

**A Joint Oversight Hearing
of the
Assembly Committee on Aging and Long-Term Care
Mariko Yamada, Chair
and
Assembly Committee on Human Services
Jim Beall, Jr., Chair**

Who Cares?

Planning, Protecting and Paying for the Future of Caregiving in California

ISSUE PAPER

California is home to the largest number of seniors in the nation and their numbers are expanding at a pace unprecedented in history. The California Department of Finance's Demographic Research Unit estimates that California's 65+ population will have grown 43 percent between 2010 and 2020 (from 4.4 million to 6.35 million). By 2030 the 65+ population will reach nearly 9 million people. The ratio of 65+ people will grow from about one in ten people today, to one in five by 2040. Though women comprise roughly half of the general population, by age 65 their proportion increases to about 57%. By age 85, women outnumber men two-to-one.

Who are Caregivers?

Given the demographics confronting California, it would come as no surprise that most people will become a caregiver at some point during their lives. Who are caregivers? According to the Family Caregiver Alliance, the short answer is: *Most of us, at some point in our lives.* "Caregivers are daughters, wives, husbands, sons, grandchildren, nieces, nephews, partners and friends. While some people receive care from paid caregivers, most rely on unpaid assistance from families, friends and neighbors." The National Alliance on Caregiving and AARP report "Caregiving in the United States, 2009," estimates 31.2% of households in the U.S. had at least one person who served as an unpaid family caregiver during the course of the year. At any one time the report estimates 37.3 million people are providing care. 66% are women and 34% are men. The typical family caregiver is a 49-year-old woman caring for her widowed 69-year-old mother who does not live with her. She is married and employed. 1.4 million children ages 8 to 18 provide care for an adult relative; 72% are caring for a parent or grandparent; and 64% live in the same household as their care recipient. The same report estimates the number of caregivers in California at any given time at 4.0 million, with an estimated 5.88 million people serving as caregivers during the course of a year.

What is Caregiving?

Caregivers can be paid or unpaid. Caregivers support the needs of dependent individuals in a variety of ways, performing a range of tasks, including companionship, light house-keeping, meal preparation, and personal care tasks. More complex and sensitive tasks include money management, medication management, communicating with health professionals, and coordinating

care. The Family Caregiver Alliance finds that many family members and friends do not consider such assistance and care “caregiving”—they are just doing what comes naturally to them: taking care of someone they love. But that care may be required for months or years, and may take an emotional, physical and financial toll on caregiving families.

Paid, or 'formal' caregiving includes services provided by professionals and paraprofessionals who are compensated to provide in-home health care and/or personal care services. According to data from the Office of Statewide Health Planning and Development (OSHPD) Annual Utilization Report of Home Health Agencies, home health visits have grown in the last decade by 23.3%, from 8.9 million visits to 11.6 million visits in 2010. Over 651,000 Californians received home health care in 2010, with Medicare paying for 64% of those visits. Private healthcare providers paid for 14% of those visits. Medi-Cal and "other" (out-of-pocket, Long-term Care Insurance) payment sources split the remaining 22% evenly. Because the state does not license or regulate home care agencies (agencies that do not provide a health service) it is difficult to estimate the prevalence of formal home care. According to the California Association of Health Services at Home, (CAHSAH), extrapolations from earning reports suggest that 1,200 home care agencies may have generated up to \$1.2 billion in revenue in 2008.

The In-Home Support Services (IHSS), a publicly funded home care program, supports the needs of over 438,000 people monthly in California, providing over 37 million hours of care at a cost just over \$400 million. The IHSS Program pays for services that help disabled people remain safely in their own home. IHSS recipients must be over 65 years of age, or disabled, or blind.

The value of the services family caregivers provide for "free," when caring, was estimated to be \$450 billion in 2009¹. The estimated value of unpaid care in California is \$47 billion, accounting for over 3.8 billion hours of care at \$12.17, the average caregiver wage in 2009. On the personal side, long term caregiving has significant financial consequences for caregivers, particularly for women. Informal caregivers personally lose about \$659,139 over a lifetime: \$25,494 in Social Security benefits; \$67,202 in pension benefits; and \$566,443 in forgone wages. Caregivers face the loss of income of the care recipient, loss of their own income if they reduce their work hours or leave their jobs, loss of employer-based medical benefits, shrinking of savings to pay caregiving costs, and a threat to their retirement income due to fewer contributions to pensions and other retirement vehicles.²

Balance

A 1997 Metropolitan Life Insurance Company and National Caregiver Alliance study found that recent medical advances, shorter hospital stays, increasing life spans with better management of chronic illnesses, limited discharge planning, a shortage of homecare workers, and the expansion of home care technology have increased the caregiving responsibilities of families. Family caregivers are being asked to shoulder greater burdens for longer periods of time. In addition to more complex

^{1,2} Valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving, Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula, AARP Public Policy Institute

care, conflicting demands of jobs and family, increasing economic pressure, and the physical and emotional demands of long-term caregiving can result in major health impacts on caregivers.³

Slowly, eldercare is becoming recognized as a strategy for recruitment and retention by a growing number of employers. Flexible work schedules, cafeteria-style benefits, employer sponsored support groups, education and referrals provided through employee assistance programs are beginning to catch on. The federal "Family Medical Leave Act" or FMLA provides for up to 12 weeks annually of unpaid leave. Nonetheless, absenteeism, the costs of replacing employees who quit to become caregivers and other employee caregiving needs, present employers with a variety of challenges. Caregiving-related workday interruptions cost businesses \$3.8 billion.⁴

Government's Role

The state of California supports caregivers, both paid and unpaid in a variety of ways. The following are three prime examples of the state's ongoing investment in caregiving, and the support of caregivers.

- California's largest public investment in caregiving is through the IHSS program administered through local Public Authorities by the California Department of Social Services. IHSS serves over 440,000 disabled and impoverished Californians through paid caregivers who perform such tasks as housecleaning, meal preparation, laundry, grocery shopping, personal care services (such as bowel and bladder care, bathing, grooming and paramedical services), accompaniment to medical appointments, and protective supervision for the mentally impaired.
- Adult Day Health Care (soon to be re-named Community Based Adult Services) offers caregivers a place to leave loved ones on a day-to-day basis under medical supervision, allowing caregivers the ability to hold down a job, or to find relief from the stress of caregiving.
- Caregiver Resource Centers administered by the Department of Mental Health serve as a point of entry to services available to caregiving families. Services are free or low cost and include: specialized information, support groups, family consultations, care planning, legal and financial consultation, respite care, education, counseling, and training. Services are specifically targeted to support the caregiver. Caregiver Resource Centers have been proposed to be eliminated in the Governor's FY 2012-2013 budget.
- National Family Caregiver Support Act provides grants to states to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. Benefits fall into one of five categories including information and assistance to caregivers about available services, individual counseling, organization of support groups, training, and respite care.

³ Family Caregiver Alliance (2007). "Caregiving in California," Issue Paper #1.

⁴ Metropolitan Life Insurance Company and National Alliance for Caregiving (1997, June). The Metlife study of employer costs for working caregivers. Connecticut: Metropolitan Life Insurance Company

Today's Hearing

The Assembly Committees on Aging and Long-Term Care and the Assembly Human Services Committee convened this hearing to review the current state of caregiving in California. Recent budget changes have placed additional challenges on caregivers in the state. This hearing is intended to explore caregiving and how we value caregivers in our communities. In an environment of restricted resources, services, and supports that caregivers may rely upon, understanding the limitations of California's caregiving community is important.