

**ACT 204**

S.B. NO. 1916

A Bill for an Act Relating to Caregiving.

*Be It Enacted by the Legislature of the State of Hawaii:*

**PART I  
FINDINGS AND PURPOSE**

SECTION 1. The legislature finds that, 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. The joint legislative committee on family caregiving was established under Act 285, Session Laws of Hawaii 2006, to develop a comprehensive public policy to strengthen support for family caregivers in Hawaii.

The committee held numerous meetings during the fall of 2006 and submitted a special committee report to the legislature outlining its proposal for the establishment of a comprehensive and sustainable, community-based family caregiver support system that will maximize resources in all communities. However, 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. The committee should be extended to enable it to continue work on its proposal for the establishment of a comprehensive and sustainable, community-based family caregiver support system.

Numerous testifiers appeared before the committee on behalf of grandparents in support of recognizing their role as family caregivers for their grandchildren. According to the United States Census Bureau, between 1990 and 2000, there was an over thirty per cent increase in the number of children under age eighteen living in grandparent-headed households in Hawaii. Of the 14,029 grandparents in Hawaii who report that they are responsible for their resident grandchildren, over one-fifth also report that the children's parents are not present in the household.

The national family caregiver support program under the reauthorized Older Americans Act includes grandparents of grandchildren age eighteen years and younger or nineteen years of age or older with physical or cognitive limitations. Grandparents who are caregivers experience similar support needs and caregiving costs as do family caregivers who provide unpaid, informal assistance to older adults with physical or cognitive disabilities. Custodial grandparenting has emotional, physical, and financial costs. Custodial grandparents report more anxiety, depression, and physical health problems than their non-caregiving peers, and they need accurate and accessible information on a myriad of issues.

A crucial element in the design and implementation of a comprehensive and sustainable, community-based family caregiver support system is an assessment of the needs of family caregivers and the care recipients. A thorough needs assessment is imperative to appropriately encourage, support, and strengthen the provision of family caregiving.

The delivery of long term care in Hawaii and, indeed, throughout the United States is fragmented and uncoordinated. As a result, frail and disabled persons of all ages have difficulty in getting information about existing services, and in obtaining appropriate assistance. In 2005, Hawaii received a federal grant to develop an aging and disability resource center program. This program is designed to help family caregivers and older and disabled adults find the information they need regarding available options for care. To date, an aging and disability resource center is under development in the county of Hawaii, and a "virtual" site is planned for the city and county of Honolulu. Additional funds are needed to fully develop this program.

Family caregivers who provide care to recipients with chronic or disabling conditions are themselves at risk for physical, emotional, and financial problems. The daily challenges and health risks that family caregivers face can impede the family caregiver's ability to provide care, lead to higher health care costs, and affect the family caregiver's quality of life and the quality of life of the care recipient.

For many family caregivers, their role as family caregiver arises as suddenly as the care recipient's health declines, leaving 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. Family caregivers themselves need support services, including respite services and training, education, and counseling in areas such as caregiving and dealing with end-of-life issues.

Kupuna care is a statewide long-term care program, administered by the executive office on aging, which was developed in partnership with the county area agencies on aging to address the growing numbers of elders with long-term care needs. Services provided by kupuna care are intended to help meet the needs of older adults who cannot live at home without adequate help from family or formal caregiving services, and include services such as adult day care, respite care, assisted transportation, attendant care, case management, chore, home delivered meals,

homemaker, transportation, and personal care. In addition to the services provided to the elderly, direct services to family caregivers can be provided to educate and assist family caregivers in coping with their roles as a caregiver.

Under Act 262, Session Laws of Hawaii 2006, the executive office on aging is required to coordinate a statewide system of caregiver support services. An appropriation should be made to assist the executive office on aging's caregiver's resource initiative project to enable it to continue its efforts in that regard.

A number of approaches have been suggested as a means to help family caregivers with the financial costs of family caregiving, including a cash and counseling program and a family caregiver refundable tax credit. However, more research and analyses of these different approaches are necessary to ensure that the State applies its resources and services toward helping family caregivers in the most efficacious manner.

