



**RECOMMENDATIONS ON FAMILY CAREGIVING AND  
LONG-TERM CARE SERVICES**

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**INTRODUCTION**

There are an estimated 4 million family caregivers in California providing informal care to family members and friends with chronic or disabling conditions. As the main provider of long-term care services, family caregivers in California provide 4.3 billion hours of care at an estimated value of \$48 billion. Nationally, family caregivers provide \$375 billion worth of care.<sup>1</sup> Given how much caregivers save taxpayers by providing uncompensated care and by helping to delay or prevent costly residential care, it is incumbent on the state to invest in programs and to promote policies that provide caregiving families with needed support and services so they can remain in their role without burning out.

Demographic trends are another reason why caregiver support should become an increasing priority for state government. Older Californians are the state’s fastest growing age group. The number of Californians age 65 and above is expected to increase by a dramatic 75.4% between 2000 and 2020, compared to a 29.4% increase for the state’s population overall. By 2020, one in seven – or more than 6 million California residents – will be seniors.<sup>2</sup>

With the aging of the population comes an increased need for caregiving and long-term care services, as adults live longer with chronic or disabling conditions and more develop Alzheimer's disease and other cognitive disorders. Because of this trend and because the majority of adults with long-term care needs remain living at home and in the community, family and friends will continue to face increased responsibilities for providing care. Given our fragmented and complex systems of long-term care, health care and social services, caregivers end up playing many roles, including hands-on health provider, care manager, companion, surrogate decision-maker and advocate.

Given the many demands of providing care, caregivers often experience adverse consequences on their health and well-being. Family caregivers suffer from higher levels of stress and depression compared to noncaregivers. Caregivers have lower levels of subjective well-being and physical health than noncaregivers. In 2005, caregivers reported chronic conditions (including heart attack/ heart disease, cancer, diabetes and arthritis) at nearly twice the rate of noncaregivers (45% versus 24%).<sup>3</sup> In a 2009 survey, 17% of caregivers reported feeling that their health had become worse as a result of caregiving.<sup>4</sup>

Caregiving affects real people in our state in all walks of life. Three in four (75%) caregivers in California are women. On average, California caregivers are 51 years old; approximately 60% are married; and 31% are sandwich caregivers, meaning they also have children under the age of 18 living at home. About half of California's caregivers are employed – 35% work full-time and 14% work part-time.<sup>5</sup>

## **POLICY OBJECTIVE #1**

**Provide adequate funding and support for programs and services that support caregiving families.**

### **Background**

In 1984, California enacted legislation to create a first-in-the-nation statewide system of Caregiver Resource Centers (CRCs) to ensure that all family caregivers in the state would have access to the same comprehensive range of services, education and support. Unfortunately, after the system's Statewide Resource Consultant, which was charged with oversight and data collection, was defunded in FY 2008-09, funding for the rest of the CRC system was reduced by 66% in the FY 2009-10 budget.

In addition to direct caregiver supports, home and community-based services that provide needed assistance to older adults and adults with disabilities are critically important to both service recipients and their caregivers. Those programs, including In-Home Supportive Services (IHSS), Adult Day Health Care (ADHC), and Department of Aging programs such as Linkages and Alzheimer's Day Care Resource Centers, ease caregiver burden, make it possible for many caregivers to work, and provide assistance the care recipient may not otherwise receive.

Previous budget cuts for those programs have already had a negative impact. In a recent online survey of 501 California caregivers, 44% of respondents reported that the economic downturn has caused services or outside help for their relative or friend to be cut back in the last twelve months, including 103 care recipients who experienced cuts in adult day services, 139 in IHSS, and 192 in CRC services. This occurs at a time when people need help the most. Two-thirds of respondents (67%) reported feeling more stress related to caregiving, and one in four caregivers (25%) reported moving in with their care recipient because of the recession.<sup>6</sup>

Failure to restore some of the funding – or worse yet, further cuts – would have a long-term, detrimental impact on thousands of Californians' health and well-being. Many of the programs enable family members to remain in their caregiving role, while others serve the most vulnerable adults, including those with Alzheimer's disease who have no where else to turn for help. Severe cuts to home and community-based services increase the stress and burden on family caregivers and affect their ability to work. Cuts also force recipients into more costly nursing home care, increase hospital stays and visits to the ER, and add to the suffering of those who rely on in-home support for their basic activities of everyday living.<sup>7</sup>

In stark contrast, *providing* services has a positive impact on caregivers, reducing their stress and decreasing government spending on nursing home care. A 2005 national survey of those who received caregiver support services revealed that the services "affected the lives of caregivers and care recipients in meaningful and diverse ways." More than three out of four (77%) caregivers reported that the support services they received helped them to better understand how to obtain resources and how to feel less stress associated with their role. In addition, over half of those surveyed (54%) said that the services enabled them to keep the care recipient living at home for a longer period of time.<sup>8</sup> Another study came to a similar conclusion: interventions that reduce high levels of caregiver stress decrease the rate of admission to a skilled nursing facility among elders from about 27% to about 10% over a two-year period.<sup>9</sup>

### **Recommended Actions**

- A. The State Legislature should restore full funding for the eleven California Caregiver Resource Centers (CRCs) and their Statewide Resource Consultant.
- B. The State Legislature should restore funding and prevent any further egregious cuts to the Department of Aging's Community-Based Services Program and Alzheimer's Day Care Resource Centers. The State Legislature should reject the Governor's proposal to eliminate Adult Day Health Care and, instead, restore adequate funding.
- C. The State Legislature should maintain adequate funding for In-Home Supportive Services (IHSS) and should reject proposals to reduce the number of IHSS recipients based on functional index scores, particularly proposals that result in the disqualification of services for recipients with dementia and other cognitive disorders.

