A BILL FOR AN ACT

RELATING TO CAREGIVING.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

1	PART I. JOINT LEGISLATIVE
2	COMMITTEE ON FAMILY CAREGIVING
3	SECTION 1. (a) The legislature finds that during the 2007
4	interim, the joint legislative committee on family caregiving
5	continued its work on creating a comprehensive and sustainable,
6	community-based family caregiver support system that includes:
7	(1) a coordinated referral and case management service; (2)
8	centralization of available services; (3) volunteers; (4)
9	education and training; and (5) financial assistance.
10	During the 2007 interim, the joint legislative committee
11	had the benefit of examining localized studies and surveys, some
12	of which contained preliminary results, which provided concrete
13	evidence of the needs of family caregivers. The joint
14	legislative committee on family caregiving also had the benefit
15	of looking at what other states have done and are doing in
16	response to the growing concern regarding eldercare issues.
17	(b) The purpose of this part is to:

1	(1)	Extend the work of the joint legislative committee on
2		family caregiving for one year and require the
3		committee to submit a report of its findings and
4		recommendations to the legislature prior to the
5		convening of the 2009 regular session;
6	(2)	Change the name of the joint legislative committee on
7		family caregiving to the "joint legislative committee
8		on aging in place"; and
9	(3)	Require the aging and disability resource center to
10		provide the joint legislative committee with an update
11		on the physical site for the center in Hawaii county
12		and the "virtual" site in the city and county of
13		Honolulu.
14	SECT	ION 2. Act 285, Session Laws of Hawaii 2006, as
15	amended by	y Act 204, Session Laws of Hawaii 2007, is amended by
16	amending	section 2 to read as follows:
17	"SEC	TION 2. (a) There is established a joint legislative
18	committee	on [family caregiving.] aging in place. The committee
19	shall be	composed of eight members as follows:
20	(1)	Four members of the house of representatives,
21		consisting of three members from the majority party

and one member from the minority party, who shall be

1		appointed by the speaker of the house of
2		representatives; and
3	(2)	Four members of the senate, consisting of three
4		members from the majority party and one member from
5		the minority party, who shall be appointed by the
6		president of the senate.
7	The	committee shall select a chairperson from its
8	membershi	p.
9	(b)	The joint legislative committee shall develop
10	comprehen	sive public policy to strengthen support for family
11	caregiver	s. For purposes of this Act, "family caregiver" means:
12	(1)	A person, including a non-relative such as a friend or
13		neighbor, who provides unpaid, informal assistance to
14		a person age sixty and older with physical or
15		cognitive disabilities; and
16	(2)	A grandparent who is a caregiver for a grandchild who
17		is age eighteen years or younger, or who is nineteen
18		years of age or older with physical or cognitive
19		limitations.
20	(c)	The joint legislative committee shall:
21	(1)	Consider providing support in categories including:
22		(A) Coordinated services and policies;

1		(B) Training and education;
2		(C) Respite services;
3		(D) Financial incentives; and
4		(E) Balancing work and caregiving; and
5	(2)	Explore establishing a paid family leave program under
6		the state temporary disability insurance law, similar
7		to the California Paid Family Leave Program, to
8		provide wage replacement benefits to employees who
9		take time off from work to care for a seriously ill
10		family member.
11	<u>(d)</u>	The joint legislative committee may explore issues of
12	"aging in	place" as they relate to family caregiving.
13	<u>(e)</u>	The Hawaii aging and disability resource center shall
14	provide a	update to the joint legislative committee of its
15	developme	nt and implementation of the physical site for the
16	center in	the county of Hawaii, and the "virtual" site planned
17	for the c	ty and county of Honolulu.
18	[(d)]	(f) The joint legislative committee shall seek input
19	from the	department of health, the department of human services
20	the depart	ment of taxation, the University of Hawaii, the
21	executive	office on aging, and the elderly, disability,
22	business,	and faith-based communities.

