

Date of Hearing: April 1, 2014

ASSEMBLY COMMITTEE ON AGING AND LONG-TERM CARE

Mariko Yamada, Chair

AB 1744 (Brown) – As Amended: March 20, 2014

SUBJECT: Older Californians Act; Blue Ribbon Committee on Family Caregiving.

SUMMARY: Establishes the California Caregiver Act of 2014. Specifically, this bill:

- 1) Makes legislative findings and declarations as follows:
  - a. That a caregiver can be any relative, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance to, an older person or an adult with a chronic or disabling condition.
  - b. At present, there is no complete inventory of caregiving programs available to Californians performing unpaid caregiving services for an aging or disabled family member, friend, or neighbor.
  - c. Rising demand and shrinking families that provide caregiving support suggest that California needs a comprehensive person-and family-centered policy for long-term services and support systems that would better serve the needs of older persons with disabilities, support family and friends in their caregiving roles, and promote greater efficiencies in public spending.
  - d. California ranked 30th out of 50 states and the District of Columbia on the 2011 State Long-Term Services and Supports Scorecard sponsored by the SCAN Foundation, American Association of Retired Persons (AARP), and the Commonwealth Fund.
  - e. Family support is a key driver to remain in one's home and community, but it comes at substantial costs to the caregivers, their families, and to society. If family caregivers were no longer available, the economic cost to California's health care and long-term services and support systems would increase astronomically.
  - f. In 2009, approximately 4 million family caregivers in California provided care to an adult with limitations in daily activities at any given point in time, and over 5.8 million provided care at some time during the year.
  - g. In 2009, California's family caregivers provided an estimated 3,850,000 hours of unpaid labor caring for their loved ones. The estimated economic value of their unpaid contributions was approximately \$47 billion.
  - h. In 2009, 59% of all family caregivers were employed full or part time. Family caregivers typically spend 20 hours a week caring for a family member who needs help with bathing, dressing, and other kinds of personal care, as well as household tasks such as shopping and managing finances.

- i. Nationally, 46% of family caregivers performed medical or nursing tasks for care recipients with multiple chronic physical and cognitive conditions. More than three-quarters of family caregivers who provided medical or nursing tasks were managing medications, including administering intravenous fluids and injections.
  - j. Almost one-half of family caregivers were administering five to nine prescription medications a day, and one in five was helping with 10 or more prescription medications a day. Yet, 61% of these caregivers reported that they trained themselves to perform medication management.
  - k. Only 31% of caregivers reported being visited at home by a health care professional. In addition, 27% of caregivers report that they have no additional assistance from a family member, health care professional, or home health aide.
  - l. Nationally, more than 8 in 10 caregivers are over the age of 50. Family caregivers are aging and are increasingly from diverse, social, racial, ethnic, and political backgrounds.
  - m. For many families in the midst of caregiving, there is deep worry and concern about the quality of care and quality of life.
  - n. Families do not know who to call or where to go to get the right kind of affordable help when they need it.
  - o. In just 13 years, as the baby boomers age into their 80s, the decline in the caregiver support ratio is projected to shift from a slow decline to a free fall in California.
  - p. To avoid bankrupting our health and social service systems serving the elderly and persons with disabilities, it is imperative that California prepare by identifying strategies that will promote appropriate, person-centered services for families struggling with providing care to a family member.
  - q. It is in the interest of the state to better serve the approximately 4,000,000 families statewide who are currently struggling to care for an aging or disabled family member, many of whom are also in the workforce.
  - r. There is an immense need for caregiving resources and services as California's population ages and as California becomes increasingly diverse.
- 2) Directs the California Department of Aging to convene a blue-ribbon panel on family caregiving and long-term services and supports, chaired jointly by the Director of the Department of Aging (or his or her designee) and the AARP; made up of 12 individuals who serve at the pleasure of the director and the AARP. Except for all decisions regarding the expenditure of state funds, decisions of the body would be joint decisions.

Membership:

- a. One member shall have experience in the field of academic research on caregiving;
- b. One member shall be a family caregiver of an adult with a chronic or disabling condition;
- c. One member shall be a representative of the mental health community;
- d. One member shall be a representative of the Family Caregiver Resource Centers;

- e. One member shall be a representative of the National Alzheimer's Association;
- f. One member shall be a representative of an organization that provides community-based adult services;
- g. One member shall be a representative of an organization that provides an adult day program;
- h. One member shall be a representative of an organization that provides services to caregivers;
- i. One member shall be a representative of an unpaid or family or family caregiver consumer organization;
- j. One member shall be a culturally and linguistically diverse caregiver;
- k. One member shall be an adult with a chronic or disabling condition who receives care from an unpaid caregiver or family member.

