

Date of Hearing: April 23, 2013

ASSEMBLY COMMITTEE ON AGING AND LONG-TERM CARE

Mariko Yamada, Chair

AB 753 (Lowenthal) – As Amended: April 18, 2013

SUBJECT: Cognitively impaired adults: caregiver resource centers

SUMMARY: Repeals and recasts statutes related to the system of caregiver resource centers (CRCs) and the recent transfer of the program from the former Department of Mental Health (DMH) to the Department of Health Care Services (DHCS) pursuant to the FY 2012-13 budget trailer bill provisions (AB 1467 Chapter 23, Statutes of 2012). Specifically, this bill:

- 1) Repeals outdated statutes authorizing CRCs within the former DMH, and creates the Comprehensive Act for Families and Caregivers of Cognitively Impaired Adults.
- 2) Makes a number of legislative findings and declarations regarding CRCs, including that:
  - a) Families caring for loved ones with cognitive impairments face significant challenges to maintaining physical and mental health due to burdens associated with caregiving;
  - b) CRCs advocate for family caregivers;
  - c) CRCs use evidence based practices to improve health outcomes for caregivers and the people for whom they care;
  - d) CRC services help families avoid or delay nursing home placement resulting in significant savings in health care costs to families, as well as government individuals and communities;
  - e) CRC's help the state's economy by assisting and supporting families care for a loved one; and,
  - f) The state shall support family caregivers taking care of adults living with cognitive impairments by funding and implementing caregiver resource centers.
- 3) Establishes various definitions for purposes of the program, for "Caregiver," "Cognitive Impairment," "Cognitively Impaired adult," among others.
- 4) Requires the director of the DHCS to:
  - a) Maintain contracts with 11 CRCs;
  - b) Maintain a CRC Operations Manual that define CRC procedures, and identifies CRC duties, responsibilities; and,
  - c) Seek funding for CRCs from federal and private resources.

- 5) Requires agencies designated as CRCs to include on their governing boards or advisory bodies, or both, representatives that reflect the ethnic and socioeconomic character of the area and people served, and establishes criteria to be used when selecting a resource center, including:
  - a) Fiscal stability, and sound financial management, including fundraising competencies;
  - b) The ability to build community support for the agency; and,
  - c) The ability to deliver services to, and advocate for, the needs of caregivers of cognitively impaired adults, including consultations, respite, counseling, support groups, legal and financial consultation, education, and training.
- 6) Establishes services that must be delivered by CRCs based upon available resources and the needs of the community, including consultations, respite, counseling, support groups, legal and financial consultation, education, and training.
- 7) Declares that recipients of services may be required to contribute to defray the cost of services received.
- 8) Requires CRCs to submit progress reports on activities, as required by the director of DHCS;
- 9) Authorizes the director of DHCS to enter into exclusive or nonexclusive contracts on a bid or negotiated basis and to amend existing contracts to provide or arrange for services provided under this bill.
- 10) Includes an urgency clause to make the provisions of this bill take effect immediately.

EXISTING LAW establishes the Comprehensive Act for Families and Caregivers of Brain-Impaired Adults, previously administered by DMH, to contract with a Statewide Resources Consultant to coordinate a statewide system of CRCs to serve caregivers of adults with Alzheimer's disease, stroke, Parkinson's, traumatic brain injury, and other adult-onset cognitive disorders.

AB 753 intends to continue the existing resource centers

FISCAL EFFECT: Unknown

- 1) PURPOSE: The Association of California CRCs has sponsored AB 753 to update CRC statutes for the first time in 30 years. By doing, AB 753 recasts obsolete code sections reflecting the program's transition from the former Department of Mental Health to the Department of Health Care Services.

There are eleven Caregiver Resource Centers:

- a) Bay Area CRC/ Family Caregiver Alliance, serving Alameda, Contra Costa, Marin, San Francisco, San Mateo and Santa Clara Counties;
- b) Redwood CRC serving Del Norte, Humboldt, Lake, Mendocino, Napa, Solano and Sonoma Counties;
- c) Los Angeles CRC, serving Los Angeles County;

- d) Inland CRC, serving Inyo, Mono, Riverside and San Bernardino Counties;
- e) Del Oro CRC, serving Alpine, Amador, Calaveras, Colusa, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Sutter, Yolo and Yuba Counties;
- f) Southern CRC, serving San Diego and Imperial Counties;
- g) Coast CRC, serving San Luis Obispo, Santa Barbara and Ventura Counties;
- h) Mountain CRC, serving Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama and Trinity Counties;
- i) Valley CRC, serving Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare and Tuolumne Counties;
- j) Del Mar CRC, serving Monterey, San Benito and Santa Cruz Counties; and,
- k) CRC of Orange County, serving Orange County.