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1 [(e)] (g) The joint legislative committee shall submit its 2 findings and recommendations to the legislature no later than twenty days prior to the convening of the regular sessions of 3 4 2007 [and], 2008[-], and 2009. 5 [-(f)-] (h) The joint legislative committee shall cease to exist on June 30, [2008.] 2009." 6 7 PART II. FINANCIAL ASSISTANCE FOR CAREGIVING 8 SECTION 3. The cash and counseling program is a national 9 initiative sponsored by the Robert Wood Johnson Foundation; the United States Department of Health and Human Services, Office of 10 the Assistant Secretary for Planning and Evaluation; and the 11 Administration on Aging. Under the program, recipients of 12 13 medicaid personal care services or home- and community-based services receive a flexible monthly allowance and can decide 14 whom to hire and what services to receive. The program's 15 16 innovative approach enables participants to direct and manage 17 their personal assistance services according to their own 18 specific needs. Participants can choose a family member or 19 friend, in lieu of an agency worker, to provide the services. They receive counseling and fiscal assistance to help them 20

manage their allowance and responsibilities. The program was

- 1 first implemented in Arkansas, New Jersey, and Florida, and has
- 2 since expanded to include other states.
- 3 During the 2007 interim, the joint legislative committee on
- 4 family caregiving received information and data related to the
- 5 family caregivers needs assessment conducted by the executive
- 6 office on aging, and cash and counseling research conducted by
- 7 the executive office on aging and the University of Hawaii
- 8 school of social work. The family caregiver needs assessment
- 9 indicated that caregivers need more affordable services and
- 10 financial assistance. The cash and counseling research
- 11 demonstrated that those states that have cash and counseling
- 12 programs reported high satisfaction by both caregivers and care
- 13 recipients and allowed informal caregivers to receive financial
- 14 recognition for their services.
- In Hawaii, there are out-of-pocket costs for families to
- 16 pay for home- and community-based programs that are available
- 17 for elders and persons with disabilities. The government pays
- 18 for such services for those who have lower incomes and qualify
- 19 for medicaid. However, a majority of Hawaii's families are
- 20 ineligible for public assistance and are having to carry the
- 21 financial burdens of caregiving. This leaves a gap in services
- 22 for those elders of modest means. As a result, this group of

- 1 individuals has the least coverage in terms of home- and
- 2 community-based services.
- 3 The work on cash and counseling being conducted by the
- 4 executive office on aging and the University of Hawaii school of
- 5 social work will continue until the end of the 2007-2008 fiscal
- 6 year. The research conducted shows that a cash and counseling
- 7 program is worth pursuing, and it is essential to continue the
- 8 work in developing phase two of a cash and counseling project
- 9 that can be completed by the end of 2008.
- 10 SECTION 4. The joint legislative committee on aging in
- 11 place shall design a cash and counseling project for non-
- 12 medicaid participants to direct and manage their personal
- 13 assistance services according to their own specific needs, while
- 14 enabling family caregivers to receive a level of financial
- 15 recognition and support. In designing a cash and counseling
- 16 project, the joint legislative committee on aging in place may
- 17 consider including a respite care component, a case management
- 18 component, a separate fiscal agent, a personal care component,
- 19 and allowing the consumer to be the employer of any service
- 20 provider, whether an agency or family member.

- 1 The joint legislative committee on aging in place may
- 2 contract with a qualified consultant to assist in to design a
- 3 cash and counseling program.
- A contract executed pursuant to this section and section 5
- 5 of this Act shall be exempt from chapter 103D, Hawaii Revised
- 6 Statutes; provided that the joint legislative committee on aging
- 7 in place shall endeavor to ensure transparency in the letting of
- 8 the contract.
- 9 The project shall include an advisory group to assist with
- 10 the design of the cash and counseling program. In order to
- 11 ensure that those who have the greatest need and the fewest
- 12 resources are able to utilize such a program, the advisory group
- 13 shall examine whether an asset limitation or restriction on
- 14 consumers shall be implemented in the design of a cash and
- 15 counseling program.
- 16 The joint legislative committee on aging in place shall
- 17 report on the results of developing its efforts to design a cash
- 18 and counseling project as part of its report to the legislature
- 19 pursuant to section 2 of this Act.
- 20 SECTION 5. There is appropriated out of the general
- 21 revenues of the State of Hawaii the sum of \$ or so
- 22 much thereof as may be necessary for fiscal year 2008-2009 for

