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Honorable Colleen Hanabusa
President of the Senate
Twenty-Fourth State Legislature
Regular Session of 2008
State of Hawaii

Honorable Calvin K. Y. Say
Speaker, House of Representatives
Twenty-Fourth State Legislature
Regular Session of 2008
State of Hawaii

Madam President and Mr. Speaker:

The Joint Legislative Committee on Family Caregiving (JLCFC), created pursuant to Act 285, Session Laws of Hawaii (SLH) 2006, and having been directed to report to the Legislature by Act 204, SLH 2007, entitled:

"A BILL FOR AN ACT RELATING TO CAREGIVING,"

begs leave to report as follows:

PART I. INTRODUCTION

The following report is the result of the work of the JLCFC conducted during the 2007 Interim. Part II of this report provides the background of the JLCFC. Part III provides a summary of the following studies and surveys:

(1) Caregivers Needs Assessment (page 6);
(2) Employer Eldercare Survey (page 9);
(3) Cash and Counseling (page 10);
(4) Cost-Benefit Analysis of Tax Credit (page 11);
(5) Grandparents Needs Assessment (page 12); and
(6) Legislative Reference Bureau (LRB) Respite Study and

Executive Office on Aging (EOA) Respite Inventory (page 12).

Part IV contains the findings and recommendations of the JLCFC, including findings and recommendations related to:

(1) Extending the work of the JLCFC (page 14);
(2) Kupuna Care (page 14);
(3) A home modification tax credit (page 14);
(4) A caregiver tax credit (page 15);
(5) Center on Aging Research and Education (page 15);
(6) Paid Family Leave (page 16);
(7) Cash and Counseling (page 17);
(8) Grandparents Raising Grandchildren (page 18);
(9) Respite (page 18); and
(10) Emergency Care (page 19).

Part V is the conclusion.

PART II. BACKGROUND

Introduction

Hawaii has a strong tradition of family caregiving. Family caregivers[1] are family members, friends, and neighbors who provide unpaid assistance to those over the age of sixty or are grandparents raising their grandchildren. 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 is a critical element of our health and long-term care system.

By 2020, more than one in four individuals is expected to be sixty or older. As Hawaii's population ages, many more families

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[1] Act 204, SLH 2007, states, in relevant part:

For purposes of this Act, "family caregiver" means:
(1) A person, including a non-relative such as a friend or neighbor, who provides unpaid, informal assistance to a person age sixty and older with physical or cognitive disabilities; and
(2) A grandparent who is a caregiver for a grandchild who is age eighteen years or younger, or who is nineteen years of age or older with physical or cognitive limitations.

will be providing higher levels of long-term care to frail and disabled older adults at home. Family caregivers provide great economic value to the State and the State must support and encourage them. Family caregiving delays institutionalization and allows people to remain in their homes.

While family caregiving is often an act of love, family caregivers play a dual role and often face added burdens in caring for their loved ones while fulfilling other family and workplace responsibilities. A continued effort to create comprehensive public policy to strengthen support for family caregivers is essential as the population ages before our eyes. The State can build on and encourage the strong tradition of family caregiving in Hawaii by making a plan for the future that includes research, development of best practices, and outcome measurement.

Legislative Mandate

The JLCFC was created by Act 285, SLH 2006. Senate Bill 1916, C.D.1, enacted as Act 204, SLH 2007, (Act 204), extended the JLCFC's mandate until June 30, 2008. 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 Karen Awana, John Mizuno, and Alex Sonson.

The purpose of Act 204 is to continue to strengthen support to family caregivers, in part, by directing the JLCFC to:

(1) Explore establishing a paid family leave program under the State's Temporary Disability Insurance Law; and

(2) Conduct a comprehensive needs assessment of the needs of family caregivers and care recipients who are age sixty and older with physical or cognitive disabilities. The needs assessment must include an evaluation of:

(A) The size of the current family caregiver population;

(B) The impact of caregiving on the family caregivers' employment and income;

(C) The percentage of care recipients' needs being met by paid versus unpaid caregivers; and

(D) The extent of unmet caregiving needs of persons age sixty and older with physical or cognitive disabilities.

The JLCFC was directed to seek input from the Department of Health, Department of Human Services, Department of Taxation, University of Hawaii (UH), EOA, and 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 2008.

