

Date of Hearing: May 5, 2015

ASSEMBLY COMMITTEE ON AGING AND LONG-TERM CARE

Cheryl Brown, Chair

ACR 38 Brown – As Amended April 27, 2015

**SUBJECT:** California Task Force on Family Caregiving

**SUMMARY:** Establish the California Task Force on Family Caregiving to meet monthly and report to the Legislature interim findings by January 1 of 2017 and final findings by January 1 of 2018 on issues relative to the challenges faced by family caregivers and opportunities to improve caregiver support and to review the current network and the services and supports available to caregivers. Specifically, **this bill:**

- 1) Identifies caregivers as people who provide a wide range of assistance to those with chronic disabling needs, such as the elderly;
- 2) Declares that three-quarters of older people living in a community setting rely solely upon unpaid caregiving;
- 3) Describes the lack of comprehensive resources describing services for the state's 5.8 million caregivers who provide 3.9 million hours of care estimated to be worth about \$ 47 billion;
- 4) Describes the value of family support as a key-driver in permitting an individual to choose a home setting, including 70% of those with Alzheimer's disease, though the physical, emotional and financial costs can be substantial, as some 59% of informal caregivers are employed;
- 5) Describes that variations of strategies undertaken by families based upon ethnic or cultural origin may provide clues to untapped strategies and resources which could relieve caregiver stress;
- 6) Describes the critical need for state leadership to compile inventories of resources available, identify access barriers, and to coordinate consistent access using the most efficient and up-to-date technologies; and,
- 7) Calls for a 20-member task force of experts to meet monthly, without compensation, under open-meeting standards, consult with stake-holders, partner with the California Commission on Aging, and report to the Legislature and the Governor by January 1, 2017, and January 1, 2018.

**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 Area Agency on Aging (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, likely negligible given that no state funds are allowed to be used to conduct the activities of the task force.

**COMMENTS:**

**Author's Statement:** "This Assembly Concurrent Resolution is relevant to California's current need to have a current and up-to-date 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 resolution will bring together a council of California's best and brightest minds in the field of caregiving to focus and determine the priorities and strategies that California caregivers need – caregivers who struggle everyday – invisible to most of us as they place their own lives aside to meet the needs of another. ACR 38 provides family caregivers, their loved ones and our State invaluable data and information as we move forward in addressing family caregiving issues."

**Discussion:** After the veto of AB 1744 last year, Assemblymember Brown, a caregiver herself, resolved to see the establishment of a broadly recognized essential strategy to advance and secure adequate support and recognition of caregivers within the state's developing patch-work of services and supports for the corresponding expanding population of older people and those who care for them.

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. Given impending demographic realities that point to a rapid expansion of the 65+ population underway, maximizing the support of informal caregivers, if better understood, may be a mechanism that could insulate the state from costs.

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.

A 2012 report issued by the California Commission on Aging (CCoA) noted that the state faces serious caregiver 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, according to the report, entitled "Celebrating Caregiving in California." The CCoA cautioned that policymakers must weigh the value of protecting the interest of family caregivers against the cost of institutionalization.

### **Previous Legislation:**

**AB 1744 (Brown) Vetoed by the Governor** required the California Department of Aging, upon securing \$200,000 in non-state funds from private sources for purposes of implementing the bill, to convene a blue-ribbon panel, comprised of at least 13 members, as specified, to make legislative recommendations to improve services for unpaid and family caregivers in California, as provided. The bill would have required the committee to prepare a report of its findings and recommendations and provide it to the Legislature on or before July 1, 2016.

*Governor's Veto Message:*

*To the Members of the California State Assembly:*

*I am returning Assembly Bill 1744 without my signature.*

*The bill would require the California Department of Aging to establish and support a 13-member blue ribbon task force on unpaid family caregiving, using only non-state funds from private sources.*

*The California State Plan on Aging, the California Plan for Alzheimer's Disease, the significant reports and action plans developed by the 33 Area Agencies on Aging, the Alzheimer's Association, the AARP and so many others have produced ample evidence for knowledgeable and caring people to recommend ways to improve support for family caregivers.*

*Establishing another task force in state law simply isn't necessary.*

*Sincerely,*

*Edmund G. Brown Jr.*

**AB 753 (Lowenthal) Chapter 708, Statutes of 2013** requires the Department of Health Care Services to contract directly with nonprofit caregiver resource centers (CRCs) to provide direct

services to caregivers of cognitively impaired adults, including specialized information, family consultation, respite care, short-term counseling, and support groups.

**SB 491 (Alquist) Chapter 339, Statutes of 2008** required the California Department of Public Health to establish an Alzheimer's Disease and Related Disorders Advisory Committee, appoint members, and develop recommendations about various policy issues related to Alzheimer's disease.

**REGISTERED SUPPORT / OPPOSITION:**

**Support**

American Association of Retired Persons (AARP) - Sponsor  
Association of California Caregiver Resource Centers – Co-Sponsor  
California Commission on Aging – Co-Sponsor  
California Senior Legislature – Co-Sponsor  
Congress of California Seniors  
National Association of Social Workers, California Chapter (NASW-CA)  
United Domestic Workers of America (UDW)

**Opposition**

None on file.

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