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1 the joint legislative committee on aging in place, which may 2 contract with a qualified consultant, to design a cash and 3 counseling model, pursuant to section 4 of this Act. The sum appropriated shall be allocated as follows: 4 5 Senate \$ House of representatives 6 The sum appropriated shall be expended by the senate and 7 house of representatives to assist the joint legislative 8 9 committee on aging in place for the purposes of this part. PART III. KUPUNA CARE 10 11 SECTION 6. On July 1, 1999, the executive office on aging launched its statewide long-term care program called kupuna 12 care. Kupuna care was developed in partnership with the county 13 area agencies-on-aging to address the growing numbers of elders 14 with long-term care needs. 15 16 Services provided by kupuna care are intended to help meet the needs of older adults who cannot live at home without 17 adequate help from family or formal services, and includes

services such as adult day care, respite care, assisted

transportation, attendant care, case management, chore, home

delivered meals, homemaker, transportation, and personal care.

1 Kupuna care was designed to assist, not totally support, Hawaii's older adults to live independently, safely, and 2 3 healthily for as long as possible. The care may cover United 4 States citizens or legal aliens sixty years or older who are not receiving other comparable government assistance, who need help 5 with activities of daily living (eating, dressing, bathing, 6 toileting, transferring, and mobility) or because they have 7 8 reduced mental capacity, and who are not residing in an 9 institution. Voluntary contributions to the service provider are 10 11 welcomed for any service provided and are used to support the cost of care of additional clients. In addition to the services 12 13 provided to the elderly, kupuna care also offers services for the family caregivers of their elderly clients. As Hawaii's 14 15 population ages, many more families will be providing higher 16 levels of long-term care to frail and disabled older adults at 17 home. For many family caregivers, their role as family caregiver arises as suddenly as the care recipient's health 18 19 declines, leaving the family caregivers with an immediate need 20 for services, but little preparation or education regarding who to contact for assistance or what services are available to 21

In addition, the family caregivers may not know who is

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capable or qualified to provide them with the services that they
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    or the care recipients need. Family caregivers themselves need
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    support services, including training, education, and counseling
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    in areas such as caregiving and dealing with end-of-life issues.
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         In addition, there are emotional, physical, and financial
    costs of being a family caregiver. The younger family
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    caregivers are often in critical need of finding ways to reduce
    the stress caused by caregiving. Respite has been shown to be
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    beneficial in lowering stress and other negative consequences of
    caregiving and the State of Hawaii Caregivers Need Assessment
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    (2007) shows that respite is something that family caregivers
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    need. Besides the everyday stress that respite can relieve,
    there are times when a family caregiver may unexpectedly become
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    unable to provide the needed caregiving services due to illness,
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    an accident, or other reasons. At these times, emergency
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    respite care becomes critical.
         The needs assessment also shows that family caregivers need
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    financial support as they carry the heavy financial burdens of
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    caring for a loved one. In addition, both caregivers and care
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    recipients need financial assistance in making necessary home
    modifications that will allow the care recipient to age in
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    place.
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1	me	тедтя	rature rinds that the kupuha care program can
2	expand it	s ser	vices and incorporate progressive ways of helping
3	to meet t	he gr	owing needs of Hawaii's older adults and allow
4	these ind	ividu	als to age in place.
5	In a	dditi	on to current kupuna care operation and services,
6	the purpo	se of	this part is to:
7	(1)	Allo	w the kupuna care program to:
8		(A)	Offer emergency, overnight, and weekend respite
9			services;
10		(B)	Provide grants for home modifications that
11			facilitate aging in place pursuant to a care plan
12			as part of a cash and counseling approach; and
13		(C)	Provide grants to family caregivers pursuant to a
14			care plan as part of a cash and counseling
15			approach; and
16	(2)	Amen	d the 2008-2009 operating budget of the executive
17		offi	ce on aging to increase program funding for kupuna
18		care	and ensure that kupuna care continues to maintain
19		the	quality of life of Hawaii's older adults and their
20		fami	ly caregivers.