Approach of the JLCFC

The JLCFC met for informational meetings on July 6, 2007; August 16, 2007; November 7, 2007; November 16, 2007; December 4, 2007; December 11, 2007; and December 18, 2007. The major issues of discussion included: the caregiver needs assessment; grandparents raising grandchildren, generally, and the grandparent needs assessment; the eldercare employer survey; a paid family leave program; a cost-benefit analysis of a caregiver tax credit; cash and counseling; and respite programs.

The JLCFC worked in collaboration with the Legislative Kupuna Caucus to solicit information on topics of mutual interest. In particular, at the September 7, 2007 Kupuna Caucus meeting, Kupuna Care and the UH Center on Aging Research and Education (CARE) were discussed. At the October 5, 2007 Kupuna Caucus meeting, the JLCFC received an update on the status of Kupuna Care funding. On November 2, 2007, plans for UH CARE were discussed.

The Co-Chairs also held several meetings on behalf of the JLCFC on various topics, including the family caregiver needs assessment, UH CARE, cash and counseling, paid family leave, temporary disability insurance, and respite care.

The JLCFC conferred with all of the organizations as directed by Act 204. Various organizations participated in the informational hearings and provided input and testimony. These organizations included:

Governmental Departments and Agencies:

(1) City and County of Honolulu, Elderly Affairs Division;

(2) County of Hawaii, Office of Aging;
(3) County of Kauai Agency on Elderly Affairs;
(4) County of Maui, Office on Aging;
(5) Department of Education;
(6) Department of Hawaiian Home Lands;
(7) Department of Health;
(8) Department of Human Resources Development;
(9) Department of Human Services;
(10) Department of Labor and Industrial Relations;
(11) Department of Taxation;
(12) EOA;
(13) Kapiolani Community College;
(14) Office of Hawaiian Affairs;
(15) Policy Advisory Board for Elder Affairs;
(16) UH Public Policy Center;
(17) UH School of Nursing and Dental Hygiene; and
(18) UH School of Social Work.

Other Interested Organizations:

(1) AARP Hawaii;
(2) Capital Consultants;
(3) Catholic Charities Hawaii;
(4) Center for Independent Living;
(5) Chamber of Commerce of Hawaii;
(6) Child and Family Services, Gerontology Program;
(7) Developmental Disabilities Council;
(8) Disability & Communication Access Board;
(9) Easter Seals Hawaii;
(10) Eldercare Hawaii;
(11) Funeral Consumers Alliance Hawaii;
(12) Hawaii Insurers Council;
(13) Hawaii Medical Service Association;
(14) Hawaii Public Policy Advocates, LLC;
(15) Hawaiian Electric Company, Inc.;
(16) ILWU, Local 142;
(17) Kahi Mohala;
(18) Kaiser Permanente Hawaii;
(19) Kokua Council;
(20) Lanakila Rehab Center;
(21) Na Tutu;
(22) National Association of Social Workers;
(23) National Federation of Independent Businesses;
(24) Queen Liliuokalani Children's Center;
(25) Society for Human Resource Management;

(26) St. Francis Healthcare Systems Hawaii;
(27) Teamsters, Local 996; and
(28) Today's Kupuna.

The JLCFC also obtained input from interested individuals and caregivers, including grandparents who are primary caregivers to their grandchildren. The JLCFC also heard testimony from representatives of the following programs currently in place in other states: The California Paid Family Leave Program and the Washington State Paid Family Leave Program.

PART III. STUDIES AND SURVEYS

Family Caregiver Needs Assessment

Act 204 mandates that a comprehensive needs assessment be conducted to determine, among other things, the size of the current family caregiver population, the percentage of care recipients' needs being met by paid versus unpaid caregivers, the impact on the family caregivers' employment and income; and the extent of unmet caregiving needs of persons age sixty and older with physical or cognitive disabilities.

A contract to conduct the needs assessment was awarded to Pacific Research and Planning Associates, and a second contract was awarded to the UH School of Social Work to analyze the data. The UH Center on Aging assisted with the family caregiver needs assessment. Respondents were identified by random digit dialing and a set of screening questions was used to identify caregiving households. Six hundred responses were obtained statewide. The JLCFC has an analysis of the weighted data, however the final version of the needs assessment is not yet available to the public. The results of the survey of Hawaii's older adults and their unmet needs were unavailable at the time of this report.

