

REPORT TO THE TWENTY-THIRD LEGISLATURE
STATE OF HAWAII
REGULAR SESSION OF 2006

PURSUANT TO HOUSE CONCURRENT RESOLUTION 96

URGING THE DEPARTMENT OF HEALTH AND THE DEPARTMENT OF HUMAN
SERVICES TO DEVELOP METHODS TO SUPPORT FAMILY CAREGIVERS WHO
PROVIDE AT-HOME CARE TO QUALIFIED RELATIVES

PREPARED BY:
STATE OF HAWAII
DEPARTMENT OF HEALTH
DEPARTMENT OF HUMAN SERVICES
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BACKGROUND

“Your parents raised you, and their end of life is give-back time,” says *Caring for Your Parents* co-author Elinor Ginzler. “But that doesn’t mean you can’t compromise. Your mom wants you five days, your kid wants you five days, so you keep one for yourself and give each of them two.” At 52, she finds that a growing number of her contemporaries are trying desperately to fit the emotional, physical and financial demands of aging parents into their already oversubscribed lives (*Help for Aging Parents, and Yourself*, New York Times, 09-23-05).

Policymakers and economists worldwide are confronting the phenomena of rapidly aging populations in modern, industrialized nations. If not for family caregiving that is fueled by love, honor, and duty, the care of disabled and aging citizens would supersede the crises and costs of military conflicts and natural disasters.

Hawaii families have a long tradition of caregiving for their loved ones. In 2003, approximately 21% of Hawaii’s adult population, or 192,390 individuals, were providing care or assistance to a person age sixty or older. This is likely a relatively low number as it identified only those caregivers for the elderly and because there are many “hidden” caregivers in Hawaii – those who do not identify themselves as “caregivers” (*2003 Caregiver Study*, Executive Office on Aging).

The caregiving tradition in Hawaii, however, is, over time, challenged by the changes in Hawaii demographics: birth rates, marriages, single-occupant households, high costs of living, and family members working outside the home, or moving away from Hawaii.

Figure 1. Estimated Number of Caregivers in Hawaii

	SOURCE OF DATA	
	BRFSS 2000 ¹	HHS 2003 ²
State	126,598	192,390
County		
Honolulu	95,261	137,501
Hawai’i	14,128	24,781
Kauai	5,631	9,579
Maui	11,578	20,529

Based on Hawai’i data.

¹ Hawai’i State Department of Health, Behavioral Risk Factor Surveillance System. 2000.

² Hawai’i State Department of Health, Hawai’i Health Survey. 2003.

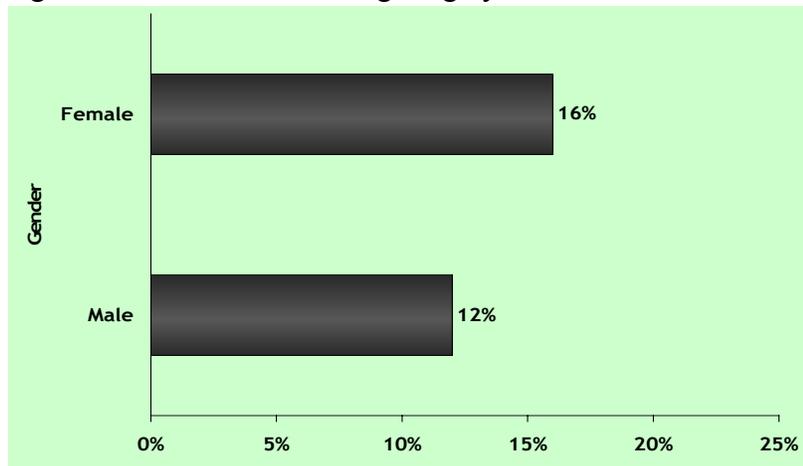
There has been growing awareness of the enormous importance of the role of family caregivers, particularly in allowing their elder and disabled family member(s) to live with dignity and in a

manner of their own choosing. The 2005 Hawaii State Legislature considered multiple measures pertaining to family caregiving.

Focus groups conducted in 2004 by the EOA identified the following major needs of family caregivers: respite care, skills based training and education, counseling, help to navigate the long-term care system, and supplemental services such as consumable supplies. Since then, public hearings, conferences, support group discussions, and assessments conducted by the aging network have consistently identified respite services and education and training as the top needs of family caregivers. Appendix A provides a more detailed description of the trends and characteristics of family caregivers in Hawaii. This is consistent with findings across the United States. See Appendix F, a 2004 report entitled, *The State of the States in Family Caregiver Support: A 50-State Study*.

State legislatures, recognizing family caregivers' role, are enacting laws to fund caregiver support services, expand family and medical leave, and include family caregiving in state long-term care efforts. As adopted by the Legislature, H.C.R. No. 96 requires the Departments of Health (DOH) and Human Services (DHS) to develop methods to support family caregivers who provide at-home care to qualified relatives. The purpose of this report is to provide the Legislature with an update on the Administration's efforts in this regard as well as to provide policy and legislative recommendations to help effectuate this goal.