### **POLICY OBJECTIVE #2**

#### **Promote caregiver-friendly policies and practices within all practice-settings and public programs in California.**

#### **Background**

California's community-based long-term care system includes 38 programs administered by five different departments with inconsistent eligibility criteria, service design, oversight, coordination, and data systems.<sup>10</sup> Not surprisingly, any consumer who needs those services often has a difficult time accessing the appropriate program. Any professional looking for reliable data on family caregivers in the state has a similar problem wading through a maze of programs with incomplete or inconsistent data, if any exists at all. In addition, because many of the programs are narrowly defined and the system is so fragmented, the important role family caregivers play in providing long-term care typically goes unrecognized, as do caregivers' needs for support and services. Program administrators and service providers miss opportunities to collaborate with caregivers as partners in providing and coordinating care and to refer caregivers to appropriate services.

#### **Recommended Actions**

- A. The State Departments of Aging, Mental Health, Health Care Services, and Public Health should work towards interagency coordination to provide less fragmented support and technical assistance for family caregivers.
- B. The State Departments of Aging and Health Care Services should include a caregiver assessment component within the assessment process for care planning for home and community-based programs and during transitions between care settings. The caregiver assessment component should include protocols for appropriate follow-up and referrals to services, and it should be culturally specific across all care settings in the state (e.g., for use in health care facilities, home care situations and community-based agencies).
- C. The State Department of Public Health should include a caregiver module in the Behavioral Risk Factor Surveillance System (BRFSS) data set. The BFRSS is the world's largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. In addition to the standard questionnaire, states have the option to conduct modules on specific issues, including questions about caregiving. This is a cost-effective way to collect information that would be enormously beneficial in developing policies and services to support caregivers in the state.

## **POLICY OBJECTIVE #3**

### **Promote caregiver-friendly employment regulations in California.**

#### **Background**

About half of California's caregivers are employed. Of those, 71% work full-time and 29% work part-time. Not only must they navigate a complex long-term care system, they must balance their work and caregiving responsibilities. Policies that support working caregivers are critical if caregivers are to remain in the workforce, provide financially for their families, and provide care to their older or ailing relative. Without such policies and protections, caregivers are more likely to leave their jobs and rely on public safety net programs to survive.

The current economic downturn has placed the spotlight once again on the need for workplace protections. In a recent survey of 501 California caregivers, 42% of respondents reported that the economic downturn has caused them to receive a cut in pay or work hours, and 15% reported having lost their job. In addition, nearly two in five caregivers (38%) reported that they feel "less comfortable with taking time off from work to care for [their] relative or friend." Only 29 respondents reported taking Paid Family Leave in the last twelve months.<sup>11</sup>

#### **Recommended Actions**

- A. The State Legislature should expand Paid Family Leave policies to include workers who care for any type of family member, including grandchildren, grandparents, siblings, parents-in-law and adult children.
- B. The State Legislature should pass paid sick days legislation (AB 1000) so no worker has to decide between staying home to care for an ill family member and a day's pay.
- C. The State Legislature should pass legislation prohibiting employment discrimination on the basis of familial status or because of caregiving responsibilities.

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<sup>1</sup> Gibson, M.J., & Houser, A. (2008, November). *Valuing the invaluable: The economic value of family caregiving, 2008 Update*. [Issue Brief]. Washington, DC: AARP Public Policy Institute.

<sup>2</sup> California Budget Project. (2008, August). *Planning for California's future: The state's population is growing, aging, and becoming more diverse*. [Budget Backgrounder] Sacramento, CA: Author.

<sup>3</sup> Family Caregiver Alliance. (2006). *Caregiver health*. [Fact Sheet] San Francisco: Author.

<sup>4</sup> National Alliance for Caregiving and AARP. (2009, Nov.). *Caregiving in the U.S. 2009*. Washington, DC: Author.

<sup>5</sup> Scharlach, A., Dal Santo, T., Lehning, A., Gustavson, K., Lee, S., Auh, E., Fox, F. & Chow, J. (2006, September). *Caregiving in California: Final report of the University of California Family Caregiver Support Project*. Berkeley, CA: University of California Berkeley, Center for the Advanced Study of Aging Services.

<sup>6</sup> Unpublished data from "Caregivers Count: A Survey of the Economic Downturn in California and its Impact on Family Caregiving" conducted online October 2009 – February 2010 by Family Caregiver Alliance, in collaboration with the California Coalition for Caregivers. Published findings forthcoming.

<sup>7</sup> Wallace, S.P., Benjamin, A.E., Villa, V.M., & Pourat, N. (2009, October). *California budget cuts fray the long-term care safety net*. Los Angeles, CA: UCLA Center for Health Policy Research.

<sup>8</sup> Beauchamp, J. & Trebino, L. (2007, March). *Results from the Administration on Aging's third national survey of Older Americans Act program participants* [Final Report submitted to U.S. Department of Health and Human Services]. Washington, DC: Mathematica Policy Research, Inc

<sup>9</sup> Spillman, B.C. & Long, S.K. (2007, January). *Does high caregiver stress lead to nursing home entry?*

Washington, DC: U.S. Department of Health & Human Services, Office of Disability, Aging and Long-Term Care.

<sup>10</sup> Wallace, S.P., et al. See endnote 7

<sup>11</sup> Unpublished data from "Caregivers Count: A Survey of the Economic Downturn in California and its Impact on Family Caregiving" See endnote 6