

Date of Hearing: April 21, 2015

ASSEMBLY COMMITTEE ON AGING AND LONG-TERM CARE

Cheryl Brown, Chair

AB 1526 (Committee on Aging and Long-Term Care) – As Introduced March 16, 2015

SUBJECT: Behavioral Risk Factor Surveillance System survey: caregiver module

SUMMARY: Directs the Department of Public Health (DPH), beginning January 1, 2016, to include the federal Centers for Disease Control and Prevention's Caregiver Module in the annual Behavioral Risk Factor Surveillance System survey. Specifically, **this bill:** Finds and declares:

- 1) That caregiving represents challenges for public health.
- 2) Finds that though there are positive and negative health outcomes associated with caregiving, informal caregivers in California are frequently overlooked as a component of the health care system though they contribute billions of dollars' worth of unpaid care to people with disabilities and chronic conditions.
- 3) Public health staff, agencies and researchers are working to understand caregivers needs.
- 4) Public health staff, agencies and researchers seek to answer questions about the number of caregivers there are, the types of care they provide, the amount of care they provide and for how long.
- 5) Understanding caregiving allows the state, and decision makers to understand the impact of caregiving, plan for services to support caregivers and care recipients, and to provide interventions.
- 6) Directs the Department of Public health to include the Federal Centers for Disease Control and Prevention's Caregiver Module in the annual Behavioral Risk Factor Surveillance System survey.

EXISTING LAW:

- 1) Federal law authorizes the Centers for Disease Control (CDC) which conducts annual surveys to assess behaviors that places humans at risk for diseases and/or other health conditions, including the Behavioral Risk Factor Surveillance System (BRFSS).
- 2) State law establishes the Department of Public Health which is dedicated to optimizing the health and well-being of the people in California.

Background:

Author's Statement: "Accurately identifying, thoroughly analyzing, and thoughtfully planning to address caregiver burden in California will improve health outcomes for both the person needing care and the caregiver, as well as lower public health and social service costs. Caregivers are a key ally to delivering health services and long-term services and supports to disabled adults and older Californians. We have a unique opportunity today to incorporate questions on California's extensive BRFSS survey to examine caregiving in our state. From this simple survey, we can learn more about California caregivers and their needs. When we support

caregivers, we support individuals affected by Alzheimer's disease, autism, cancer, diabetes, heart disease, mental health and substance abuse too. We can't afford to wait for a crisis and then embark on planning. We have the desire and the ability now to take the first step, measuring caregiver burden in California with the expertise of our own Department of Public Health through an existing BRFSS survey tool with a CDC approved question. The pieces are all in place to move forward. For minimal cost we can better plan to meet the growing needs of caregivers through the Caregiver Module."

BRFSS: The Behavioral Risk Factor Surveillance System (BRFSS) is a cross-sectional telephone survey that state health departments conduct monthly over landline telephones and cellular telephones with a standardized questionnaire and technical and methodological assistance from CDC. BRFSS is used to collect prevalence data among adult U.S. residents regarding their risk behaviors and preventive health practices that can affect their health status. Respondent data are forwarded to CDC to be aggregated for each state, returned with standard tabulations, and published at year's end by each state. In 2011, more than 500,000 interviews were conducted in the states, the District of Columbia, and participating U.S. territories and other geographic areas.

By collecting behavioral health risk data at the state and local level, BRFSS has become a powerful tool for targeting and building health promotion activities. As a result, BRFSS users have increasingly demanded more data and asked for more questions on the survey. Currently, there is a wide sponsorship of the BRFSS survey, including most divisions in the CDC National Center for Chronic Disease Prevention and Health Promotion; other CDC centers; and federal agencies, such as the Health Resources and Services Administration, Administration on Aging, Department of Veterans Affairs, and Substance Abuse and Mental Health Services Administration.

BRFSS Caregiver Module: Beginning in 2009, a special set of 10 questions have been available to examine various aspects of caregiving, referred to as the "Caregiver Module." The questions allow states to determine who is a caregiver; the relationship between the caregiver and the care recipient; the average hours of caregiving per week; the most difficult problem facing the caregiver; the age and gender of the care recipient; the types of assistance needed by the care recipient; the major health problem, long-term illness, or disability of the care recipient; the duration of caregiving; and whether the person has had more difficulty with thinking or remembering in the past year. The responses from the caregiver module are then paired with information from the main BRFSS questionnaire, which allow for additional information about the health and well-being of caregivers.

Caregiving: 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 percent. By age 85, women outnumber men two-to-one.

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.” 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.

FISCAL EFFECT: This measure has not been analyzed by a fiscal committee.

REGISTERED SUPPORT / OPPOSITION:

Support

Alzheimer’s Association

Opposition

None on file.

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