Figure 2. Prevalence of Caregiving by Gender



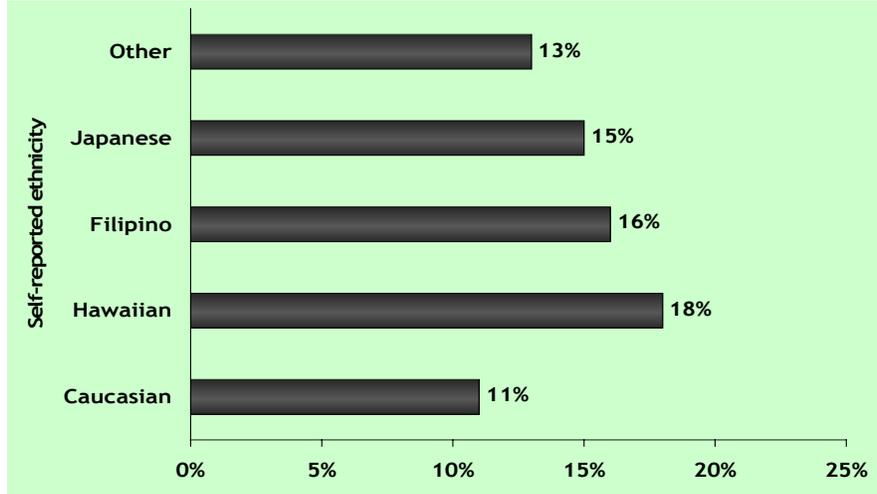
Based on Hawai'i data.

Source: Hawai'i State Department of Health, Behavioral Risk Factor Surveillance System. 2000.

Public policy debate over the provision of social services, or long term care reform specifically, has many facets. Often, the underlying differences of opinion depend on private versus public sector approaches to dealing with the issues. These differences are based on how much emphasis to place on each sector. Some believe that the primary responsibility for care of the elderly and disabled lies with individuals and their families and that government should act as a payer of last resort for those unable to provide for themselves. Conversely, others feel that government should take the lead in

ensuring care, regardless of financial need, by providing comprehensive mandatory social insurance. In this view, the private sector plays little or no role. Between these polar positions, many combinations of private and public sector responsibility are possible, and most people would opt for some middle ground. The choice of emphasis depends on political ideology, whether public initiatives are affordable and whom they would benefit, and whether they can reduce catastrophic costs and realign the delivery system. Understanding this, and in recognition of the rapidly increasing elder population and the potential impact on the health care delivery system, the Governor's Long Term Living Initiative was developed.

Figure 3. Prevalence of Caregiving by Ethnicity



Based on Hawai'i data.
Source: Hawai'i State Department of Health, Behavioral Risk Factor Surveillance System. 2000.

STATE STRATEGIES FOR LONG TERM CARE

Long Term Living Initiative

The Hawaii State Department of Health (DOH) and Department of Human Services (DHS) recognize the need to establish a comprehensive plan to address long-term care for the elderly and disabled populations of the State, including support for our family caregivers. As such, DOH and DHS are working together to spearhead the Governor's Long- Term Living Initiative which focuses on a four-part approach that addresses the growing financial, systemic, and social problems associated with the long-term care of our aging and disabled populations.

Initiated in the spring of 2004, the Long Term Living Initiative work group is a public-private collaborative effort comprised of individuals from various State agencies, including the Department of Health, Department of Human Services, Department of Taxation (DoTAX), Department of Commerce and Consumer Affairs (DCCA), Department of Labor and Industrial Relations (DLIR), and the Executive Office On Aging (EOA), members of the Legislature, US Department of Labor, health care sector, long-term care insurance industry, and the University of Hawaii community college system.

Given the broad representation of individuals who participate in the Governor's Long Term Living Initiative, widely varying views have been put forth. After thoughtful discussion, much of which focused on the role of government, the private sector, and the individual, partners in this effort proposed a middle ground plan that carefully balances the responsibilities of both the public and private sectors.

Figure 4. Prevalence of Caregiving by Household Income



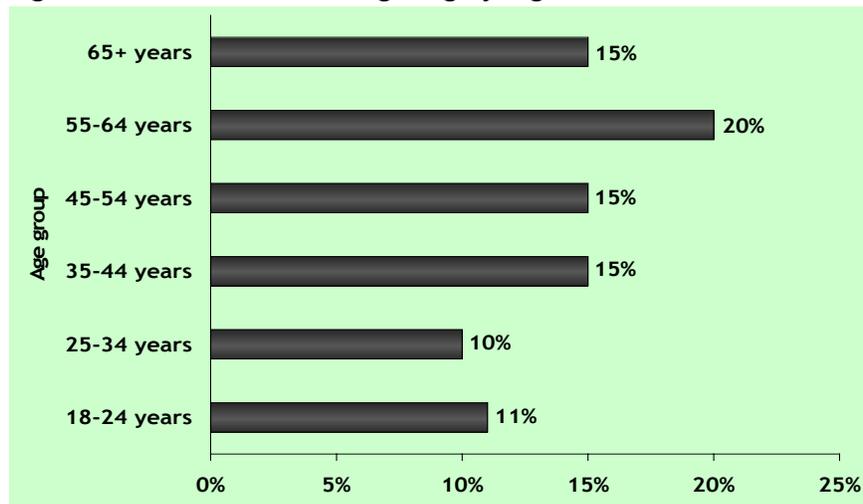
Based on Hawai'i data.

Source: Hawai'i State Department of Health, Behavioral Risk Factor Surveillance System. 2000.

