

SPEC. COM. REP. NO. 1

Honolulu, Hawaii

December 27, 2006

RE: S.B. No. 3253
S.D. 1
H.D. 1
C.D. 1

Honorable Colleen Hanabusa
President of the Senate
Twenty-Fourth State Legislature
Regular Session of 2007
State of Hawaii

Honorable Calvin K. Y. Say
Speaker, House of Representatives
Twenty-Fourth State Legislature
Regular Session of 2007
State of Hawaii

Madam President and Mr. Speaker:

Your Joint Legislative Committee on Family Caregiving, created pursuant to Act 285, Session Laws of Hawaii 2006, and having been directed to report to the Legislature by S.B. No. 3253, S.D. 1, H.D. 1, C.D. 1 (2006), entitled:

"A BILL FOR AN ACT RELATING TO CAREGIVING,"

begs leave to report as follows:

PART I. BACKGROUND

Introduction

Family caregiving has always been a universal experience of all ethnicities, lifestyles, and income levels. Recently, however, caregiving of family elders has become more than an act of love and familial responsibility. Due to a shortage of care providers in Hawaii, family caregiving has become a critical element of our health and long-term care system. By 2020, more than one in four individuals is expected to be sixty years old or older. The need for personal care assistance due to physical, sensory, cognitive, and self-care disabilities increases with age.



As Hawaii's population ages, many more families will be providing higher levels of long-term care to frail and disabled older adults at home. A comprehensive public policy to strengthen support for family caregivers is essential.

Legislative Mandate

Your Joint Legislative Committee (JLCFC) was created by Senate Bill No. 3253, S.D. 1, H.D. 1, C.D. 1, which was enacted as Act 285, Session Laws of Hawaii (SLH) 2006. The JLCFC members are: Senator Les Ihara, Jr. and Representative Marilyn B. Lee, Co-Chairs; Senators Rosalyn Baker, Suzanne Chun Oakland, and Gordon Trimble; and Representatives Josh Green, M.D., and Alex Sonson. Former Representatives Dennis A. Arakaki and Anne V. Stevens have also served on the JLCFC.

Act 285, SLH 2006, directed the JLCFC to develop a comprehensive public policy to strengthen support for family caregivers who provide unpaid, informal assistance to persons age sixty and older with physical or cognitive disabilities. At the request of several testifiers, the JLCFC clarified that the definition of family caregivers included non-family members who are often friends, neighbors or good Samaritans. The JLCFC was also directed to consider providing support in categories including:

- (1) Coordinated services and policies;
- (2) Training and education;
- (3) Respite services;
- (4) Financial incentives; and
- (5) Balancing work and caregiving.

The JLCFC was directed to seek input from the Department of Health, Department of Human Services, Department of Taxation, University of Hawaii, Executive Office on Aging, and the elderly, disability, business, and faith-based communities. The JLCFC was also directed to submit its findings and recommendations to the Legislature no later than twenty days prior to the convening of the Regular Session of 2007.



Approach of the JLCFC

The JLCFC met for informational briefings on September 27, October 3, October 18, November 1, and November 16, 2006. In addition, the JLCFC met with the Legislature's Kupuna Caucus for a joint informational briefing on November 3, 2006, and held meetings on November 17 and December 13, 2007.

The JLCFC conferred with all of the organizations as directed by Act 285, SLH 2006. Input was obtained from individual members of the public and representatives of the following organizations: Department of Health; Department of Human Services; Department of Taxation; Executive Office on Aging (EOA); Policy Advisory Board for Elder Affairs; University of Hawaii at Manoa, School of Social Work; University of Hawaii at Hilo; State Council on Developmental Disabilities; University of Hawaii Community College System; City and County of Honolulu, Elderly Affairs Division; County of Hawaii, Office of Aging; County of Maui, Office on Aging; County of Kauai Agency on Elderly Affairs; Hawaii Caregiver Coalition; Hawaii Alliance for Retired Americans; AARP Hawaii; Project Dana; Aging and Disability Resource Center; Alzheimer's Association, Aloha Chapter; ARC in Hawaii; Child & Family Service; Chamber of Commerce of Hawaii, Health Committee; National Federation of Independent Businesses; Society of Human Resource Management; Faith Action for Community Equity; Catholic Charities Hawaii; Hawaii Conference United Church of Christ and Church of the Crossroads; Muriel Sisters; Kilohana Adult Day Care Program; National Alliance on Mental Illness Oahu; Mental Health Association in Hawaii; Goodwill Industries of Hawaii; Queen Lili'uokalani Children's Center; and Brain Injury Association of Hawaii.