1	SECTION 7. The kupuna care program, as administered by	the
2	executive office on aging, may, in addition to its current	
3	operation and services:	
4	(1) Offer emergency, overnight, and weekend respite	
5	services;	
6	(2) Provide grants for home modifications that facility	ate
7	aging in place pursuant to a care plan as part of	3
8	cash and counseling approach; and	
9	(3) Provide grants to family caregivers pursuant to a	care
10	plan as part of a cash and counseling approach.	
11	SECTION 8. Act 213, Session Laws of Hawaii 2007, is	
12	amended by adding a new section to part III to be appropriate	ely
13	designated and to read as follows:	
14	"SECTION . Provided that of the general fund	
15	appropriation for the executive office on aging (HTH 904), t	<u>ne</u>
16	sum of \$ or so much thereof as may be necessary for	r
17	fiscal year 2008-2009 shall be expended by the executive off	<u>ice</u>
18	on aging for the expansion of its kupuna care program."	
19	SECTION 9. There is appropriated out of the general	
20	revenues of the State of Hawaii the sum of \$ or so	much
21	thereof as may be necessary for fiscal year 2008-2009 to add	ress
22	the kupuna care program waitlist.	

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         The sum appropriated shall be expended by the executive
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    office on aging for the purposes of this Act.
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         SECTION 10. Act 213, Session Laws of Hawaii 2007, is
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    amended by amending part II, section 3, item F.26 to read as
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    follows:
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         "26. HTH904 - EXECUTIVE OFFICE ON AGING
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                                          3.30*
                                                          3.30*
8
         OPERATING
                             HTH
                                     6,370,552A
                                                   [6,119,214A]
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                                          7.45*
                                                         7.45*
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                                     7,443,720N
                             HTH
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         INVESTMENT CAPITAL HTH
                                       250,000C
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         PART IV. GRANDPARENTS RAISING GRANDCHILDREN TASK FORCE
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         SECTION 11. Act 204, Session Laws of Hawaii 2007 (Act
    204), expanded the mandate of the joint legislative committee on
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    family caregiving by including grandparents of children aged
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    eighteen years and younger, or nineteen years of age or older
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    with physical or cognitive limitations, in Act 204's definition
    of family caregiver. The revised definition is now more
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    consistent with the scope of the National Family Caregiver
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    Support Program. Act 204 also required the joint legislative
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    committee to examine the issues facing this population of
    grandparents raising grandchildren.
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         Since then, numerous government agencies have testified
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    before the joint legislative committee regarding how the
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- 1 agencies identify and address the needs of grandparents raising
- 2 grandchildren. In addition, the executive office on aging
- 3 presented the 2007 Needs Assessment of Grandparents Raising
- 4 Grandchildren in the State of Hawaii, prepared by the University
- 5 of Hawaii department of family and consumer science.
- 6 The needs assessment indicates that, in Hawaii, over
- 7 fourteen thousand grandparents are the primary caregivers for
- 8 more than thirty-three thousand grandchildren, and that these
- 9 numbers are expected to grow. While there is a wide range of
- 10 service needs within this population, the most often-cited are
- 11 those that relate to children's programs, financial assistance,
- 12 respite, and grandparents rights. Many of these services are
- 13 available, but barriers are preventing grandparents from
- 14 accessing them. Barriers may include a lack of information
- 15 regarding the availability of services, a lack of services in a
- 16 particular county, or legal or financial impediments. For
- 17 instance, in focus groups, some grandparents expressed a fear of
- 18 losing their grandchildren. Others identified a need for an
- 19 advocate or case worker to help guide them to the services and
- 20 through the various systems.
- 21 The legislature finds that the needs assessment provides
- 22 critical demographic information and feedback regarding what

- 1 programs and services grandparents require to care for their
- 2 grandchildren. The findings indicate that the population of
- 3 grandparents raising grandchildren faces particular challenges,
- 4 different in some ways from the general caregiver population,
- 5 and should have a focused task force to specifically address
- 6 those concerns. The legislature further finds that a
- 7 comprehensive, coordinated effort is needed to identify:
- 8 (1) The services that exist to meet the identified needs;
- 9 (2) Any service deficiencies;
- 10 (3) Barriers that prevent grandparents from accessing
- 11 services; and
- 12 (4) What can be done to facilitate the provision of
- services to grandparents raising grandchildren.
- 14 The purpose of this part is to establish a task force to
- 15 focus specifically on the needs and issues of grandparents
- 16 raising grandchildren.
- 17 SECTION 12. (a) There is established a grandparents
- 18 raising grandchildren task force to focus on the needs and
- 19 issues of grandparents raising grandchildren. The task force
- 20 shall consist of a representative of:
- 21 (1) The University of Hawaii, center on aging research and
- 22 education, to serve as co-chair;