Key assumptions and goals made by the collaborative include:

- Work to develop a coordinated system of long term care to ensure efficient use of resources
- Identify and develop infrastructure to meet projected long term care needs
- Encourage personal responsibility and planning to ensure consumer choice and dignity, financial security, and to help preserve our safety net programs for those who truly need services
- Individual components must be examined within the context of an overall state plan for long term care
- Avoid calling for the implementation of any new taxes
- Seek alternate funding sources for our efforts rather than relying on State revenue (i.e. grant money)

Figure 5. Prevalence of Caregiving by Age



Based on Hawai'i data.

Source: Hawai'i State Department of Health, Behavioral Risk Factor Surveillance System. 2000.

While the initiative is a work in progress, the four areas of priority identified to date include:

1) Infrastructure and Projected Long-Term Care Need

- **Predicting** the facilities and services that Hawaii will need is critical in planning to meet those needs. DOH continues working to refine its estimates of the number and types of beds that will be necessary to adequately serve this growing population as an essential first step in providing workable solutions.

- **Measuring** how effective different approaches are in meeting identified needs is a necessary component to success. DOH is developing evaluation tools to monitor the impact of efforts on improving the quality of life of our seniors.

- **Exploring** the development of retirement communities and the long-term living service industry can be accomplished by the formation of a task force which can plan for both the needs of our aging population and broaden economic diversification for the State.

2) Financing

One of the major tasks of this group is to address the cost of long-term care and how it can be made more affordable. After much research and deliberation, the group developed tax credit legislation to encourage and enable Hawaii residents to purchase private long-term care insurance. This includes the concept of providing incentives to employers to provide long-term care insurance as a benefit. Options are being explored to cover gap group seniors who do not qualify for Medicaid, and cannot afford nor qualify for long-term care insurance.

Figure 6. Relation to Older Person Who Receives Care

RELATION TO OLDER PERSON CARED FOR	% OF ALL CAREGIVERS				
	HONOLULU	HAWAI'I	KAUAI	MAUI	STATE
Spouse/ partner	31%	29%	28%	22%	29%
Child	19%	27%	31%	27%	21%

Based on Hawai'i data.

Source: State Department of Health. Hawai'i Health Survey. 2003.

3) Workforce Development

- **Certified Nurse Aides** (CNAs) are the front line, hands-on providers in long-term care. In order to increase the number of these trained workers to care for our growing elderly population, DOH has created a U.S. Department of Labor Certified Apprenticeship Program. This innovative program provides the flexibility to allow CNAs the opportunity to advance to Licensed Practical Nurses and Registered Nurses, or develop other advanced skills to improve treatment and encourage the formation of qualified businesses in this industry. This federally supported program will increase the number of qualified caregivers for our elderly in all settings. [Note: Hawaii is the only State that has a government sponsored CNA training and apprenticeship program]

Since June, 2004, DOH has been working with the University of Hawaii community colleges statewide to develop a universal curriculum for nurse aides. The training offers a lateral lattice for competency in medication administration, restorative activities, behavior management and recreation, and a vertical lattice for advancement to the Licensed Practical Nurse or Registered Nurse capacity.

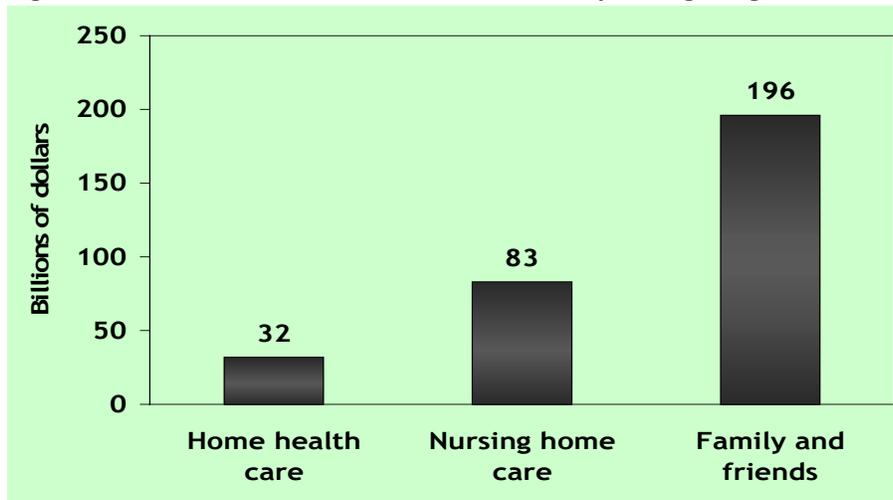
The first ten students started training under this new curriculum at the Molokai Community College site on January 3, 2005. Through a community member's endowment each student received a \$500 scholarship to provide for payment of books and miscellaneous items needed. After completion of the curriculum, these students were provided with the opportunity to take the Certification exam and apprentice at a local hospital or nursing facility.

Classes have begun on Molokai, Hawaii, Maui and Oahu and will begin on Kauai and Lanai in the Spring of 2006.

Grant monies from the Rural Health Development Program provided for a coordinator to complete the curriculum and materials development, convene workgroup meetings, interview students, develop and maintain a tracking system and work with the community colleges to provide mentoring and/or tutorial services for students as necessary.

•**Caregiver support.** This subcommittee was formed with the goal of identifying and implementing strategies to support family caregivers. Two key issues have been identified by this subcommittee as being most needed by caregivers: (1) training/education to ensure quality care provision; and, (2) respite services to prevent burn-out. (See Appendix E)

Figure 7. Estimated Economic Value of Family Caregiving, Per Year



Based on national data.