Based on the survey results, over one quarter of Hawaii households contain at least one individual providing care for adults over sixty. The family caregiver needs assessment estimated that of the 443,275 households in the State, approximately 118,350 are caregiving households. This did not necessarily mean that the caregiver and care recipient lived together.

Of the family caregivers who responded to the survey, 27.2 per cent are Caucasian, 30.8 per cent are Japanese, and 20.7 per cent are Hawaiian or part Hawaiian.

Over 73 per cent (73.6 per cent) of family caregivers are female and the average age is 54. Generally, most of the caregivers are caring for their parents (55.9 per cent) and spouses (approximately 16 per cent). Care recipients are largely female (64.8 per cent) and the average age of care recipients is approximately 80 years of age. The majority of care recipients either live alone or with their caregiver. The family caregiver needs assessment highlighted that 3 per cent of care recipient reside in a nursing home, which emphasizes the fact that almost all caregiving takes place in a community-based setting and not in an institutional setting.

More than 17 per cent of caregivers are also raising their grandchildren. Just over one quarter of caregiving households (27.5 per cent) include children under the age of 18.

The needs assessment confirms that the household income levels of caregivers tend to be low, with approximately 15.1 per cent in the $25,000 to $29,000 income range, and 13.2 per cent falling into the $30,000 to $34,999 income range. In general, more than 53 per cent of caregivers report earning less than $35,000 annually.

The most common health problems of those receiving care include hypertension, heart disease, arthritis, dementia, and mental health problems, which may include Alzheimer's disease.

The majority of family caregivers are providing assistance with instrumental activities of daily living (IADL), such as shopping and transportation, as well as meal preparation and laundry, to a lesser degree. These types of services tend to require higher cognitive abilities and are often more complex tasks that may not be covered by long-term care insurance. Medical needs and activities of daily living (ADL), such as bathing and dressing, are also high on the list of types of care provided.

Most caregivers provide care for a period of one to five years. The caregivers tend to be the primary providers of care. The average hours of caregiving provided is approximately 20 hours per week. Approximately 29 per cent of caregivers surveyed state

that they provide constant care. Fifty-one of the respondents report using paid help and those that did report using paid help use an average of 8.7 hours a week. Caregivers use an average of a little less than seven hours per week of unpaid help from other family members or friends.

Seven to twenty-five per cent of family caregivers use various types of community services such as nursing services, training services, legal services, and transportation services. The family caregiver needs assessment indicates that this percentage is higher than other national studies that have reported service utilization at less that 10 per cent.

Most respondents state that other types of assistance such as more affordable services, general community services, lower taxes, and other types of financial assistance would be helpful. Better medical service would also be helpful.

Most caregivers also support a paid family allowance (80.7 per cent) and case management (77.6 per cent), which are instrumental parts of a cash and counseling program.

In addition, respite care is one of the top choices of assistance that caregivers think would be helpful. Younger caregivers are more supportive of respite, including daytime, overnight, and weekend respite. Some caregivers report using respite care, provided by informal (unpaid) or formal sources.

Approximately 17 per cent of respondents report that they encounter problems trying to get the services they need.

With regard to the negative effects of caregiving, on a scale of one (no hardship) to five (a great deal of hardship), caregivers rank emotional strain the highest, physical strain the second highest, and financial strain the lowest. Overall, however, the mean scores indicate low levels of negative effects from caregiving.

The needs assessment reveals that caregiving directly affects the workplace. With regard to employment, approximately 55 per cent of caregivers are employed, with about 78 per cent of employed caregivers working full time in addition to providing care.

In addition, many employed caregivers report changes in their work situations due to caregiving. For example, 94 per cent rearrange their work schedules, 77.9 per cent take time off during the work day, and 52.7 per cent experience interruptions to their work day for crisis care. For employed caregivers, 7.3 per cent of their employers offer some form of paid family leave, and 7.8 per cent provide leave without pay. Approximately 9.7 per cent of employers offer part-time work as an eldercare benefit.

Family caregivers support government intervention. According to the caregiver needs assessment, out of the thirteen types of government intervention identified, family caregivers are interested in some type of caregiver tax credit, with 94 per cent of caregivers selecting this option. Caregivers preferences also include the following types of government intervention: requiring employers to offer unpaid family leave (88.9 per cent); providing a place for information and support (90.7 per cent); making community services more affordable (88.3 per cent); authorizing a state income tax credit for long-term care insurance (84.3 per cent); and providing training and education for caregivers (86.4 per cent).