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The University of Hawaii, college of tropical
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          (2)
               agriculture and human resources, to serve as co-chair;
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               The department of education;
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         (3)
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               The department of human services;
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               The department of health, executive office on aging;
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               The department of public safety;
         (6)
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         (7)
              The judiciary:
         (8)
               The department of the attorney general, child support
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               enforcement agency;
              Each area office on aging;
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         (9)
              The policy advisory board for elder affairs;
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        (10)
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        (11)
              Na Tutu Coalition;
              Oueen Lili'uokalani Children's Center;
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        (12)
              Legal Aid Society of Hawaii;
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        (14)
              Volunteer Legal Services Hawaii;
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        (15)
             Partners in Development; and
              An individual who is a grandparent.
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        (16)
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              In assessing the needs and issues of grandparents
          (b)
    raising grandchildren, the task force shall, among other things:
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         (1) Review the 2007 Needs Assessment of Grandparents
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              Raising Grandchildren in the State of Hawaii, prepared
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1		by the University of Hawaii, department of family and
2		consumer science;
3	(2)	Review the most recent Four Year State Plan on Aging
4		submitted to the United States Administration on Aging
5		by the executive office on aging and the area agencies
6		on aging;
7	(3)	Review the testimony of the various agencies submitted
8		to the joint legislative committee on family
9		caregiving at its hearing on August 16, 2007,
10		regarding issues facing grandparents raising
11		grandchildren;
12	(4)	Review laws relating to issues of grandparents raising
13		grandchildren, including:
14		(A) Section 302A-482, Hawaii Revised Statutes,
15		regarding the affidavit for caregiver consent,
16		which permits a caregiver, under certain
17		circumstances, to enroll a minor in school and
18		consent to participation in curricular and
19		co-curricular activities;
20		(B) Chapters 571, Hawaii Revised Statutes, regarding
21		child custody and support; and

1		(c) chapter 567, hawari kevised statutes, regarding
2		child protective services;
3	(5)	The memorandum prepared by the department of education
4		to guide school personnel when enrolling students who
5		reside with caregivers;
6	(6)	Review the supports and services offered to caregivers
7		by the department of education through its
8		comprehensive student support system;
9	(7)	Investigate whether a need arises when a minor
10		residing, formally or informally, with a grandparent
11		requires consent for medical service, including when a
12		student needs consent for programs and services under
13		the federal Individuals with Disabilities Act or
14		Section 504 of the Rehabilitation Act of 1973;
15	(8)	Investigate the issues that arise when a minor
16		residing formally or informally with a grandparent is
17		returned to the custody of a parent;
18	(9)	Investigate any housing issues that may arise when a
19		grandparent is raising a grandchild, particularly when
20		the grandparent resides in senior housing, and
21		identify any state or federal laws or rules that would

1		render a grandparent cohabiting with a grandchild
2		ineligible for housing under a particular scheme;
3	(10)	Review how each area office on aging allocates the
4		federal funds it receives under the National Family
5		Caregiver Support Program for grandparent programs;
6	(11)	Identify the agencies that collect data relating to
7		grandparents raising grandchildren and whether the
8		data can be more comprehensive, uniform, and readily
9		available or exchanged; and
10	(12)	Identify legal needs and whether these needs are being
11		adequately addressed.
12	(c)	The task force on grandparents raising grandchildren
13	shall sub	mit an interim report to the legislature and the joint
14	legislati [.]	ve committee on aging in place no later than twenty
15	days prio	r to the convening of the 2009 regular session and a
16	final repo	ort to the legislature and the joint legislative
17	committee	on aging in place no later than twenty days prior to
18	June 30, 2	2009. The final report shall include, to the greatest
19	extent pos	ssible:
20	(1)	A list of the services that exist in each county to
21		meet grandparents' identified needs;
22	(2)	A discussion of service deficiencies in each county;