Source: Arno P, Levine C, and Memmott M. The Economic Value of Informal Caregiving. Health Affairs 18:182-188. 1999.

4) Education

Recognizing that the most important component of social change is educating individuals and families on the issues, this workgroup has been focusing on developing a campaign to discuss the role of government in long term care and the need to plan for our future and take personal responsibility to ensure choice and dignity. In addition, the State has received a federal grant to establish one-stop long-term care access centers that will facilitate public education and understanding about issues, needs, and public and private long term care resources. The planned physical and perhaps virtual access centers will also promote consumer-driven planning and address family caregiver needs.

Current Successes of the Long Term Living Initiative

The Long Term Living Initiative provides a structure for integrating the needs of family caregivers and the planning of the various state departments into the overall planning for Long Term Care needs in the state.

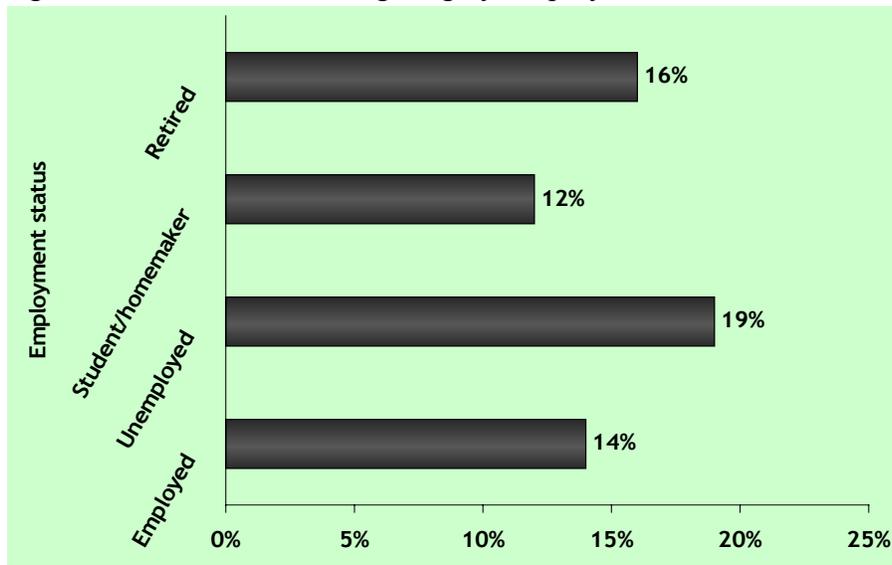
Department of Health

A. State-approved CNA Certification Program

DOH worked with DHS, DCCA, the American Red Cross, and long term care providers to develop a state-approved CNA training program as mandated by federal law for those nurse aides working in Medicare and Medicaid (M/M) certified nursing facilities. For the past 10 years there have been few state-approved training programs in Hawaii, which has raised concerns regarding the competency and skill development of nurse aide training. Due to this collaboration, nine state-approved training programs now exist. Additionally, a system was created to assess the competency level of all CNAs currently working in M/M certified nursing facilities to meet the new state standards and to ensure there is reciprocity for those Hawaii CNAs wishing to relocate to other states, which was not available previously.

DOH simultaneously worked with the above entities to provide for recertification of those nurse aides working in programs, facilities, agencies and/ or who are self-employed, outside of the M/M certified facilities. Current state law requires certification of only those nurse aides working in M/M certified facilities. Efforts are under way to introduce legislation to allow for recertification of those nurse aides working outside of the M/M certified facilities, and development of baseline competency level.

Figure 8. Prevalence of Caregiving by Employment Status

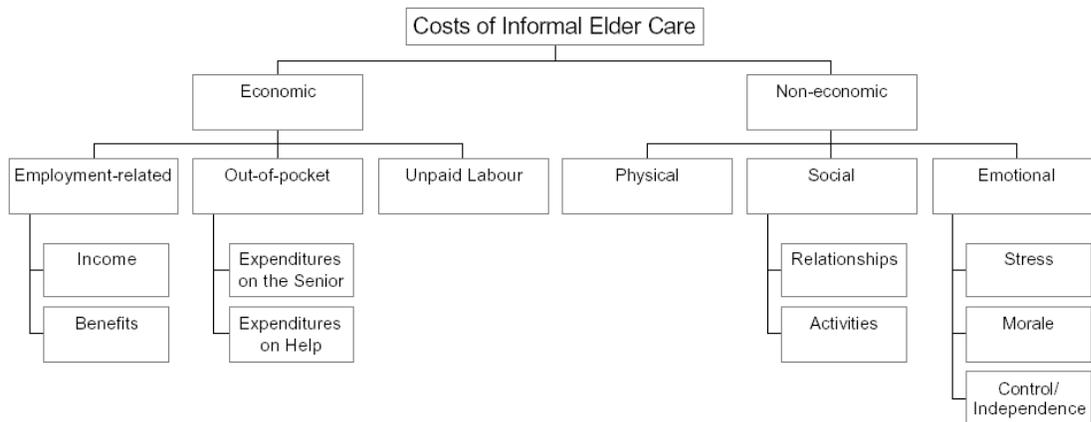


Based on Hawai'i data.

Source: Hawai'i State Department of Health, Behavioral Risk Factor Surveillance System. 2000.

