

**MAJOR CAREGIVER RESOURCES IN CALIFORNIA:  
AN INVENTORY ANALYSIS**

**Executive Summary**

Andrew Scharlach, Stephanie Whittier, Kelly Mills-Dick, Nancy Giunta,  
Teresa Dal Santo, David Coon<sup>1</sup> Pat Fox<sup>2</sup>, and Kelly Tobin-Glazer

Center for the Advanced Study of Aging Services  
University of California Berkeley  
Berkeley, CA

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<sup>1</sup> Institute on Aging, San Francisco, CA

<sup>2</sup> Institute for Health & Aging and Department of Social and Behavioral Sciences,  
School of Nursing, University of California, San Francisco

## **I. Executive Summary**

This report provides an inventory and analysis of the major caregiver resources in California, including services for caregivers of individuals over age 60 and grandparent/kinship caregivers for children. This report, prepared by the Center for the Advanced Study of Aging Services under contract with the California Department of Aging, provides an overview of services available to caregivers as the implementation of the National Family Caregiver Support Program (NFCSP) begins. The analysis was conducted with the much-appreciated cooperation of local Area Agencies on Aging and other key informants throughout the aging and kinship care networks. The purpose of this report is to describe the major providers of caregiver support services in California, identify service gaps and barriers that currently exist, and provide recommendations for improving supports for caregivers through enhancements to California's existing service network.

This report represents one component of a three-year effort to assist in the implementation and evaluation of the NFCSP in California. It is being submitted with a companion report entitled *Local Caregiver Needs Assessment Under California's Family Caregiver Support Program*. Other reports submitted to CDA to date under the NFCSP project include: *Family Caregivers In California: Needs, Interventions And Model Programs* (December, 2001); *California's Grandparents Raising Children: What The Aging Network Needs To Know As It Implements The National Family Caregiver Support Program* (December, 2001); and *Family Caregiver Support Program: Report on the Analysis of Data Collection Systems* (March 2002).

The report is organized into five sections. The first section describes the methodology used to identify caregiver services and service gaps statewide. The second section provides a description of services, current providers, and service gaps in each NFCSP service category. Third, a more detailed description of the major providers of caregiver services throughout California, including those that offer services under multiple NFCSP categories, is provided. Fourth, the major service gaps identified across service categories are presented and discussed. Finally, a comprehensive framework for supporting family caregivers is presented and specific recommendations are proposed.

### *Methodology*

Several research methods were utilized to identify existing services and service gaps for caregivers of individuals over age 60 and grandparent/kinship caregivers, including:

- A review of the addenda to the AAA 2001 – 2005 Area Plans
- An e-mail survey of AAAs, asking them to identify key providers, service gaps, barriers to service and barriers to conducting reliable needs assessments that currently exist within each of their Planning and Service Areas (PSA)
- An extensive internet search of caregiver and grandparent/kinship support services in California

In addition, key informants within the Department of Social Services Kinship Support Services Program, University of California at Berkeley, and other provider agencies were interviewed in an effort to collect relevant information on grandparent/kinship services throughout California.

## *Results*

*Information.* Information is provided to caregivers through various avenues, including written literature, access to a resource library, and telephone and internet information sources. Major information providers include the Alzheimer's Association, AAA Information and Assistance services, Caregiver Resource Centers, the nationwide Eldercare Locator, and local faith-based and community-based organizations. The information gap identified most often was the need for more linguistically- and culturally-appropriate information for caregivers and grandparent/kinship caregivers. Specifically, languages in which information services were not considered adequate were Russian, Farsi, Portuguese, Spanish, Lao, Mien, Cambodian, Korean, Chinese, and Hmong.

*Access.* Major providers that offer assistance with access to services or case management include the Alzheimer's Association, Alzheimer's Day Resource Centers, Caregiver Resource Centers, Multipurpose Senior Service Programs, Linkages, and other local community and faith-based programs. Gaps in access most often identified included the availability of multilingual or culturally appropriate services, especially translation services.

*Counseling, support groups, and caregiver training programs.* Adult Day Care Programs, including Social Day Care, Adult Day Health Care, and Alzheimer's Day Care Resource Centers (ADCRCs), are major providers of support groups and training opportunities for caregivers. The ADCRCs also make training opportunities available to professionals and other persons providing care and treatment for this population. Other major providers of counseling, support groups, and/or caregiver trainings include the

Alzheimer's Association, Caregiver Resource Centers, local community and faith-based organizations, and health care providers such as home health or hospice agencies.

Services for grandparent/kinship caregivers are most often found in the form of support groups, with fewer programs offering training or counseling. Similar to other service categories, substantial gaps exist with regard to multilingual and/or culturally appropriate counseling, support groups, and training.

*Respite.* Major organizations that provide respite services or assist with locating respite providers include adult day care and adult day health care facilities, the Alzheimer's Association, Alzheimer's Day Care Resource Centers, Caregiver Resource Centers, Linkages, MSSP, residential care facilities, and health care providers such as skilled nursing facilities, home health or hospice agencies. For grandparent or kinship caregivers, respite can be available through Catholic Charities, Family Support Services of the Bay Area (FSSBA), Kinship Support Network providers, other local providers such as the Grandparent Network of Northern California's kinship Respite Care Project, and local licensed childcare providers or emergency nurseries. Emergency, unplanned respite services were identified most often as a service gap for both caregivers and grandparent/kinship caregivers.

