleiner Foundation & Center Scholarship Recipients

James Midgley, Dean of the University of California at Berkeley, School of Social Welfare presided at the School's Annual Awards Ceremony held at the Women's Faculty Club, where several students in the aging specialization were recognized for their academic and professional promise: Erica Erney, Kelly Tobin-Glazer and Soo Yeon Kim.

Erica Erney was awarded the 2002-2003 Rose Kleiner Foundation scholarship. She is a second year MSW at the School of Social Welfare. Erica received her BSW and Women's Studies Certificate from Humboldt State University, in 1998, and has volunteered and worked in numerous agencies serving diverse populations.

Kelly Tobin-Glazer was awarded the 2002-2003 Center for the Advanced Study of Aging Services scholarship. She is a first year Master in Social Welfare student specializing in direct practice with older adults. Her first year placement is at Laguna Honda Hospital. She also is a graduate student researcher at the Center working on the National Family Caregiver Support Project. Prior to beginning graduate school, Kelly was a healthcare marketing services professional.

Soo Yeon Kim also was awarded the 2002-2003 Center for the Advanced Study of Aging Services scholarship. She is a second year MSW student specializing in gerontology. She received her B.A. in psychology and French literature from Sungshin Woman's University in Seoul, Korea. Before coming to Berkeley, she volunteered in the rehabilitation program with the University's Psychological Health Institute as well as in the nursing care unit for Alzheimer patients at Song-pa General Welfare Center. Her main professional interests include quality of life for vulnerable elderly, caregiver issues, women's issues and aging.
**New Staff Members**

**Kris Helé** is a second year student in the dual MSW (Health) and MPH (Health and Social Behavior) program. She received her B.A. in Psychology from UC San Diego, and worked as a case manager for a subsidized child care agency. Last year she was a social work intern in Alta Bates Medical Center's perinatal units, as well as a research assistant for the Alcohol Research Group. She is currently working on the National Family Caregiver Support Project (NFCSP), in addition to part-time work with the Berkeley Media Studies Group. Her interests include employed family caregivers, health policy, and domestic violence prevention.

**Kristin Ryan** is a first year MSW student specializing in gerontology. She is originally from Medford, New Jersey, and received her undergraduate degree at the University of Pennsylvania. After graduating, Ms. Ryan worked as a health policy analyst at the United Hospital Fund in New York City, focusing on immigrant health issues. Since moving to San Francisco, Ms. Ryan has worked at the Family Caregiver Alliance, and is presently interning at OnLok Senior Health Services. At the Center, Ms. Ryan is a part of the research team evaluating results and providing analyses of a statewide survey of California caregivers providing assistance to individuals aged 50 or older, as part of the NFCSP. Ms. Ryan will also assist the Center in conducting focus groups of specific caregiver populations.

**Steven Williams** is an Undergraduate Research Apprentice at the Center. He is originally from Sacramento, and will be completing his B.A. in Social Welfare this year. After completing his B.A., Mr. Williams intends to gain more experience in social work practice before entering an MSW program. He is assisting with the compilation and summary of data for NFCSP reports, and will also assist in conducting center focus groups of specific under-represented caregiver populations.

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**Consortium for Social Work Training in Aging**

The dramatic increase in the aging population has produced a need and demand for social workers who are skilled in working with older adults, their families, and the systems that serve them. To help meet this demand for competently trained gerontological social workers, the School of Social Welfare at the University of California, Berkeley, facilitated the development of the Consortium for Social Work Training in Aging, which consists of three Bay Area schools of social work and six county Departments of Adult and Aging Services. In 2000, the consortium received initial funding with a three-year grant from the John A. Hartford Foundation of New York to create and implement the training program.

The consortium has developed a comprehensive training program that includes: primary placement in a county department of aging services, rotations throughout all aging programs administered by the county, and seminars designed to introduce and provide advanced knowledge on emerging practice and policy issues. Additionally, students are awarded stipends and provided funding to attend aging-related conferences.

To date, the consortium has trained a total 37 MSW students in public aging services. There have been 11 students from University of California, Berkeley, 16 from San Francisco State University, and 10 from San Jose State University. The average age of the students was 35, with a range from ages 23 to 55. The ethnicities of students include: African-American (4), Caucasian (16), Asian American/Pacific Islander (13), Hispanic/Latino (3), and Native American (1). Ten students have been hired by county agencies, affording them a qualified pool of gerontological social workers. The Consortium is exploring new ways to fund this program to continue to assist in meeting the need and demand for gerontological social workers. Please visit the Consortium website <http://cssr.berkeley.edu/aging/consortium/default.asp> for more information about the training model.