The purpose of this Act is to strengthen support of family caregiving by:

- (1) Extending the life of the joint legislative committee on family caregiving;
- (2) Authorizing the joint legislative committee to explore establishing a paid family leave program under the state temporary disability insurance law;
- (3) Providing a broader definition of "family caregiver" by including grandparents who are caregivers for grandchildren who are age eighteen years or younger or nineteen years of age or older with physical or cognitive limitations;
- (4) Requiring the joint legislative committee on caregiving to conduct a comprehensive assessment of the needs of care recipients who are age sixty and older with physical or cognitive disabilities, and the needs of their family caregivers;
- (5) Appropriating funds to supplement development of the aging and disability resource center program;
- (6) Appropriating funds to expand the kupuna care program's in-home and access services for qualified care recipients;
- (7) Appropriating funds to provide direct services to family caregivers.

## PART II JOINT LEGISLATIVE COMMITTEE ON FAMILY CAREGIVING

SECTION 2. Act 285, Session Laws of Hawaii 2006, is amended by amending section 2 to read as follows:

"SECTION 2. (a) There is established a joint legislative committee on family caregiving. The committee shall be composed of eight members as follows:

- (1) Four members of the house of representatives, consisting of three members from the majority party and one member from the minority party, who shall be appointed by the speaker of the house of representatives; and
- (2) Four members of the senate, consisting of three members from the majority party and one member from the minority party, who shall be appointed by the president of the senate.

The committee shall select a chairperson from its membership.

(b) The joint legislative committee shall develop 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~~]. 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.
- (c) The joint legislative committee shall ~~consider~~:
  - (1) ~~Consider~~ providing support in categories including ~~[but not limited to]~~:
    - ~~[(1)]~~ (A) Coordinated services and policies;
    - ~~[(2)]~~ (B) Training and education;
    - ~~[(3)]~~ (C) Respite services;
    - ~~[(4)]~~ (D) Financial incentives; and
    - ~~[(5)]~~ (E) Balancing work and caregiving[-]; and
  - (2) Explore establishing 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.
- (d) The joint legislative committee shall seek input from the department of health, the department of human services, the department of taxation, the University of Hawaii, the executive office on aging, and the elderly, disability, business, and faith-based communities.
- (e) The joint legislative committee shall submit its findings and recommendations to the legislature no later than twenty days prior to the convening of the regular ~~[session]~~ sessions of 2007[-] and 2008.
- (f) The joint legislative committee shall cease to exist on ~~[June 30, 2007-]~~ June 30, 2008.”

### PART III NEEDS ASSESSMENT OF FAMILY CAREGIVERS

SECTION 3. (a) The joint legislative committee on family caregiving shall conduct a comprehensive assessment of the needs of care recipients who are age sixty years and older with physical or cognitive disabilities and the needs of their family caregivers. The needs assessment should include an evaluation of:

- (1) The extent of the unmet caregiving needs of persons age sixty years and older with physical or cognitive disabilities;
- (2) The size of the current family caregiver population;
- (3) The percentage of care recipients’ needs being met by paid versus unpaid caregivers; and
- (4) The impact of caregiving on family caregivers’ employment and income.

(b) In conducting the needs assessment, the joint legislative committee on family caregiving shall identify and review past surveys, such as the *2003 Hawaii Health Survey*, include focus groups, and develop policy questions to guide the focus of the needs assessment.

(c) In conducting the needs assessment, the joint legislative committee on family caregiving may utilize telephone surveys or other methods of gathering reliable data regarding care recipients’ needs and the needs of their family caregivers, including purchasing additional questions for the upcoming *Hawaii Health Survey*.

(d) The joint legislative committee on family caregiving shall incorporate the completed needs assessment into the joint legislative committee report to the legislature.

(e) For purposes of this section, “family caregiver” means 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.

SECTION 4. The joint legislative committee on family caregiving shall submit a report, including the completed needs assessment pursuant to section 3 and any proposed legislation, to the legislature no later than twenty days prior to the convening of the regular session of 2008.