- B. **Statewide CNA Training and Apprenticeship Program**
 In conjunction with the community college system, DOH developed an enhanced CNA training program that is being expanded statewide. They also worked with the U.S. Department of Labor and local providers to establish an apprenticeship program. DOH also received financial support from the Rural Health Development Program, private individuals, and a pledge from the Office of Hawaiian Affairs for student support services. Additionally, DOH applied for a \$1.98 million earmark grant from the U.S. Department of Labor to help fund program expansion and support services for students. This assures standard training across the State for nurse aides, developing a lattice for additional recognition within the nurse aide profession as well as to licensed nursing capacity. (See Appendix B.)

Figure 9. Costs of Caregiving



Source: Fast JE, Keating NC. Informal Caregivers in Canada: A Snapshot. 2001.

- C. **Executive Office on Aging**
 As a State Unit on Aging, EOA, an attached agency of DOH, is charged with supporting, regardless of income, adults 60+ years, caregivers of older adults, and older adults who are primary caregivers of grandchildren below the age of 18 years. Supporting family caregivers is meant to help older adults remain in their home setting for as long as possible and prevent caregiver burnout or abuse or neglect of the care recipient. Family or informal caregiving reduces or delays the demand for costly institutionalized care.

Per Section 373 of the Older Americans Act, federal funds are awarded by the EOA to the four County/Area Agencies on Aging (AAA) to provide information, assistance, counseling, respite care, and supplemental care services to support persons who are providing family/informal caregiving to older adults and older adults are providing primary care for their grandchildren.

The EOA awarded a total of \$627,325 in federal National Family Caregiver Support Program (NFCSP) funds to the County/AAs between July 1, 2004, and June 30, 2005, and

served a total of 10,832 caregivers. Standardized service data collection and management were developed in 2004 and implemented through 2005. (See Appendix C)

In NFCSP funding administered by the EOA, supplemental services are limited to 20% of the total award; services to grandparents caring for grandchildren are limited to 10% of the total; and respite and supplemental services must be for persons 60+ who cannot perform two or more activities of daily living.

Assuring family caregiver support is a priority and major initiative of EOA, in recognition of the critical contribution caregivers make to the well-being of care recipients who want to remain in their homes for as long as possible. While the EOA serves older adults who do not qualify for Medicaid and other assistance, these federal and state resources are limited, so that the EOA – through its County/Area Agencies on Aging – prioritize personal care services for persons of greatest need.

Recognizing caregivers is a grassroots movement begun with support groups, most notably with Alzheimer's disease families. The EOA works closely with the grassroots network to enable information exchange, training, education, and some reimbursement help to family caregivers. This is a good example of public/private partnerships that allow the innovations and resources of the private sector to be augmented by the efforts of the public sector; thus resulting in a more efficient and effective management of limited resources benefiting the community as a whole.

Finally, EOA, in partnership with the Hawaii County Office on Aging and the City and County of Honolulu Elderly Affairs Division, will develop an Aging and Disability Resource Center (ADRC) in Hawaii. The Center will be established on the Island of Hawaii and with a possible second Center on the Island of Oahu. The ADRC Center will offer information and referral; counseling; assessment; eligibility functions for both publically and privately funded services; coordination with other programs; and prospective planning to help people plan ahead for their long term service and support needs.

Department of Human Services

DHS serves individuals and caregivers of individuals who qualify for Medicaid assistance. Respite services are a component of all Medicaid waivers, along with case managers who assist families in identifying when burn-out is becoming a factor that is influencing the care of their family member. DHS also operates a program called Senior Companions which pays a small stipend to low income older citizens to provide respite care in the home to eligible elderly and disabled clients. Some Adult Protective Services clients also receive short term case management, respite, and support services in order to maintain their safety. See Appendix D for a breakdown of DHS programs that provide respite or supportive services to eligible individuals and their families.

ONGOING EFFORTS TO STRENGTHEN THE SUPPORT TO FAMILY CAREGIVERS AND THE LONG TERM LIVING INITIATIVE

1. DOH is moving forward on the following:
 - A. Working with owners/operators of our nursing facilities (NFs), adult residential care homes (ARCHs), and assisted living facilities (ALFs) to encourage their offering of respite care and day care services within their licensed capacity. Participating entities will be posted on the DOH website to aid getting information to consumers.
 - B. Working with DHS, EOA, State Civil Defense, the American Red Cross, and other stakeholders on emergency preparedness plans for our vulnerable populations.
 - C. Examining cooperative ventures through the U.S. Department of Agriculture, for ownership of home care and home health agencies by CNAs wishing to provide community-based services but lacking the resources to start a business.
 - D. Considering cross training programs with the hotel industry for housekeeping staff to be trained as nurse aides.
 - E. Working with the University of Hawaii John A. Burns School of Medicine, Department of Geriatrics, to include in the curriculum training of physicians an awareness of home and community based resources and to look at creative methods to address in-home care and choice of care settings for our elderly and disabled populations.
2. The Department of Health is utilizing U.S. Department of Labor and other resources to train, certify and increase the number of Certified Nurses Aides that would be employed in licensed care facilities.
3. By 2008, all Medicaid services for the aged, blind, and disabled may be provided by managed care contractors. The goal of this program is to increase the quality of and access to services, both of which will assist clients and their caregivers.
4. Caregiver advocacy training, support group development for grandparents, caregiver networking/information exchange, and integration of caregiver issues in policy and program development are among the tasks performed by the UH Center on Aging (COA) in partnership with the EOA. A multi-agency coalition was formed in 2004 that promotes opportunities for caregivers to have a voice in policies and programs that affect them. In 2005, the COA received a small Brookdale Foundation grant to initiate grandparent support groups in Hawaii and, through a state Office of Community Services conference, expanded coalition development to the faith-based community. EOA is acquiring resources to enable the UH Center on Aging to support development of the caregiver component in planned single entry access to long term care resources statewide and to address the impact of family caregiving on both employers and employees.