The research indicates in its overall findings that of all the family caregivers, the younger, employed family caregivers are the most impacted by their caregiving responsibilities.

Eldercare Policies in the Workplace

In 2007, the EOA, UH Center on Aging, and UH School of Social Work conducted an *Eldercare Policies in the Workplace* survey.

The employer survey findings indicate that employers are aware of the increase in family caregivers among their employees. One third of employers felt that at least 15 per cent of their employees are providing eldercare.

Employers identify the most common effects of caregiving on the workplace as being employees rearranging their work schedules, as well as employees arriving late or leaving early.

Almost 60 per cent of the respondents agree that employers should provide benefits to their employees affected by family caregiving responsibilities. Employers favor a tax credit to purchase long-term care insurance (70 per cent), while a little

less than half of the employers surveyed favor some type of state subsidy to provide eldercare benefits or wage replacement.

The employer survey indicates that employers are more supportive of eldercare policies when they perceive the policies as increasing productivity. Younger, female executives, and human resource managers tend to be more positive in their attitude about eldercare benefits and public policies to address eldercare.

Research on Cash and Counseling

Pursuant to Act 204, EOA researched cash and counseling programs in other states, including Arkansas, New Jersey, and Florida. EOA contracted with the UH School of Social Work to conduct research and prepare a report to the Legislature. The research indicated that cash and counseling programs are promising programs that help to ensure consumer directed home- and community-based care for elders and persons with disabilities, while benefiting caregivers as well. Under the cash and counseling program, recipients of Medicaid personal care services or home- and community-based services receive a flexible monthly allowance and decide who to hire and what services they want to receive.

The program's innovative approach enables participants to direct and manage their personal assistance services according to their own specific needs based on a care plan developed with their case workers. Participants receive counseling and fiscal assistance to help them manage their allowance and responsibilities. Participants can choose a family member or friend, in lieu of an agency worker, to provide the services. This enables family caregivers to receive a level of financial recognition and support for their efforts and offsets some of the financial sacrifices that family caregivers make to care for loved ones.

These programs have been successful in three state Medicaid-waiver demonstration programs, and fifteen states now offer cash and counseling programs. The research shows that more needs were met, both care recipients and caregivers report higher levels of satisfaction than those who participated in traditional program services, and the consumer impact was substantial. Some program planners also believe that participants tend to be more frugal in expending funds allotted to them in order to maximize the amount of services received. The biggest limitation was the issue of the

costs associated with providing this type of program, however, some of the increased costs could be explained by the fact that persons who participated in cash and counseling programs were receiving the proper services, which they had not been receiving under traditional programs.

Illinois is currently offering a non-Medicaid cash and counseling program and West Virginia and Vermont are close to implementing similar programs. By 2009, an evaluation of the Illinois program should be available.

Cost-Benefit Analysis of Tax Incentives for Family Caregivers

Act 204 mandates EOA to prepare a cost-benefit analysis of a family caregiver refundable income tax credit as proposed in S.B. No. 1199, S.D. 2 (2007). The tax incentive examined contemplates a cash payment to caregivers in the form of a maximum $1,000 credit to go towards the caregivers' state income tax.

The cost-benefit analysis was based on the preliminary, unweighted results of the family caregiver needs assessment. In looking at the cost benefit analysis of a refundable caregiver tax credit, the report indicates that the focus was the cost not to the state government but to the state economy.

The report indicates that the Department of Taxation estimated that 46,943 family caregivers would claim the credit. According to the report, based on this number, the general revenue loss to the general fund would be $30.7 million. This is based on the assumption that not all those who were eligible would claim the tax credit.

The report also indicates that approximately $2.3 million would be generated in the State's economy by the money received as a tax credit and later spent by the family caregivers. In examining how the money would be spent, 40 per cent said personal and family spending; 40 per cent said retirement/personal savings; and 20 per cent said on adult care and home care for the care recipient. According to the report, the 20 per cent spent on adult and home care may provide a stimulus for the home care industry and may increase the labor market.