SECTION 5. There is appropriated out of the general revenues of the State of Hawaii the sum of \$120,000 or so much thereof as may be necessary for fiscal year 2007-2008 for the joint legislative committee on family caregiving, which may contract with a qualified consultant, to conduct a comprehensive needs assessment of family caregivers pursuant to section 3. A contract executed pursuant to this section and section 3 shall be exempt from chapter 103D, Hawaii Revised Statutes; provided that the joint legislative committee shall endeavor to ensure transparency in the letting of the contract. The sum appropriated shall be allotted as follows:

Senate	\$60,000
House of representatives	\$60,000

The sum appropriated shall be expended by the senate and the house of representatives to assist the joint legislative committee on family caregiving for the purposes of this part.

#### **PART IV NEEDS ASSESSMENT OF GRANDPARENTS RAISING GRANDCHILDREN**

SECTION 6. The executive office on aging, or its consultant, shall conduct an assessment of the issues facing, and the needs of grandparents raising grandchildren in Hawaii. The executive office on aging shall submit a report, including the completed needs assessment and any proposed legislation, to the joint legislative committee on family caregiving by November 7, 2007.

#### **PART V AGING AND DISABILITY RESOURCE CENTER**

SECTION 7. The delivery of long term care in Hawaii has characteristically been uncoordinated, making it difficult for consumers to obtain information about long term care options and services. Much of this has to do with the fact that different programs have their own eligibility requirements, funding mandates, care benefits, provider participation regulations, administrative structure, and service delivery mechanisms. Consequently, it is difficult to coordinate a comprehensive continuum of long term care (ranging from nursing homes to home- and community-based services) for the elderly and the disabled.

In 2005, Hawaii was selected to receive a grant from the United States Department of Health and Human Services to develop an aging and disability resource center program. The grant is intended to help Hawaii develop "one-stop shop" programs at the community level that can serve as the entry point to the long term services and support system. The vision is to have resource centers in every community serving as highly visible and trusted places where people can turn for information on the full range of long term care support options, and with a streamlined process for screening, intake, assessment, and eligibility determination. Long term care support refers to a wide range of in-home, community-based, and institutional services and programs that are designed to help individuals with disabilities.

The executive office on aging, in partnership with the Hawaii county office of aging and the city and county of Honolulu elderly affairs division, is already

developing an aging and disability resource center in Hawaii county. The three-year project commenced in October, 2005, and is due for completion by September, 2008. A second resource center is planned for the city and county of Honolulu. A state advisory board has already been established to provide public input and feedback on the project development and to develop a statewide access plan for future replication. Each project will also have its own steering committee or advisory board at the county level to assist in the specific site development.

The Hawaii county project received additional funding from the Hawaii county council, with support from the Hawaii county mayor, to enable the project to lease the former Sun Sun Lau Chinese Restaurant in Hilo as the physical site. Renovations are currently underway at the Hilo site with a target completion date of late 2007. The Hawaii county office of aging will co-locate in this centralized facility with other aging and disability services and providers, including the department of human services' programs and the Legal Aid Society.

The city and county of Honolulu project will initially be a virtual site. It will build upon the city and county of Honolulu elderly affairs division's current senior hotline telephone information and assistance program and will develop a comprehensive resource website. The overall goal is to eventually establish aging and disability resource center sites in all of the counties to provide statewide access.

The legislature finds that the aging and disability resource center program will improve access to long term care information and options for family caregivers, the elderly, and the disabled by facilitating their search for needed services.

The purpose of this part is to support the aging and disability resource center program by appropriating funds to supplement its development. The funds shall be used to:

- (1) Contract with a management information consultant to:
  - (A) Identify management information system needs;
  - (B) Assist with vendor selection;
  - (C) Ensure compliance with management information system requirements;
  - (D) Provide resources and technical assistance for project evaluation, intake, and database development;
  - (E) Troubleshoot technical problems; and
  - (F) Assist with systems integration;
- (2) Purchase additional management information system products, including software licensing, server clusters, installation, staff training, computer hardware, and technical support;
- (3) Install a statewide toll-free telephone system for the public to contact the aging and disability resource center sites. This includes the installation of the single server number, telephone equipment, cable lines, phone system upgrades, and special equipment for the blind and deaf consumers;
- (4) Coordinate and implement consumer education and outreach campaigns, including outreach coordination, the production and printing of brochures and posters, media ads, presentations and exhibits at senior and disability events or focal centers, bilingual translation, and other promotional activities that will educate the consumers and general public about aging and disability resource center services;
- (5) Continue the coordination and implementation of the Hawaii county site;
- (6) Continue the coordination and implementation of the city and county of Honolulu site;
- (7) Continue the state-level coordination and evaluation activities of the project; and
- (8) Provide training to aging and disability resource center staff.

SECTION 8. There is appropriated out of the general revenues of the State of Hawaii the sum of \$300,000 or so much thereof as may be necessary for fiscal year 2007-2008 and the sum of \$230,000 or so much thereof as may be necessary for fiscal year 2008-2009 to the executive office on aging to support the continuous development of the aging and disability resource center project in Hawaii.

The sums appropriated shall be expended by the department of health for the purposes of this section.

## **PART VI SERVICES**

SECTION 9. There is appropriated out of the general revenues of the State of Hawaii the sum of \$475,000 or so much thereof as may be necessary for fiscal year 2007-2008 and \$525,000 or so much thereof as may be necessary for fiscal year 2008-2009 to the executive office on aging to expand the kupuna care program's in-home and access services to qualified care recipients and to provide direct services to family caregivers.

The sums appropriated shall be expended by the department of health for the purposes of this part.

## **PART VII APPROACHES TO FINANCIAL NEEDS OF FAMILY CAREGIVERS**

SECTION 10. (a) The cash and counseling program is a national initiative sponsored by the Robert Wood Johnson Foundation; the United States Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation; and the Administration on Aging. Under the 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. Participants can choose a family member or friend, in lieu of an agency worker, to provide the services. They receive counseling and fiscal assistance to help them manage their allowance and responsibilities. The program was first implemented in Arkansas, New Jersey, and Florida, and has since expanded to include twelve other states.

The potential exists to establish a similar program here in Hawaii to serve the needs of residents receiving medicaid personal care services or home- and community-based services, as well as residents who are not medicaid recipients.

(b) A tax credit to caregivers who care for qualified care recipients is another approach to helping family caregivers defray some of the cost of providing invaluable caregiving services. One measure introduced during the 2007 legislative session, Senate Bill No. 1199, S.D. 2 (2007)<sup>1</sup>, provides eligible taxpayers with a refundable income tax credit on a sliding scale basis.

SECTION 11. (a) The executive office on aging shall:

- (1) Research the cash and counseling program and its implementation in other states, including Arkansas, New Jersey, and Florida;
- (2) In completing its research:
  - (A) Contact the national program office at the Boston college graduate school of social work, which coordinates replications of the program;
  - (B) Consult with the Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation at the United

States Department of Health and Human Services, the Administration on Aging, the department of human services, and the department of health; and

- (C) Examine models that include individuals receiving medicaid personal care services or home- and community-based services, as well as individuals who are not medicaid recipients;
- (3) Submit an interim report of its research findings to the joint legislative committee on family caregiving by November 1, 2007.
- (b) The executive office on aging shall also:
  - (1) Prepare a cost-benefit analysis of a \$1,000, \$750, and \$500 family caregiver refundable tax credit as proposed in Senate Bill No. 1199, S.D. 2 (2007)<sup>1</sup>; and
  - (2) Submit a report, including the results of the cost-benefit analysis, to the joint legislative committee on family caregiving by November 1, 2007.

## **PART VIII MISCELLANEOUS PROVISIONS**

SECTION 12. Statutory material to be repealed is bracketed and stricken. New statutory material is underscored.

SECTION 13. This Act shall take effect upon its approval; provided that sections 5, 8, and 9 shall take effect on July 1, 2007; and further provided that section 2 shall take effect on June 29, 2007.

(Approved June 21, 2007.)

### **Note**

- 1. Did not pass legislature.