POLICY RECOMMENDATIONS

DOH and DHS are committed to working together to look at family caregiving issues to ensure that the elderly and disabled can be supported in their effort to remain in a setting of their choice. We are proposing that the leadership of the Long Term Living Initiative and the Workforce Committee with its Subcommittee on Caregiving continue to spearhead the state's efforts in addressing family caregiver issues. As identified previously in this report, the priority issues for 2006 will be respite services and caregiver education/training. For more information, see Appendix E.

EOA is requesting an increase of \$302,400 in the federal budget ceiling to accommodate the first year of a three-year federal grant to plan and develop one-stop long term care access information centers that will greatly benefit informal and family caregivers. A long-term care access plan will be completed in October 2006, a major component of which will address the capacity of informal and family caregiving in Hawaii. The goal of the one-stop centers is to streamline access to: information and referrals; counseling; assessment; eligibility functions; coordination among long-term care resources; and resources to help people plan ahead for their long-term care needs. DOH plans to provide intake and eligibility functions through the planned one-stop long-term care access centers described above.

It is recommended that the Legislature support individual and employer tax credit legislation for the purchase of long term care insurance (H.B. 728/ S.B. 837, H.B. 732/S.B. 841, H.B. 97 SD2). Increasing the number of individuals with private long term care insurance coverage will help to reduce the need for family caregiving in the future.

“Hawaii caregivers are remarkably similar to their non-caregiving counterparts in the State, in terms of age, ethnicity, education, income, household size, health, and other characteristics.” - Report to the 23rd Legislature of 2005, Pursuant to H.C.R. No. 154 (2004).

CHARACTERISTICS AND TRENDS OF FAMILY CAREGIVERS IN HAWAII

Caregiving has always been a universal experience affecting people of all ethnicities, lifestyles, and income levels. But recently, family caregiving has become more than an act of love and familial responsibility. It has become an essential element of our health and long-term care system.

Characteristics

Families, rather than institutions, are the primary providers of long-term care in the State. In 2003, approximately 21% of Hawaii's adult population, or 192,390 individuals, were providing care or assistance to a person age sixty or older, with 29% caring for a spouse or partner, and 21% caring for a parent. These may be a relatively low numbers since there are many “hidden” caregivers in Hawaii – those who do not identify themselves as “caregivers”.

In Hawaii, the likelihood of becoming a caregiver is similar across different demographic groups and among persons with varied socioeconomic characteristics. Adults of any household income have a similar likelihood of caregiving. Married persons in Hawaii are just as likely to provide care as their unmarried counterparts.

Among the different ethnic groups in Hawaii, native Hawaiians are most likely to provide regular care to a loved one, followed by Filipinos, Japanese, and Caucasians. 12% of men and 16% of women provide care or assistance to someone age sixty or older. Women, however, are more likely than men to be primary caregivers, providing higher intensities and frequencies of care, according to national studies.

65% of Hawaii's caregivers are employed. To balance their employment and caregiving roles, working caregivers take leaves of absence, report to work late or leave early, change from full-time to part-time employment, change to less demanding jobs, retire early, or give up work completely. As a consequence, caregiving may reduce a caregiver's retirement income since reduced hours on the job or fewer years in the workforce may mean fewer contributions to pensions, social security, and other retirement savings.

Trends

Significant changes in Medicare and Medicaid health insurance programs nationally and locally will impose greater responsibilities upon individuals and families to be well-informed and astute about long-term care planning, financing, and the options that may assist them in the future or the present. Expert, one-to-one counseling continues to be a significant demand by consumers who often need help articulating their questions before being able to ask for specific information or help.

Hawaii is facing a growing healthcare worker shortage, while at the same time health and long-term care needs continue to rise. As a result of cost-containment policies and practices, people with healthcare needs are being discharged from hospitals and other care facilities with complex healthcare requirements

The caregiving tradition in Hawaii is, over time, challenged by the changes in Hawaii demographics: birth rates, marriages, single-occupant households, high costs of living, and family members working outside the home or moving away from Hawaii.

By 2020, more than one in four individuals will be sixty years old or older. The need for personal care 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.

DEPARTMENT OF HEALTH INITIATIVES

Program/Service	Description	Eligible population	Number served annually	Source and amount of funding
Nurse Aide certification recertification	Certification exam and competency evaluation every 2 years	All Nurse Aides	Recertification of 9,212 every two years; certification of 200-300 annually	Payment by individuals, if Medicaid eligible reimbursement by DHS; community funding sources
Earmark Grant	Nurse Aide training and apprenticeship program	18 years old; High School Diploma or GED; 10 th grade reading level; interest in health care; meet community college requirements	140 students annually	U.S. DOL grant through DLIR \$1.98 million (over 2 years)
Rural Health Development Program	Development of Coordinator position for curriculum development; work with students	All students admitted to Community Colleges statewide	All students admitted to Community Colleges statewide	\$200,000

**EXECUTIVE OFFICE OF AGING INITIATIVES
SERVICES FUNDED BY TITLE III-E
(NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM)**