In addition, the JLCFC obtained input from unpaid, individual family caregivers representing the following family caregiver categories: older adult family caregiver taking care of an older adult; family caregiver who does not live with the care recipient; family caregiver who is employed; family caregiver who is taking care of someone at end-of-life; family caregiver taking care of someone with Alzheimer's Disease; family caregiver taking care of multiple care recipients; family caregiver support group facilitator; and long-distance family caregiver. The JLCFC also heard testimony from representatives of the following programs currently in place in other states: Oregon's Lifespan Respite Care System, Minnesota's Alternate Care Program, the California



Paid Family Leave Program, and the Virginia Caregivers Grant Program.

The JLCFC is aware that Senate Concurrent Resolution No. 13 (2006) is related to Act 285, SLH 2006, as it requests the Governor to convene a Work-Family Task Force to review Hawaii's work-family laws and policies, and requests the Legislative Reference Bureau (LRB) to study other states' laws and practices that promote good work-family policy. Therefore, the JLCFC obtained input from a member of the Governor's Long Term Living Initiative Subcommittee on Family Caregivers, as well. As of the time this report was written, the LRB study was not available for publication.

PART II. SUBSTANTIVE ISSUES

The JLCFC adopted a policy of determining what the State can do to foster a person's ability to age-in-place, particularly through the support of family caregivers. After hearing all of the testimony presented, and cognizant of its direction to consider providing support in the categories designated in Act 285, SLH 2006, the JLCFC also adopted a policy of establishing a comprehensive and sustainable, community-based family caregiver support system to maximize resources in all communities.

The JLCFC envisions a comprehensive and sustainable, community-based family caregiver support system that has components including:

- (1) A coordinated referral and case management service;
- (2) Centralization of available services;
- (3) Volunteers;
- (4) Education and training; and
- (5) Financial assistance.

In making its recommendations, the JLCFC focused on addressing the immediate needs of family caregivers, as well as, facilitating the development of a comprehensive, community-based family caregiver support system by recommending measures that will contribute to that goal.



Finding A: In 2003, the *Hawaii Health Survey* reported that an estimated 192,390 individuals in the State provide regular care or assistance to a person aged sixty years or older. The figure may be higher as testifiers noted the possibility of many "hidden" family caregivers in Hawaii who do not identify themselves as family caregivers. According to a publication by the EOA entitled *Family Caregivers: A Summary of National and Local Data, December 2004*, the EOA "has been sponsoring collection of a limited number of data elements on caregiving through the Hawaii Health Survey." While the EOA's data collection yields helpful family caregiving data, it is still necessary to gather more information on this subject to enable the State to apply resources and services in a more efficacious manner.

Recommendation A: The JLCFC recommends that a comprehensive needs assessment be conducted to determine, among other things, the size of the current family caregiver population, extent of unmet caregiving needs of elders, what percentage of care recipients' needs being met by paid versus family caregivers, and the impact of family caregiving on employment and the family caregiver's income. The comprehensive needs assessment should identify past surveys, such as the 2003 *Hawaii Health Survey*, and include focus groups. The needs assessment may include a telephone survey or other method for gathering reliable data regarding family caregivers' needs, such as, adding additional family caregiving questions to the upcoming *Hawaii Health Survey*. Policy questions should be developed to guide the needs assessment. The findings of the needs assessment can be used to facilitate the development of a comprehensive and sustainable, community-based family caregiver support system.

Finding B: For many family caregivers, their role as family caregiver arises as suddenly as the care recipient's health declines, leaving the family caregivers with an immediate need for services, but little preparation or education regarding who to contact for assistance or what services are available to them. In addition, the family caregivers may not know who is capable or qualified to provide them with the services that they or the care recipients need. The testimony revealed that family caregivers would benefit from a single point of access system that coordinates services and policies, and that provides referrals to services and providers. Also, family caregivers themselves need support services, including respite services and training, education, and counseling on areas such as caregiving and dealing with end-of-life issues.



Recommendation B: The JLCFC recommends that:

- (B1) The work of the JLCFC be extended for one year beyond its sunset date of June 30, 2007, to develop a comprehensive and sustainable, community-based family caregiver support system. The JLCFC should focus on how the Hawaii Aging and Disability Resource Center (ADRC) can serve as a single-entry, one stop source for family caregiver services and referrals in Hawaii County (where it currently being developed), as well as, in the other counties. The JLCFC should consider how successful service referral models, such as, the Palolo Chinese Home HiNOA Program and the Beacon Hill Village concierge service in Boston, Massachusetts can be expanded or replicated to provide similar referral services in Hawaii communities. The JLCFC should also monitor any pilot programs recommended herein and report on their possible integration into a comprehensive, community-based family caregiver support system;
- (B2) A pilot program be established and funded to reimburse family caregivers who provide free and continuing day-to-day care in the home to a qualified relative who is a functionally dependent person or who is suffering from cognitive impairment. The pilot program should include a report to the Legislature on the outcomes and costs of the pilot program;
- (B3) A volunteer-hours exchange pilot program be established and funded to develop a Hawaii community model based on volunteer credit banking programs on the mainland and in other countries. The pilot program should include a report to the Legislature on the outcomes and costs of the pilot program;
- (B4) A pilot program be established and funded to provide emergency and evening respite services. The pilot program should include a report to the Legislature on the outcomes and costs of the pilot program;
- (B5) During the 2007 legislative interim, the JLCFC explore a paid family leave program under the state Temporary Disability Insurance Law, similar to the California Paid Family Leave Program, to provide wage replacement



