

ASSEMBLY BILL 1526

Assembly Aging and Long-Term Care Committee: Cheryl Brown, Chair

Bill proposal – This is a one-time request to establish a benchmark for California. In effect, this is a census-taking of caregiver burden in California to acknowledge individuals who provide support to people living with:

Arthritis

Asthma

Cancer

Chronic respiratory conditions

Dementia or other cognitive impairments

Developmental disabilities

Diabetes

Heart disease

HIV/AIDS

Mental illness

Organ failure

Substance abuse or addiction

The Alzheimer's Association is sponsoring AB 1526 (Assembly Aging and LTC Committee) to ensure the Centers for Disease Control (CDC) optional caregiver burden module is included on the 2016 California Behavioral Risk Factor Surveillance System (BRFSS) statewide survey administered annually by the California Department of Public Health (CDPH).

Bill purpose – In order to prepare the most efficient and effective infrastructure to support caregivers, we must first determine the full scope and extent of caregiving in California. Currently, there is no statewide or public source of accurate or reliable caregiver data. Prudent planning requires high-level, evidence based data such as the BRFSS under the appropriate jurisdiction of the CDPH, the state's primary source of population research and surveillance.

More than one in six American workers cares for an elderly or disabled family member. While this bill proposal is comprehensive and not disease-specific, as a frame of reference, within the nationwide Alzheimer's community, 15.6 million caregivers provided an estimated 17.7 billion hours of unpaid care valued at more than \$220 billion. **In California alone, families impacted by Alzheimer's disease contribute \$22 billion in unpaid care for their loved ones – more than government sources pay for direct dementia costs.**

As the population ages and demographics shift (smaller families, more women employed in the workforce, increasingly mobile society, longer life spans, etc.), the pool of available family caregivers to assist children, siblings, parents and other relatives is diminishing. These demographic forces will significantly impact public programs such as Medi-Cal and other state and federally funded health, education and human services.

Bill cost – CDPH charges \$7,500 per (sub) question to add an optional module to the BRFSS survey. At nine questions, the caregiver burden module totals \$67,500 in one-time state costs.

Why Support This Bill?

1. The caregiver burden question is comprehensive; it includes arthritis, asthma, cancer, chronic respiratory conditions, dementia and other cognitive impairments,

developmental disabilities such as autism and Down's syndrome, diabetes, heart disease, HIV, mental illness, organ failure and substance abuse.

2. The BRFSS survey is administered annually by CDPH; this is an incremental change to an existing major statewide undertaking.
3. The data collected will be California-specific, current, accurate and relevant. Data can be used for policy development, budget forecasting, program planning and grant seeking/funding.
4. Existing state funds may be available for this use, either surplus or unused.
5. The California State Senate Select Committee on Aging report issued in January 2015 concluded that our state aging and long-term care infrastructure is crumbling and we need to build for our future. This is a strategic investment in future planning.
6. AB 1526 supports California's State Plan for Alzheimer's Disease, which states "Create a coordinated state infrastructure that enhances the delivery of care," with the BRFSS survey a specific recommendation. Further, the State Plan called on lawmakers to "Establish a Comprehensive Approach to Support Family Caregivers."

About the Behavioral Risk Factor Surveillance System

By the early 1980s, scientific research clearly showed that personal health behaviors played a major role in premature morbidity and mortality. Although national estimates of health risk behaviors among U.S. adult populations had been periodically obtained through surveys conducted by the National Center for Health Statistics (NCHS), these data were not available on a state-specific basis. This deficiency was viewed as a critical obstacle to state health agencies trying to target resources to reduce behavioral risks and their consequent illnesses. National data may not be applicable to the conditions found in any given state; however, achieving national health goals required state and local agency participation.

About the same time as personal health behaviors received wider recognition in relation to chronic disease morbidity and mortality, telephone surveys emerged as an acceptable method for determining the prevalence of many health risk behaviors among populations. In addition to their cost advantages, telephone surveys were especially desirable at the state and local level, where the necessary expertise and resources for conducting area probability sampling for in-person household interviews were not likely to be available.

As a result, surveys were developed and conducted to monitor state-level prevalence of the major behavioral risks among adults associated with premature morbidity and mortality. The basic philosophy was to collect data on actual behaviors, rather than on attitudes or knowledge, that would be especially useful for planning, initiating, supporting, and evaluating health promotion and disease prevention programs. Today, the California Department of Public Health administers the BRFSS survey under contract with California State University, Sacramento.

Contact: Susan DeMarois

State Policy Director, California Council of the Alzheimer's Association

Phone: 916-447-2731

sdemarois@alz.org