Services 7/04-6/05	Cost	# Units of Services	Number served
Counseling Session	\$107,899	1,924 sessions	283
Support Group	\$ 86,584	260 sessions	592
Training Session	\$ 28,428	44 sessions	509
Respite			
In-home (not PC, Homemaker)	\$ 80,339	7,202 hours	86
Adult Day Care (short term)	\$ 32,169	2,375 hours	90
Homemaker	\$ 13,319	895 hours	42
Personal Care	\$ 48,766	2,282 hours	98
Supplemental Services			
Assistive Technologies	\$ 1,808	10 requests	7
Home Modifications	\$ 154	4 requests	1
Incontinence Supplies	\$ 3,440	22 requests	22
Nutrition Supp.	\$ 655	5 requests	5
Transportation	\$ 724	35 requests	6
Legal Assistance for grandfamily caregivers	\$ 3,130	78 hours	10
Other	\$ 1,682	27 requests	7
Aggregate Services			
Access Assistance	\$143,504	5,187 sessions	1,737

One-to-one contact Information Services	\$ 78,164	92 sessions	7,337
TOTAL	\$627,325		10,832

DEPARTMENT OF HUMAN SERVICES PROGRAMS

Program/ Service	Description	Eligible population	Number served annually	Source and amount of funding
Adult Day Care	Structured settings with specified activities for older adults and clients with disabilities who need supervision	Eligible for SSI, Medicaid, or financial assistance from DHS and meet other program related requirements.	85	State funding 333,479
Chore and Homemaker	Essential housekeeping services to enable eligible adults to remain in the community. Services include housecleaning, laundering, shopping and meal preparation.	Eligible for SSI, Medicaid, or financial assistance from DHS and meet other program related requirements.	1,011	Federal \$2,9898,375 State- Rainy day \$900,000 POS \$406,630 State \$2,601,157 Grand Total \$6,896,162
Adult Foster Care	Provides placement and limited short-term case management services to adults residing in licensed adult residential care homes.	Eligible for SSI, Medicaid, or financial assistance from DHS and meet other program related requirements.	62	State funding \$150,000
Nursing Home Without Walls	Support services for individuals with serious or chronic illnesses or disabilities who want to remain in their own homes. Includes case management, personal assistance, private duty nursing, home-delivered meals, respite, personal emergency response system, environmental accessibility adaptations, non-medical transportation, adult day health, counseling and training for nutrition, coping, and support and crisis management.	Eligible for Medicaid, require nursing facility level of care and meet other program-related requirements. Primary caregiver necessary to assure health and welfare of individual at home on a 24-hour basis.	929	State funds \$8,548,031 Federal \$8,795,891 Total \$17,335,922

Program/ Service	Description	Eligible population	Number served annually	Source and amount of funding
Medically Fragile Community Care	Designed for children who are born with or develop complex medical problems and whose families need support to keep them in the home or in licensed child foster home. Services include case management, family training, specialized day care, respite care, attendant care, environmental accessibility adaptations, specialized medical equipment and supplies, home maintenance, moving assistance and non-medical transportation.	Child must be eligible for Medicaid, under 21 years old, require subacute or skilled nursing facility level of care and meet other program-related requirements.	62	State \$406,289 Federal \$479,761 Total \$886,050
HIV/AIDS Community Care	Provides support services similar to Nursing Home Without Walls for individuals who are diagnosed with HIV/AIDS.	Eligible for Medicaid, require nursing facility level of care and meet other program-related requirements. Individual does not need a family or primary caretaker.	61	State \$302,419 Federal \$362,421 Total \$664,840
Developmental Disabilities/ Mental Retardation	Provides individuals with developmental disabilities/mental retardation support and services to enable them to live independently. Services include adult day health, personal assistance, respite, habilitation, habilitation-supported employment, skilled nursing, specialized services, personal emergency response system, non-medical transportation, specialized medical equipment and supplies and environmental accessibility adaptations.	Eligible for Medicaid, require care in Intermediate Care Facilities for Mentally Retarded, be referred by DOH-Developmental Disabilities Division case manager and meet other program-related requirements	2,006	State \$23,793,802 Federal \$34,742,500 Total \$58,536,302

Program/ Service	Description	Eligible population	Number served annually	Source and amount of funding
Residential Alternatives Community Care	Serves adults who are in need of a residence as well as assistance with their care needs. Individuals may be served in an Assisted Living Facility or in RACC family home that provides personal care, homemaker services, transportation, private duty nursing services, respite care and/or adult day health services.	Eligible for Medicaid, require nursing facility level of care and meet other program-related requirements.	1,144	State \$6,581,348 Federal \$8,368,171 Total \$14,949,519
Program of All Inclusive Care for the Elderly (PACE)	Managed care program that serves adults 55 years of older living in urban Honolulu. Clients attend PACE Adult Day Health program where serves such as speech therapy, occupational and/or physical therapy, dental services, audiology, optometry, podiatry, home medical care services, and transportation are provided	Eligible for Medicaid, require nursing facility level of care and meet other program-related requirements.	90	State \$1,083,277 Federal \$1,397,889 Total \$2,481,166
Senior Companion	Enrolls low-income seniors to provide in-home companionship and limited personal care to frail elders and respite to caregivers.	Individual must be 60 years of age, physically able to work 20 hours a week and meet income/program requirements. To receive services, individual or family must meet program-related requirements.	488	
Respite Companion Service	Enrolls low-income seniors to serve frail homebound elders on Oahu. Services include limited in-home personal care and other support services and respite to caregivers.	Individual must be 55 years old, physically able to work 19 hours a week and meet income/program requirements. To receive services, individual or family must meet program-related requirements.	170	

THE NEED FOR RESPITE SERVICES AND TRAINING/EDUCATION

Respite Services

Caregivers assume responsibility for many tasks for their loved ones such as grocery shopping, cooking, driving their parent to medical appointments, giving injections, changing bandages, calming and dressing their agitated parent suffering from Alzheimer's, or helping a disabled partner get from the bed to the bathroom. When around-the-clock care becomes necessary, caregiving can become overwhelming.