Grandparents Raising Grandchildren Needs Assessment

During the 2006 Interim, numerous testifiers appeared on behalf of grandparents in support of recognizing their role as family caregivers for their grandchildren. At the time, this group fell outside the scope of the JLCFC and the definition of family caregiver was revised by Act 204 to include this population of family caregivers.

During the 2007 Interim, the UH Department of Family and Consumer Science prepared the *Needs Assessment of Grandparents Raising Grandchildren*. The grandparent needs assessment indicates that over 14,000 grandparents are primary caregivers for over 33,000 grandchildren in the State. These grandparents are providing a great service to the State by caring for these children outside of the foster care system. The needs assessment also shows that grandparents who provide care to their grandchildren often suffer emotional, physical, and financial costs, and these grandparents are a vulnerable population. The types of services needed by these grandparents include: support groups; financial assistance; respite; and assistance in dealing with legal issues such as custody.

Legislative Reference Bureau Report and Respite Care Inventory

During the 2007 Interim, pursuant to H.C.R. No. 187 (2007), LRB researched how other states address the issue of respite care. While the report is not yet in its final form, the LRB report indicates that there are forty-four million unpaid family caregivers nationwide and that only 5 per cent of caregivers receive respite services. The benefits of respite include a decrease in stress and a delay in institutionalization of the care recipient.

At least sixteen states currently address respite care in their statutes. The types of statutes vary, with some focusing on services for older adults, others having financial requirements, and others specifying the types of settings in which respite can take place. In addition, while there are some stand-alone respite care programs in other states, most are offered as part of a package of programs including home care, transportation, and health care.

During the 2007 Interim, pursuant to H.C.R. No. 187 (2007), EOA contracted with the UH School of Social Work to compile an

inventory of respite care in the State. Respite agencies were contacted by telephone throughout the State and information was gathered as to the type of respite provided; the method of payment required; whether the agency had a waiting list; and the population served by the agency. While the inventory has not yet been completed, it appears that Oahu has approximately forty-three agencies that provide respite care. Twenty-three are private pay only and tend not to have wait lists.

PART IV. SUBSTANTIVE ISSUES

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.

The JLCFC has had the benefit of examining localized studies and surveys, some of which contained preliminary results, that provide concrete evidence of the needs of family caregivers. The JLCFC has also had the benefit of looking at what other states have done and are doing in response to the growing concern of eldercare issues.

In making its recommendations, the JLCFC examined the information and data provided by the studies and surveys conducted and 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.

After hearing all of the testimony and discussion, as well as examining the various studies and surveys presented, the JLCFC makes the findings and recommendations described below.

Finding A: For many family caregivers, their role as caregiver arises as suddenly as the care recipient's health declines, leaving the caregivers with an immediate need for services. Family caregivers often do not have any education regarding what services are available to them. In addition, the family caregivers may not know where to find the services that they or the care recipients need. The caregiver needs assessment reveals that family caregivers would benefit from a greater access

system that coordinates services and policies and that provides referrals to services and providers. The family caregiver needs assessment clearly shows that family caregivers themselves need support services, including respite services, financial services, and training, education, and counseling on caregiving.

The JLCFC finds that as the baby boomer population ages, there is a national trend to address eldercare issues. Hawaii has a high proportion of older citizens in its population when compared to other states. Therefore, the impact of aging on Hawaii will arguably be greater, and the State needs to take a proactive role in addressing these issues.

Recommendation A: The JLCFC recommends that:

(A1) The work of the JLCFC be extended for one year beyond its sunset date of June 30, 2008, to continue to develop a comprehensive and sustainable, community-based family caregiver support system. In keeping with the JLCFC's policy of determining what the State can do to foster a person's ability to age-in-place, the name of the JLCFC should be changed to the "Joint Legislative Committee on Aging in Place" and the mandate expanded to allow members of the committee to look into issues and concerns that are related to "aging in place." In addition, as part of the continuation of the committee, the Hawaii Aging and Disability Resource Center (ADRC) should provide an update to the JLCFC of its development and implementation of the physical site in the County of Hawaii, and the "virtual" site planned for the City and County of Honolulu;

(A2) An appropriation be made, for inclusion in EOA's base budget within the Executive Budget, for the Kupuna Care program administered by EOA to continue providing services to qualified care recipients and their family caregivers;

(A3) 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, or as an alternative, providing grants for home modification through Kupuna Care using a cash and counseling approach; and

(A4) A caregiver tax credit be established for family caregivers who provide care for qualified care recipients, or in the alternative, providing grants through Kupuna Care using a cash and counseling approach.