3) The Blue Ribbon Panel would be required to:

- a. Review current policies and practices of state, local and community programs available to caregivers of adults with chronic disabling conditions, and consider how the needs of family caregivers should be assessed and addressed so that they may avoid overburdening themselves, and remain in their caregiving role.
- b. Consider other state plans, including State Olmstead plan, the Long-Range Strategic Plan on Aging, the State Plan for Alzheimer's disease, and the State Plan on Aging.
- c. Compile and inventory resources available to family caregivers.
- d. Determine gaps in services to family caregivers and identify barriers to participation in current programs.
- e. Consider cultural and linguistic factors that impact caregivers and care recipients who are from diverse backgrounds.
- f. Consult with a broad range of stakeholders, including but not limited to people diagnosed with Alzheimer's, adults with disabling and chronic conditions, family caregivers, community-based and institutional providers, caregiving researchers and academicians, formal caregivers, the caregiver resource centers, the California commission on aging and other state entities.
- g. Solicit testimony on the needs of family caregivers including the designation of caregivers, training, respite services, medical leave policies, delegation of tasks to non-medical aides, and other policies.
- h. Identify best practice in other states.
- i. Explore expanding those best practices in caregiving programs to populations that are not currently targeted.
- j. Develop at least three legislative recommendations to improve the provisions of services for unpaid and family caregivers in California to address the following:

- i. Community-based support for California's diverse populations of caregivers for adults with chronic or disabling conditions;
  - ii. Choices for care and residence for persons with Alzheimer's disease and their families;
  - iii. The family caregiving "competencies" of health care professionals.
- k. Prepare a report to the legislature on or before July of 2016 in digital format.
- l. Provide ongoing advice and assistance to the department and the legislature as to the needs of unpaid and relative caregivers.
- 4) Members shall serve without compensation but shall receive reimbursement for travel and other expenses incurred in the performance of their official duties, and meet publicly every-other month.

EXISTING LAW:

- 1) Establishes the Older Californians Act (OCA) and assures older adults have equal access to programs and services provided through the OCA regardless of physical or mental disabilities, language barriers, cultural or social isolation, including that caused by actual or perceived racial and ethnic status, including, but not limited to, African-American, Hispanic, American Indian, and Asian American, ancestry, national origin, religion, sex, gender identity, marital status, familial status, sexual orientation, or by association with a person or persons with one or more of these actual or perceived characteristics, that restrict an individual's ability to perform normal daily tasks or that threaten his or her capacity to live independently.
- 2) Establishes the California Department of Aging (CDA) to provide leadership to the area agencies on aging in developing systems of home-and community-based services that maintain individuals in their own homes or least restrictive, homelike environments.
- 3) Establishes 33 area agencies on aging to receive federal, state, and local funds to contract with local organizations for service to seniors. There are 33 area agencies on aging designated by the CDA as the local Planning Services Agencies
- 4) Establishes the Title IIIIE program, also known as the National Family Caregiver Support Program (NFCSP), established in 2000, to coordinate local community-service systems for assisting caregivers of seniors. Services are available to family and other unpaid caregivers supporting older individuals, as well as grandparents and older relatives caring for children. Each AAA is responsible for determining the array of services, including caregiver information, assistance in gaining access to services, counseling and training support, temporary respite, and limited supplemental services to complement the care provided by caregivers. Services are provided directly by AAA staff, or through partnerships with other public or private agencies.
- 5) Establishes Caregiver Resource Centers to deliver services to and advocate for caregivers of cognitively impaired adults, by offering specialized information on chronic and disabling

conditions and diseases, aging, caregiving issues, community resources and family consultation. Professional staff work with families and caregivers to provide support, alleviate stress, examine options, and enable them to make decisions related to the care, respite, and counseling in legal and financial aid.