benefits to employees who take time off from work to care for a seriously ill family member; and

- (B6) Support be given to including an appropriation in the Executive Budget for the UH Center for Aging Research and Education (CARE) to transition from a volunteer staff to a paid director and paid faculty to establish a bonafide research and training center.

Finding C: There is an immediate need to expand in-home services (e.g., housekeeping, bathing services, home-delivered meals, etc.) and access services (e.g., transportation, case management, escort, etc.), both on Oahu, and particularly on the neighbor islands, to facilitate family caregiving and aging-in-place. Most of the family caregivers and others who testified noted an immediate need for financial assistance, as well. Many family caregivers are faced with the difficult choice of continuing employment or leaving work to care for a family member. This places a financial strain on the family caregiver. However, the State benefits from the value of the services that family caregivers provide to care recipients by way of deferred paid caregiving and institutionalization. According to *Family Caregivers: A Summary of National and Local Data, December 2004*, one study "estimated that approximately 115,000 family caregivers in Hawaii provided personal care to persons aged 15 years old and older, for a total of approximately 107 million hours, resulting in an estimated economic value of caregiving of approximately \$875 million per year."

Recommendation C: The JLCFC recommends that:

- (C1) An appropriation be made to Kupuna Care to expand its in-home and access services statewide and to add the flexibility to provide services to the caregivers of the qualified care recipients, as well;
- (C2) An appropriation be made for the Sage PLUS Program to expand its health insurance information, counseling, and referral services to the neighbor islands and to support its operating costs;
- (C3) Proposed federal funding cuts to successful, established programs be monitored to determine if alternative



sources of funding are necessary to maintain the programs;

- (C4) A tax credit be provided for the cost of home modifications to enable the family caregiver to better assist the care recipient in the home;
- (C5) A narrow tax credit, a grant-in-aid to the counties, or a "cash and counseling" model be explored to address family caregivers' present needs. Any tax credit, grant, or "cash and counseling" model should be targeted to a specific population and should include a mechanism for supporting family caregivers' purchase of "quality-of-life" items for the care recipient (e.g., adult incontinence products, lotions, etc.); and
- (C6) A resolution be passed requesting the Board of Professional Engineers, Architects, Surveyors and Landscape Architects at the Department of Commerce and Consumer Affairs promote awareness of family caregiving needs in the architectural design of new residences.

Finding D: Numerous testifiers appeared on behalf of grandparents in support of recognizing their role as family caregivers for their grandchildren. As the JLCFC's was directed to focus on family caregivers who provide unpaid, informal assistance to persons age sixty and older with physical or cognitive disabilities, this group fell outside the scope of this report. However, it should be noted that the National Family Caregiver Support Program under the reauthorized Older Americans Act is available to family caregivers of older adults age sixty and older, as well as grandparents of children age eighteen years and younger.

Recommendation D: The JLCFC recommends that the definition of family caregiver be amended to include this population of family caregivers, as well.

Finding E: Local communities must be prepared to accommodate their aging population. Planning should be done now to accommodate "aging in place" in the community and to accommodate those facilities and services that will make aging in place possible. Local governments should review existing policies, programs, and services that affect the aging population and aging services and develop an "aging in place" in the community plan.



Recommendation E: The JLCFC recommends that the counties examine current zoning laws, building codes, and subdivision requirements and eliminate encumbrances to family caregiving and aging in place as may be appropriate to prepare to meet our aging population's needs.

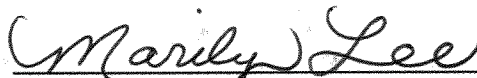
PART III. CONCLUSION

The JLCFC recommends that legislation be introduced in the 2007 legislative session to implement the recommendations outlined in this report. Co-chairs Senator Les Ihara, Jr. and Representative Marilyn B. Lee, and other members of the JLCFC will jointly sponsor the necessary legislation.

Respectfully submitted on
behalf of the members of the
Joint Legislative Committee on
Family Caregiving,



LES IHARA, JR., Co-Chair



MARILYN LEE, Acting Co-Chair