Finding B: The information and data provided by all of the studies and surveys presented to the JLCFC emphasize the importance of research, education, and training in building a family caregiver and "aging in place" support system in the State. An inclusive, information sharing, interdisciplinary center on aging is needed to address the issues of eldercare in the State.

Because of its expressed commitment to serve in this role, the JLCFC has identified UH as the appropriate partner to coordinate the research, education, and training needs in developing a comprehensive family caregiver support system that would allow Hawaii's elderly to age in place.

A center on aging research and education will recognize the important role of aging in the future of our State and officially establishing a research center focusing on aging at the university level elevates the importance of this issue.

Recommendation B: The JLCFC recommends that UH, in collaboration with the entire UH system, the state and county governments, and other interested entities, coordinate people and resources on behalf of the State to lead research, training, education, outreach, and public policy activities on elder issues, as well as to follow up on the outcomes of initiatives. An interdisciplinary center on aging should be formally and physically established and should serve as the focal point of all information related to eldercare.

The JLCFC recommends appropriations be made for UH CARE to provide for additional faculty positions and to assist UH CARE in carrying out its mission of establishing a research, education, and training center on eldercare issues for the benefit of the entire State. Among its projects, UH CARE should develop a cash and counseling model for use in delivering cost-effective services and grants to enable Hawaii's elderly to age in place.

Finding C: Both the family caregivers needs assessment and employer survey discussed above demonstrate that many people who find themselves faced with the demands of providing informal

caregiving are also employed in the workforce. Oftentimes, to accommodate the demands of caregiving that grow as dependency of the care recipient increases, family caregivers tend to reduce work hours, adjust or abandon career and personal goals, and retire earlier than planned. This is especially true of younger caregivers who put their earning potential on hold while caring for a loved one. These younger caregivers tend to have high levels of stress because they often have caregiving responsibilities on top of their work responsibilities and the responsibility of raising their children. These caregivers experience great strain in trying to balance all of these responsibilities and some of these stresses are manifested in the workplace.

In addition, the fact that employees are leaving the workplace to provide care for family members directly affects employers by decreasing the available workforce and increasing the costs associated with lost productivity. The aging of the population brings with it a decline in the number of people gainfully employed and this decline may be further exacerbated by caregivers having to give up or reduce employment. With the unprecedented growth of older adults in Hawaii, the State can expect to see a significant increase in the number of employed family members who will be providing care to their parents or grandparents.

A paid family leave program can address the impact caregiving has, and will continue to have, on the workplace and could be beneficial to both the employed caregiver and the employer. A paid family leave program is also the most far reaching caregiving benefit available as it can be utilized by a larger group of caregivers, including those who have to provide care to relatives living on the mainland or overseas.

Recommendation C: The JLCFC recommends establishing an employee-financed paid family leave program under the state Temporary Disability Insurance Law to provide wage replacement benefits to employees who take time off from work to care for a seriously ill family member.

Finding D: The family caregiver needs assessment shows that caregivers need more affordable services and financial assistance. The cash and counseling research demonstrated that those states that had cash and counseling programs reported high satisfaction

by both caregivers and care recipients and allowed informal caregivers to receive financial recognition for their services.

In Hawaii, there are out-of-pocket costs for families to pay for home- and community-based programs that are available for elders and persons with disabilities. The government pays for such services for those who have lower incomes and qualify for Medicaid. However, a majority of Hawaii's families are ineligible for public assistance and are having to carry the financial burdens of caregiving. This leaves a gap in services for those elders of modest means. As a result, this group of individuals has the least coverage in terms of home- and community-based services. The JLCFC believes that Hawaii should consider providing a cash and counseling program to non-Medicaid eligible elders to allow this group of individuals to have control over their care, while benefiting their caregivers.

The work on cash and counseling being conducted by EOA and the UH School of Social Work will continue until the end of the 2007-2008 fiscal year. The research conducted shows that a cash and counseling program is worth pursuing, and it is essential to continue the work in developing phase two of a cash and counseling program that can be completed by the end of 2008.

