

*Celebrating Caregiving in California*



*A Report of the California Commission on Aging*

*March, 2012*

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### Executive Summary

The California Commission on Aging (CCoA) focused its efforts in 2011 on informal caregiving, a role that more family members are taking on as the population is living longer with chronic conditions. To learn more about this trend, the Commission explored the range of federal and state caregiving programs, local program innovation, and the continuing concerns of caregivers and those who hope to meet their needs. With more than half of the Commission members having their own caregiving experience during the last five years, the topic was of special interest.

As part of its statutory responsibilities, the CCoA holds public hearings across the state to gather input from older adults, their families and service providers on issues of importance. The 2011 public hearings on caregiving explored a range of topics affecting caregivers, providers of caregiver services and policymakers. The theme for the three hearings, *Celebrating Caregiving in California*, was selected to coincide with the federal designation of 2011 as the “Year of the Family Caregiver.” The CCoA hearings took place in February in Sacramento, April in Aptos, and June in San Diego.

Hearing from federal and state officials, local providers and caregivers, the CCoA found universal themes of innovation and creativity to be essential for programs to meet caregiver needs. Often, community collaboration was key in developing caregiver training, respite programs, and in building culturally competent programming.

To better address the needs of caregivers, presenters called for use of a universal assessment tool to identify caregiver needs, use of evidence-based programs, and more opportunities for respite care. Caregiver resources and information should be more readily available through social media and other online resources. Funding to meet current and ongoing caregiver support needs is of utmost importance as the state moves to provide more long-term care services in the home, as are flexible workplace policies to help caregivers keep loved ones at home.

## Introduction

The concerns of informal caregivers have drawn heightened attention as the numbers of frail elderly who wish to remain at home increase across the nation. Informal caregiving crosses all economic, geographic, gender and age borders. Providing care at home is a way to fulfill family obligations and to postpone or possibly avoid the stress and expense of moving a loved one into skilled nursing. Keeping a loved one at home can preserve the health and emotional well-being of a frail elder, yet the costs to caregivers – emotional, physical, and economic – can be great.

Shining a spotlight on caregivers' concerns and the programs and policies to help them were the main themes addressed in a series of three hearings held in 2011 by the California Commission on Aging (CCoA). Co-hosted by the Administration on Aging, the hearings were attended by Region IX Administrator David Ishida and Aging Services Programs Specialist Darrick Lam. The federal officials recognized the CCoA for its leadership in holding the nation's first hearing on the topic during the Year of the Family Caregiver, which celebrated the 10-year anniversary of the National Family Caregiver Support Program (NFCSP). Part of the Older Americans Act OAA Title III-E program, NFCSP receives approximately \$154 million per year with a separate \$6 million allocation through the Title VI-C Native American Caregiver Program. The program serves over 223,626 caregivers of older adults and 16,000 grandparent caregivers. In 2011, national program statistics revealed:

- ✓ 54% of all caregivers were white; 46% were minorities.
- ✓ 67% of grandparent caregivers were minorities; 33% were white.
- ✓ 86% found that receiving caregiver services made it easier to care for the care-recipient.
- ✓ 89% felt caregiver support services helped them to be a better caregiver.
- ✓ 77% of caregivers indicated that caregiver support services helped them to keep care-recipients at home longer.
- ✓ 66% indicated that without caregiver support services, the recipient would be living in a nursing home.
- ✓ 66% of recipients had three or more ADLs meeting Medicaid nursing home eligibility criteria.

## What is family caregiving?

Informal or family caregiving can be described as a community-wide dynamic, impacting almost everyone either directly or indirectly. Caregiving is called an “all-in proposition;” once an individual takes on the role of caregiver, it can overwhelm all other aspects of life. Caregiving is a major life change: grandparents may find themselves suddenly with sole responsibility for raising their own children's children; a working mother may be the only person available to care for an aging parent newly discharged from the hospital.

Caregiving crosses all boundaries, affecting people of all ages in all walks of life, ignoring gender or occupation or family relationships. Caregiving affects an elderly spouse caring for his

wife who can no longer walk just as significantly as it affects a young working mother whose 98-year-old great aunt has been abandoned by the rest of the family because her dementia frightens them. The task is every bit as daunting to the adult child who works in healthcare as it is to the elderly wife whose husband has been disabled by a stroke.