2) CAREGIVING IN CALIFORNIA: 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 44 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 2035. 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.

3) 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:

- a) 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.
- b) At any one time the report estimates 37.3 million people are providing care.
- c) 66% are women and 34% are men.
- d) 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.
- e) 1.4 million children ages 8 to 18 provide care for an adult relative;
- f) 72% are caring for a parent or grandparent; and
- g) 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.

4) 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 (FCA) 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.

- 5) HISTORY: CRC were first authorized under legislation when Governor Deukmejian signed AB 2913 in 1984. The "Comprehensive Act for Family Caregivers of Brain-Impaired Adults" established 11 regional agencies known as Caregiver Resource Centers under the Department of Mental Health. CRCs were legislatively mandated to assist families who provide care for loved ones with Alzheimer's Disease, stroke, Parkinson's, Huntington's Disease, Traumatic Brain Injury (TBI), Multiple Sclerosis and other brain disorders acquired after the age of 18. The CRC system was the first of its kind in the nation and was looked to as a model for the development of similar services now available in all 50 states.

CRCs emerged as the brain-child of research carried out by the FCA, a San Francisco based resource and research center where the study of family-centered care for older adults developed into a special expertise in creating and replicating family caregiver support programs, and translating research to promote policy change.

CRC Services are somewhat unique. Unlike most publicly supported services and programs, CRC services are not means tested. They are not intended to address the needs of the disabled family member who is being cared for directly -- but instead directed to the caregiver, in order to support and preserve the informal family caregiving relationship. The public value lies in extending the caregiving relationship through respite, counseling and other supports to caregivers. Doing so assures caregivers endure the unremitting demands of caregiving and delays institutionalization, the likelihood of imminent impoverishment, and other debilitating conditions that caregivers are known experience, which could lead to a dependency upon public social resources.

- 6) FUNDING: Funding for CRCs has been reduced by 74% since 2009. As a result of these budget reductions, all CRCs maintain waiting lists for various services; the CRC serving the Los Angeles area has a waiting list of over 900 people for respite services alone.

When the CRC program was under the authority of DMH, the FCA, the original CRC, was selected to serve as the Statewide Resources Consultant. In this capacity, FCA assisted in statewide program development, data analysis, reporting functions, and technical assistance.

The Governor's 2012-13 Budget proposed to eliminate all funding for CRCs. In rejecting this proposal, the Legislature noted that CRCs are a valuable component of the state's overall safety net that allows caregivers to continue providing long-term care in homes, thereby enabling many disabled Californians to continue living in the community rather than in nursing facilities, hospitals, or institutionalized settings, at costs that typically exceed most individual or family savings, leading to impoverishment, and ultimately, dependency upon public social services.

According to a recent joint informational hearing of this committee and the Assembly Human Services Committee, 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<sup>1</sup>.

- 7) **SUPPORT:** Several individual CRCs note in support that dedicated families, not institutions, provide most of the long-term care for loved ones with cognitive impairments, often at great physical, emotional, and financial sacrifice. They state that this bill ensures that the state continues to support and fund these programs that give caregivers a place to turn for services. The Peninsula Stroke Association writes in support that the small investment the state makes in CRCs results in large monetary savings over the long-term by preventing or delaying the placement of adults with cognitive impairments in nursing homes or hospitals.

**This bill passed out of Assembly Health with a vote of 19-0 with a recommendation to consent.**

**REGISTERED SUPPORT / OPPOSITION:**

**Support**

Alzheimer's Association  
 Association of California Caregiver Resource Centers (CRC)  
 California Association for Health Services at Home (CAHSAH)  
 Coast Caregiver Resource Centers  
 Del Oro caregiver Resource Center  
 Family Caregiver Alliance  
 Health Projects Center's Del Mar CRC  
 Inland Caregiver Resource Center  
 Multipurpose Senior Services Program Site Association (MSA)  
 Orange County Caregiver Resource Center  
 Peninsula Stroke Association  
 Redwood Caregiver Resource Center  
 Southern Caregiver Resource Center  
 Traumatic Brain Injury Services of California  
 Valley Caregiver Resource Centers

**Opposition**

None on file.

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<sup>1</sup> 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