Recommendation D: The JLCFC recommends that funds be appropriated for the design of a cash and counseling program for non-Medicaid participants to direct and manage their personal assistance services according to their own specific needs, while enabling family caregivers to receive a level of financial recognition and support.

In addition, the design program may consider including a respite care component, a case management component, a separate fiscal agent, a personal care component, and allowing the consumer to be the employer of any service provider, whether an agency or family member. The design project should report back to the JLCFC twenty days prior to the start of the 2009 Regular Session.

Part of the funding is to coordinate an advisory group to assist with the design of the cash and counseling program. The advisory group should specifically look at whether there should be an asset limitation or restriction on consumers in order to ensure that those who have the greatest need and the fewest resources are able to utilize such a program.

Finding E: The family caregiver needs assessment demonstrated that while services for grandparents raising grandchildren exist, many grandparents do not know that they are eligible for these services, are unaware of how to obtain these services, or do not have access to these services. Grandparents raising grandchildren play an important role in ensuring the well-being of Hawaii's children and they provide care to their grandchildren. It is vital to support these grandparents and address their needs.

Recommendation E: The JLCFC recommends that a task force be established to follow up on the issues raised by the grandparents raising grandchildren needs assessment in order to identify barriers grandparents raising grandchildren face and how to overcome these barriers, as well as how to address legal issues, such as custody. The JLCFC recommends that the task force be co-chaired by representatives of EOA and UH College of Tropical Agriculture and Human Resources. The task force should report back to the JLCFC prior to the start of the 2009 Regular Session. The establishment of this task force will allow grandparents raising grandchildren and other interested parties to have their own forum to address these important issues.

Finding F: The family caregiver needs assessment demonstrated that there are emotional, physical, and financial costs of being a family caregiver. The younger caregivers are often in critical need of finding ways to reduce the stress caused by caregiving.

The LRB respite report indicates that respite has been shown to be beneficial in lowering stress and other negative consequences of caregiving and the family caregiver needs assessment shows that respite is something family caregivers need.

Besides the everyday stress that respite can relieve, there are times when a family caregiver may unexpectedly become unable to provide the needed caregiving services due to illness, an accident, or other reasons. At these times, emergency respite care becomes critical.

More work is needed to determine a full inventory of respite care providers and to determine the specific types of respite care provided; for example, whether the services provided are planned respite care, short term respite, or emergency respite care. In addition, while there may be respite services available,

caregivers who need respite services must be able to have access to this information.

Recommendation F: The JLCFC recommends that:

(F1) Emergency respite, overnight respite, and weekend respite be added as covered services under the Kupuna Care program administered by EOA; and

(F2) Funding be provided to EOA to continue its respite inventory project in collaboration with the UH School of Social Work. Specifically, a definition of "respite" and a more detailed description of each of the respite services available in the State are needed.

Finding G: The JLCFC finds that in a natural disaster, caregivers may not be able to get to a care recipient who is "aging in place" and elderly "shut-ins" who live alone may be cut off from assistance needed during such times. Informal and community caregivers such as a neighbor or friend may be needed to step in to provide emergency replacement care. Elderly shut-ins may need assistance to avoid harm and an increase in IADLs as a result of the emergency. This is especially critical as many elders are "aging in place" in condominiums and multi-unit buildings. The safety of residents with special needs must be taken into consideration in case of emergencies or natural disasters.

UH has been included in recent congressional legislation to conduct national disaster planning, as a part of a national emergency preparedness program. UH's funding authorization is for $200 million over ten years, with the first appropriations planned for October 2008.

Recommendation G: The JLCFC recommends adoption of a bill and a concurrent resolution to request UH to include in its natural disaster planning program provisions to address the needs of Hawaii's elderly, particularly caregivers, care recipients, and elderly shut-ins. The JLCFC also recommends that condominium associations and managers of other multi-unit buildings create voluntary lists of residents that have special needs in case of an emergency. The associations and manager should keep this list on file and have a procedure for updating the list every six months.

PART V. CONCLUSION

The JLCFC recommends that legislation be introduced in the 2008 Regular Session to implement the recommendations outlined in this report. Co-chairs Senator Les Ihara, Jr. and Representative Marilyn B. Lee will draft legislation pursuant to these recommendations and offer co-sponsorship of the legislation to members of the JLCFC and any other legislators.

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

LES IHARA, JR., Co-Chair

MARILYN LEE, Co-Chair