Yet all of these are scenarios that are – or could be – quite real. People with no experience and no knowledge of available services or how to provide for a frail loved one find themselves suddenly responsible when their family member is released from the hospital with ongoing care needs.

According to a 2007 issue paper from the Family Caregiver Alliance, “California has the highest number of family and informal caregivers of any state in the nation, with an estimated 3.4 million Californians providing care for adult family members and friends.” By 2009, California caregivers had provided approximately 4 billion hours of care at a value of nearly \$47 billion.

### Program Innovations

Creativity and innovation are hallmarks of caregiver programs in California. As the first state in the nation to pass family caregiver support legislation, California set many benchmarks in the field. Creation of the Caregiver Resource Center system in 1984 focused services on caregivers of brain-impaired adults through intake assessments, family consultation, legal services, counseling, respite services and more. The development of evidence-based practices has kept California in the forefront of innovation, with data collection and analysis serving to inform and guide policy-makers, researchers and practitioners.

Changes in federal law enabled California Department of Aging (CDA) to work with the Area Agency on Aging (AAA) network and the Caregiver Resource Centers on program design and implementation, incorporating a focus on caregiver needs into the AAA area planning process. The state’s partnership with the University of California at Berkeley yielded best practice guidance for evaluating caregiver needs, for data collection, taking inventory of existing services and service gaps and a needs assessment tool.

One of the FCSP’s early grant recipients, Asian Community Center of the Sacramento Valley, identified a need for caregiver support in the community, along with the problem of getting caregivers to see beyond their relationship with the care recipient in order to actually self-identify as “caregivers.” Through wellness and lifelong learning programs, family members were drawn to the center, where a drop-in respite center provides care for the care-recipient. With the support of a cooperative organized by family caregivers, the respite center has expanded, increasing hours of operation and adding transportation services to increase participation.

California’s paid family leave program was the first in the nation to grant benefits to family caregivers. At the federal level, the new Caregivers and Veteran’s Omnibus Health Services Act is an innovation that recognizes the financial implications of caregiving, providing stipends, health benefits and support services to informal caregivers of new veterans.

The new federal health care reform law recognizes the role of family caregivers in the broader healthcare system. The law stresses the importance of incorporating person- and family-centered care in new models of care to improve the overall quality and efficiency of health care, including assessment of the family caregiver's experience of care.

The result of these innovations for caregivers is improved well-being through better coping and problem-solving skills, greater access to information and knowledge of support services. Federal support for the program has allowed caregiving supports to reach Native American caregivers and to grandparent caregivers. These services help to keep loved ones at home longer and make the work of informal caregiving easier.

### Local Solutions

Around the state, program flexibility has enabled communities to develop their own solutions to meet family caregiving needs. In Santa Cruz County, questions about caregiving rose to such prominence during a senior summit that a Caregiver Action Group was formed. One of the group's initiatives was creation of a six-week caregiver training and certification course offered through Cabrillo College. The effort draws upon the expertise of professionals, non-profit service providers and educators, establishing a collaboration that continues to benefit caregivers in community.

Part of the state's Caregiver Resource Center system, the Del Mar Caregiver Resource Center (DMCRC) serves caregivers in Santa Cruz, Monterey and San Benito counties. The DMCRC offers a one-day "Caregiver University" to provide a day of training for family caregivers. The program is offered annually in communities across the service area, taking the knowledge of providers out into rural areas as well as into larger population centers.

The "for-profit" model of homecare is another viable approach to keeping frail loved ones at home. The Visiting Angel agency provides professional caregivers to work in the home with clients who are often bedridden or on hospice. Along with direct care, the agency provides respite care and trains family members, improving the quality of care overall. In Santa Cruz County, Visiting Angel staff participates as educators in the Cabrillo College training program.

The Southern Caregiver Resource Center (SCRC) in San Diego County has developed culturally-appropriate programs to reach a diverse ethnic population. With a fast-growing population of Mexican Americans and African Americans in the region and high risk of chronic disease in both groups, finding the right community partners is key to successfully meeting family caregiver needs. Considering literacy levels when developing materials provides a way for SCAC's printed materials to have greater impact. By assessing community attitudes toward services and providers, SCRC was able to collaborate with trusted organizations where caregiver support resources can be shared. By adapting its program model, the SCRC is able to deliver caregiver supports from within a social service network, creating a "no wrong door" approach.