1	(3)	A discussion of identifiable barriers that prevent
2		grandparents from accessing services;
3	(4)	A summary of the task force's work and any findings
4		regarding the task force's responsibilities as
5		detailed in section 11(b) of this Act; and
6	(5)	Recommendations, including any proposed legislation.
7	(d)	The task force shall cease to exist on June 30, 2009.
8		PART V. RESPITE CARE
9	SECT	ION 13. The joint legislative committee on family
10	caregiving	g has been diligent in its role to strengthen support
11	to family	caregivers through respite care. The legislative
12	reference	bureau conducted a study pursuant to House Concurrent
13	Resolution	n No. 187, Session Laws of Hawaii 2007, regarding how
14	other sta	tes address the issue of respite care. The report
15	indicated	that respite has been beneficial in ameliorating
16	stress and	d other negative consequences of caregiving.
17	Additional	lly, a comprehensive family caregiver needs assessment
18	conducted	pursuant to Act 204, Session Laws of Hawaii 2007,
19	indicated	that respite care is one of the top choices of
20	assistance	e that caregivers feel would be helpful.
21	Resp:	ite care can relieve the everyday stress of providing
22	round-the-	-clock care. However, there are times when emergency

- 1 respite care becomes critical when a family caregiver is
- 2 unexpectedly unable to provide care because of illness, an
- 3 accident, or other reasons.
- 4 The legislature finds that more needs to be done to
- 5 determine the full inventory of respite care providers and the
- 6 specific types of respite care provided in the State. The types
- 7 of respite care can include planned respite care, short term
- 8 respite, or emergency respite care. Additionally, although
- 9 respite services may be available, caregivers are not always
- 10 aware that such services are offered, or may not know where to
- 11 go to seek assistance.
- 12 The purpose of this part is to appropriate funds to the
- 13 executive office on aging to continue its respite inventory
- 14 project pursuant to H.C.R. No. 187 (2007), in collaboration with
- 15 the University of Hawaii school of social work.
- 16 SECTION 14. There is appropriated out of the general
- 17 revenues of the State of Hawaii the sum of \$ or so
- 18 much thereof as may be necessary for fiscal year 2008-2009 in
- 19 order for the executive office on aging, in collaboration with
- 20 the University of Hawaii school of social work, to:
- 21 (1) Continue to conduct an inventory of respite services
- in Hawaii;

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July 1, 2008.

1 (2) Establish a definition of "respite care"; 2 (3) Establish more detailed descriptions of each of the various types of respite services provided in the 3 4 State; and Review the legislative reference bureau's 2007 report (4)5 on respite policies in other states to identify the 6 7 most promising approaches for Hawaii to support expanding respite services, including how much support 8 9 is financed, what types of respite are provided and to whom, and who performs the respite services. 10 The sum appropriated shall be expended by the department of 11 health, executive office on aging, for the purposes of this 12 13 part. 14 SECTION 15. Statutory material to be repealed is bracketed and stricken. New statutory material is underscored. 15

SECTION 16. This Act shall take effect on June 30, 2008;

provided that sections 5, 8, 9, 10, and 14 shall take effect on

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Report Title:

Joint Legislative Committee on Family Caregiving; Kupuna Care; Grandparents Raising Grandchildren Task Force; Respite Care; Appropriations

Description:

Extends the joint legislative committee on family caregiving; changes the committee's name to the joint legislative committee on aging in place; expands the committee's mandate to include aging in place issues related to family caregiving; requires the aging and disability resource center to report to the committee; requires the joint legislative committee to develop a model for a cash and counseling project; appropriates funds to the joint legislative committee; allows kupuna care to include overnight, weekend, and emergency respite, as well as provide grants to caregivers and for home modification; appropriates funds to the kupuna care program; establishes a task force to focus on the needs and issues of grandparents raising grandchildren; appropriates funds to the executive office on aging to continue its respite inventory project in collaboration with the University of Hawaii. (SD1)