FISCAL EFFECT: Unknown

COMMENTS:

Author's Statement: "This bill is relevant to California's current need, through a collaborative joint study committee, to inventory, assess and report on the status of existing caregiver programs. Caregivers come from a wide range of economic, social, racial and ethnic backgrounds. Research by the AARP Public Policy Institute indicates that 27% of caregivers have no additional assistance from family members, a healthcare professional or a home health aide. Only 31% report having been visited by a healthcare professional in the home. For many families in the midst of caregiving, there is deep worry and concern about the quality of care and quality of life of the relative for whom they are providing care. Many caregivers do not know who to call or where to go to get the right kind of affordable help when they need it. This bill will provide family caregivers, their loved ones and our State invaluable data and information as we move forward in addressing family caregiving and long-term support service issues."

Background: Families are the major provider of long-term care, but research has shown that caregiving exacts a heavy emotional, physical and financial toll. Many caregivers who work and provide care experience conflicts between their responsibilities. Twenty two percent of caregivers are assisting two individuals, while eight percent are caring for three or more. Almost half of all caregivers are over age 50, making them more vulnerable to a decline in their own health, and one-third describe their own health as fair to poor.

Women make up the majority of the unpaid caregiver workforce, often interrupting work careers to take on the burden of caring for a relative. Caregiving women face uncertain economic futures due to breaks from employment and the corresponding reductions to retirement plans and the Social Security system.

At a joint Hearing of Assembly Committees on Aging and Long-Term Care and the Assembly Committee on Human Services in 2011, the committees heard testimony about caregiving in California. Given the demographics confronting California, it would come as no surprise that most people will become a caregiver at some point during their lives. According to the Family Caregiver Alliance, 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.

The value of the services family caregivers provide for "free," when caring, was estimated to be \$450 billion in 2009. 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.

Discussion:

AB 1744 would amend the Older Californians Act to require the California Department of Aging to convene a joint Blue Ribbon Task Force on family caregiving, and long-term supports and services. The proposed Blue Ribbon Task Force committee would be co-chaired by the AARP and the director of the CDA. The Task force's joint study mandates would be multi-faceted:

- 1) To consult a range of stakeholders, including people living with Alzheimer's disease, people living with chronic and disabling conditions, family caregiver, service providers, researchers, formal caregivers, Caregiver Resource Centers, and the California Commission on Aging, among others.
- 2) To solicit testimony on the needs of family caregivers, including the designation of caregivers, training, respite services, medical leave policies, delegation of tasks to non-medical aides, and other policies.
- 3) To identify best practices in California as well as other states, and explore ways to replicate them, and expand them to populations not currently served.

The Blue Ribbon Panel would prepare a report to the Legislature by July 1, 2016 and provide ongoing advice to the department and the legislature.

Questions:

1. Is it the intent of the author to compel the panel to produce three legislative initiatives separate from the report that is due to the legislature on July 1, 2016?

2. Given the broad cultural representation of people in California, besides reviewing best practices within the state of California and other states, does it serve the residents of the state to assess best practices developed in other countries as well?

Proposed Amendments:

Amendment #1:

On Page 2, line 34, replace "3,850,000" with "3,850,000,000"

Amendment #2:

On page 4, lines 20-28, amend as follows:

9104. (a) The department shall convene a blue-ribbon panel on family caregiving and long-term services and supports. The panel shall be jointly chaired by the director of the department or his or her designee and a representative **elected by the members of the blue-ribbon panel.** ~~of AARP-California, except that all~~ **All** decisions regarding the expenditure of state funds shall be made by the department representative. The panel shall **serve at the pleasure of the department and** be comprised of at least 12 members, **each of whom shall be representative of at least one of the following:** ~~who shall serve at the pleasure of the department, and AARP, and shall include all of the following:~~

Amendment #3: On Page 5, line 5, amend as follows:

(10) One **representative with experience and knowledge of the specific needs of** culturally and linguistically diverse **caregivers, and the specific challenges of delivering services to family caregivers challenged by cultural or linguistic barriers.** ~~caregiver.~~

REGISTERED SUPPORT / OPPOSITION:

Support:

American Association of Retired Persons (AARP) California (Sponsor)  
Alzheimer's Association  
American Federation of State, County and Municipal Employees (AFSCME), AFL-CIO  
California Assisted Living Association (CALA)  
California Association for Health Services at Home (CAHSAH) – Support if Amended  
California Association of Area Agencies on Aging (C4A)  
California Caregiver Resource Centers  
California Commission on Aging  
Congress of California Seniors  
Family Caregiver Alliance  
Pacific Clinics  
United Domestic Workers of America (UDW) AFSCME Local 3930

Opposition:

None on file.

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