## Continuing concerns

Long-distance caregiving remains a challenge for family members and service providers alike. CRCs must find ways to help caregivers to identify trusted resources in other states and to assure access to information in emergencies. State programs must make room for assisting caregivers outside California. Long-distance caregivers spend an average of \$390 traveling to and from a loved one's home to provide help with household upkeep, finances, among other things, yet such financial concerns are not accounted for.

The lost wages and retirement benefits of caregivers are also ongoing concerns. For those who must take extended leave to provide care at home, the economic losses are compounded by the costs of providing care.

Family leave policies in California have yet to address the full range of familial relations that may call for caregiving. At present, grandparents, aunts and uncles, domestic partners and adult children are among those not included in the caregiving provisions of the state's Family Rights Act.

Demand is growing for online caregiver supports, such as social networking, practical guidance and assistance with legal and health-related matters. The possibility of a "virtual support" network could make these services universally available, extending locally-developed online seminars and workshops to anyone with an interest.

## Recommendations

For California:

- Require use of a uniform caregiver assessment tool in Title III-E and home and community based service programs.
- Develop a State Strategic Plan for California Caregivers to identify challenges for integrating caregivers into the state's system of care.
- Require applicants for health and home and community based demonstration projects to account for family caregivers and to include caregiver assessments as necessary.
- Implement licensure and regulation of home care agencies.
- Require discharge planning to include information on and assistance with home-care resources.
- Develop workplace policies to help family caregivers.
- Expand caregiver services to keep pace with the rising incidence of older adults with chronic conditions.
- Develop a more person- and family-centered system of care.

For the Federal Government:

- Increase Older Americans Act funding for family caregivers.
- Require use of a uniform caregiver assessment tool.

- Develop outcome-driven quality assurance evaluations for caregiver interventions.
- Continue use of the National Technical Assistance Centers on Caregiving and Lifespan Respite.
- Fully fund the Patient Protection and Affordable Care Act caregiver provisions and reauthorization of the Lifespan Respite Care Act.

For local providers:

- Utilize evidence-based programs in all caregiver support services.
- Make caregiver information available online for “sandwich-generation” caregivers.
- Allow for flexibility in developing local caregiver resources.
- Provide more opportunities for respite care and more accessible information.
- Strengthen rural caregiver support programs.

### Conclusion

California’s role as an innovator in the field of caregiving faces serious challenges in today’s economic climate. As budgets are cut at the state level, state policies are moving rapidly toward providing more services to frail elders in the home. Federal program support for caregivers is also increasing, despite ongoing pressure to reduce spending.

With the state’s population of over 6.5 million older adults projected to double by 2040, how can we support the growing number of family caregivers who will at some point be expected to provide their care? Will employers provide the flexibility employees need to care for family members? Will the Caregiver Resource Center system have the means to meet the increased need for support services? It will be up to the policy-makers to weigh the value of protecting the interest of family caregivers against the cost of institutionalization.



## **Roster of Expert Witnesses**

### Sacramento, CA February 2, 2011

Moderator: Cheryl Phillips, Member, California Commission on Aging  
David Ishida, Region IX Administrator, Administration on Aging  
Mariko Yamada, Chair, California Assembly Committee on Aging & Long-Term Care  
Ed Long, Deputy Director for Long-Term Care and Aging Services, California  
Department of Aging  
Donna Yee, CEO, Asian Community Center of the Sacramento Valley  
Jane Stan, Program Director, Area 4 Agency on Aging  
Kathleen Kelly, Executive Director, Family Caregiver Alliance

### Aptos, CA April 6, 2011

Moderator: Barbara Mitchell, Member, California Commission on Aging  
Darrick Lam, Aging Services Program Specialist, Administration on Aging  
Clay Kempf, Executive Director, Seniors Council of Santa Cruz  
John Beletz, Executive Director, Del Mar Caregiver Resource Center  
Jeanette Pagliaro, Executive Director, Visiting Angels  
Donna Benton, Executive Director, Los Angeles Caregiver Resource Center

### San Diego, CA June 28, 2011

Moderator: Donna Benton, Member, California Commission on Aging, Research Assistant Professor at USC and Executive Director, Los Angeles Caregiver Resource Center  
Roberto Velasquez, Director of Development/Multicultural Services, Southern Caregiver Resource Center  
Martha Rañon, Client, Southern Caregiver Resource Center's "Partners in Caring" Project  
Martin Dare, MSW, San Diego County Caregiver Support Program Manager