*Supplementary services.* Providers of supplemental services can be found in many forms through many settings. Financial Assistance can be offered through tax incentives such as the Dependent Parent Tax Credit. Long-term care insurance may help to alleviate some of the financial hardship experienced by families caring for disabled elderly persons. Friendly visitor and senior companion programs provide companionship for people who do not have family or friends nearby. Legal assistance for caregivers is

available through Legal Service Projects and the Health Insurance Counseling and Advocacy Program (HICAP). Nutrition services and meal providers such as Meals on Wheels can provide caregivers a nutritious meal, or an opportunity for them to focus their energy on other things while the nutritional needs of the care recipient are met. Other formal and informal programs such as Faith in Action support the development of volunteer caregiving services.

Supplemental services for kinship caregivers such as transportation services, child clothing and food banks, and emergency financial assistance during times of crisis can be found through agencies such as Grandparents Parenting Again, KSN Providers, and local faith-based organizations. The California Department of Social Services KinGAP program provides long-term financial support for kinship caregivers. Service gaps found in the area of supplemental services nearly always include transportation and financial assistance for both caregivers in general and grandparent/kinship caregivers.

#### *Major Resources for Family Caregivers*

The major providers of caregiver resources identified across all service categories include the Caregiver Resource Center network, the Kinship Support Network of KSSP providers, Area Agency on Aging Information and Assistance services, as well as local community-based organizations, adult day care programs, health care providers, Alzheimer's Association and other disease-specific organizations, and electronic media resources such as websites and county search engines.

#### *Major Gaps*

The major gaps identified through our analyses include the following:

- *Culturally and linguistically appropriate services:* Information, access, assessment, case management, counseling, and other support services

were often identified by AAA survey respondents as insufficient in meeting cultural and linguistic needs.

- *Respite care:* Unplanned respite for both older adults and children was identified as a significant service gap for caregivers.
- *Transportation:* In both rural and urban communities, transportation is a challenge for older adults as both driving and taking public transportation become increasingly difficult. The lack of transportation available to caregivers serves as a barrier to accessing services both for themselves as well as for those for whom they are providing care.
- *Financial Assistance:* Nearly two-thirds of AAA survey respondents described the availability of financial assistance for caregivers as inadequate.
- *Care in rural areas:* Community services in rural areas, especially the availability of in-home workers, is a service gap for grandparent caregivers as well as caregivers of older adults.
- *Training:* A gap in multilingual/culturally appropriate training programs for both caregivers of older adults and grandparent/kinship caregivers was often identified. Training of caregivers can take place through psycho-educational groups, peer counseling programs, or other family consultation programs. Trainings for service providers, although identified less frequently as a service gap in AAA surveys, was identified as a need by key informants, especially training in the area of providing culturally appropriate services for clients.

### *Discussion*

California has a rich array of formal and informal resources for family caregivers and grandparent/kin carers, including the statewide Caregiver Resource Centers and the Kinship Support Network of KSSP providers. Existing resources include programs administered by various state departments, services offered by numerous public, not-for-profit, and private organizations, and supports available through a variety of religious, social, and health care organizations. With better coordination and collaboration locally and statewide, these resources appear to provide the basic building blocks upon which to develop a more comprehensive system of support for California's caregiving families.

In this report, we propose a general framework for California's efforts to support family caregivers. Components of this general framework include the following:

- Public awareness campaigns designed to promote public recognition and discussion of the prevalence and realities of family care
- Readily-available information for caregivers regarding supportive services and resources
- Information and training of health care professionals and paraprofessionals regarding identification and assessment of caregiver needs and available community resources for caregivers
- Family-oriented approach to home and community-based care, wherein caregiver needs and resources are an integral part of care planning and service delivery efforts
- Adequate caregiver-specific programs and services (e.g., respite, counseling, support groups, etc.)
- Enhanced capacity of natural communities (e.g., churches, fraternal organizations, ethnic community groups) to support their caregivers
- Advocacy by and for caregivers in program and policy development
- Quality improvement mechanisms, including processes for collecting information regarding caregiver needs and the adequacy of existing caregiver support efforts.

While portions of this framework may be beyond the scope of the NFCSP, a comprehensive effort to improve the well being of caregivers and those for whom they care requires consideration of all of these components.

### *Recommendations*

Through the framework presented in this report, we offer the following specific recommendations:

- *Coordination and collaboration.* The state Long-Term Care Council should create a task force charged with developing and administering a

state plan for meeting the needs of family caregivers, and including representatives from the major state departments with responsibility for administering caregiver support programs. At the local level, ad hoc caregiver planning committees should be established to improve community supports for caregivers, and including representatives from major local caregiver service providers and advocacy organizations.

- *Regional equity:* Families should have access to at least a minimum level of caregiver support services and respite care regardless of where in California they reside.
- *Family-centered LTC programs:* Family support should be an explicit objective of all state long-term care policies and programs.
- *Employer initiatives:* AAAs and local community organizations should seek ways to partner with employers to enhance support for employees who have family care responsibilities.
- *Home care providers:* Dramatic increases are required in the number of home care providers available to assist persons with disabilities, as well as major improvements in their training and skills.
- *Research and demonstration projects:* Research is needed regarding the efficacy of specific programs designed to assist caregiving families.
- *Definition of “caregiver”:* Caregiver support programs in most other states serve families with a broad spectrum of care situations. With this in mind, current programs should be expanded to include families caring for elderly and adults with all types of disabilities, and non-parental relatives of all ages who have primary care responsibility for young children.