Respite care addresses one of the most pressing needs identified by families, namely temporary relief to reduce the strain that caregivers experience on a day-to-day basis. Respite services are primarily to provide substitute support for care recipients in order to provide a period of relief or rest for the caregiver. Respite care can allow time for the caregiver to, for example, address their own personal needs, attend a class to learn caregiving skills, participate in a support group, take care of other business, or attend to an unexpected emergency.

Respite decreases the individual and family stresses associated with caregiving. It benefits both the caregiver and care recipient. Respite care can relieve the burden of the caregiving situation and allow families to continue to care for their loved ones who would otherwise have been placed in a nursing home. Respite services can be provided at home or in a group or institutional setting such as adult day centers, nursing homes, respite camps, and other facilities.

Although the need for respite services is a priority for many caregivers, respite remains in short supply or are inaccessible to the family for reasons such as attitudes about respite services, eligibility requirements, geographic barriers, cost, or the lack of culturally sensitive programs.

Training and Education

Family caregiving is a complex responsibility involving emotional support, household management, medical care, dealing with a variety of governmental and other agencies, and decision-making. Yet family caregivers consistently report that they are not prepared for these roles. This lack of training occurs throughout the caregiving experience, but is most apparent when care recipients are discharged from hospitals or short-term nursing home stays after an illness or accident. One national survey found that 43% of caregivers performed at least one medical task, defined as bandaging and wound care, operating medical equipment, or managing a medication regimen. Yet formal instruction is sporadic and inadequate. Families are expected to perform skilled nursing care, but without the training that professionals must receive.

Family caregiver needs for information and training change throughout the course of their loved one's illness. They must have opportunities to learn new skills as they become necessary, access new resources, and learn about care options as the situation changes. Family caregivers need help with the basic skills for assisting their loved ones in areas such as: lifting; transporting; CPR; bathing; learning to deal with loved ones with dementia; coping and other related psychological skills and emotional support; communication skills to help them deal with concerns expressed by their loved ones; and selecting and using of various aids that are available. Families also need

honest information about the financial, social, and health-related consequences of various arrangements for care, and they must share in the decision-making about care arrangements.

Family caregivers must have appropriate, timely, and ongoing education and training in order to successfully meet their caregiving responsibilities and to be advocates for their loved ones across care settings. Additionally, family caregivers and their loved ones must be assured of an affordable, well qualified, and sustainable eldercare workforce across all care settings.

**THE STATE OF THE STATES IN FAMILY CAREGIVER SUPPORT:
A 50-STATE STUDY**

This report profiles the experience of all 50 states and the District of Columbia since the passage of the National Family Caregiver Support Program (NFCSP) in providing publicly funded support services to family and informal caregivers of older people and adults with disabilities. The report arises from a two-year project to provide an understanding of the range and scope of federal and state-funded caregiver support programs in each of the 50 states and across states. The study was designed to take a broad focus; it examines policy choices and approaches to caregiver support through state agencies responsible for the administration of the NFCSP, Aged/Disabled Medicaid HCBS waiver programs, and state-funded programs that have either a caregiver-specific focus or include a family caregiving component in their service package. This first 50-state study of caregiver support services in the U.S. is intended to inform policy discussions among federal and state leaders in caregiving and long-term care throughout the nation.

This study found that state-administered programs offer an array of services to support family and informal caregivers; respite care tops the list.

- At least half of all programs in this survey (76 out of 150 programs) provide one or more of the following eight services: respite care (95%), information and assistance (69%), education and training (62%), care management/family consultation (58%), homemaker/chore/personal care (58%), assistive technology/emergency response systems (54%), individual and/or family counseling (52%), and home modifications (51%).
- Respite is the service strategy most commonly offered to support caregivers and is available in all 50 states, although the amount of respite to family members varies substantially from state to state and program to program within states.
- Respite care takes many forms; the most common types of respite offered in state programs surveyed are in-home respite, adult day services, and overnight respite in a facility. To control costs and distribute services equitably, 66 programs in 38 states and the District of Columbia that offer respite assistance utilize a respite care of some type.
- Caregiver education and training is offered by nearly two out of three (62%) programs surveyed. Education and training can include conferences or classes covering a broad range of topics of interest to family caregivers, or can teach caregivers “hands-on” skills and knowledge to improve confidence and competence in the caregiving role (e.g. training for lifting or bathing a person, techniques for managing behavioral problems, methods for coping with stress).
- Caregiver education and training is much more commonly offered by the NFCSPs (94%) than the state-funded (56%) or Medicaid waiver programs (35%).

To download a copy of the Executive Summary, please visit:

http://www.caregiver.org/caregiver/jsp/content/pdfs/executive_summary.pdf

To download a copy of the full report, please visit:

http://www.caregiver.org/caregiver/jsp/content/pdfs/50_state_report_complete.pdf