
Family Caregiver Support:
*Policies, Perceptions and Practices in 10 States Since Passage
of the National Family Caregiver Support Program*

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OVERVIEW

Hawaii is unique in its geographic location and boundaries as well as in its ethnic and cultural diversity. Hawaii's current long-term care system is constrained by a long tradition of reliance on families to "take care of their own." A shortage of nursing home beds, home and community-based service options and trained direct care workers adds further challenges to Hawaii's long-term care system, with an even greater impact on the rural neighbor islands.

Hawaii does not yet have a system of support in place for family caregivers, although the needs of families have received increased attention in recent years. In February 2002, Hawaii Governor Ben Cayetano (D) proclaimed the year 2002 as "The Year of the Caregiver" in recognition of the new National Family Caregiver Support Program (NFCSP).

The state's emerging caregiver support services are characterized by:

- ❖ A focus on collaboration and partnerships through a state-level caregiver coordinator whose position is state funded rather than federally funded under the NFCSP
- ❖ The development of culturally appropriate caregiver support services on each of the Hawaiian islands
- ❖ Pursuit of a decentralized approach to program development and service delivery

Hawaii's respondents noted that the major service needs of family caregivers are (1) respite care, (2) counseling, (3) help to navigate the long-term care system, particularly in rural areas and for Native Hawaiians, (4) supplemental services (e.g., consumable supplies) and (5) education, specifically skills-based training.

As Hawaii addresses long-term care reform and develops a statewide caregiver support system, a key consideration will be how the state is to achieve its goal: to integrate caregiver support services into Hawaii's other long-term care programs and to build on the infrastructure in place.

INTRODUCTION

Hawaii represents a "new" state that is beginning to explicitly provide caregiver support services as a result of the passage of the NFCSP. The project team conducted a site visit on May 21 and 22, 2002, with in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies interviewed include:

Hawaii Department of Health, Executive Office on Aging

- ❖ Family caregiver support program (NFCSP funded)
- ❖ Kupuna Care program for home and community-based care (state funded)

Hawaii Department of Human Services, Social Services Division, Adult and Community Care Services Branch

- ✧ Aged/Disabled Medicaid waivers
- ✧ Real Choice Systems Change grant

Stakeholders interviewed were from

- ✧ Hawaii Area Agency on Aging Directors and Program Specialists
- ✧ University of Hawaii, Center on Aging
- ✧ Alzheimer's Association, Aloha Chapter
- ✧ Honolulu Gerontology Program
- ✧ Alu Like, Native Hawaiian Elderly Services Project

Three programs are featured:

1. Family caregiver support program
2. Kupuna Care
3. Aged/Disabled Medicaid waivers

BACKGROUND

Hawaii is 2,400 miles from the west coast of the continental United States. It is unique in its geographic location and boundaries as well as in its ethnic and cultural diversity. Hawaii ranks 42nd in population nationally, with about 1.2 million persons residing in four counties covering eight major islands. Hawaii is considered one of the healthiest states in the nation, with low infant mortality rates and high life expectancy.¹

The vast majority of Hawaii's population (72%) reside on the island of Oahu in the city and county of Honolulu. The remainder of the state's residents (28%) reside on the rural "neighbor islands" in the counties of Hawaii (12%), Maui (11%) and Kauai (5%). In 2000, personal income per capita was \$28,221. Although Hawaii's per capita income is under the national average (\$29,676² U.S.), Hawaii has proportionately fewer people living below the federal poverty level than the United States as a whole (11.1% vs. 13.3% U.S.).³ About 43% of Hawaii's households have Internet access, with the state ranking 18th nationally⁴ (table 1).

Hawaii is a multicultural state, with a minority of white residents. In 2000, the ethnic breakdown for the state was Hawaiian/part Hawaiian (22.1%), Caucasian (20.5%), Japanese (18.3%), Filipino (12.3%) and Chinese (4.1%).⁵

Hawaii's elders are known as *na Kupuna*. The state's older population is both increasing and aging at a rapid rate. Between 1990 and 2000, the 60+ population increased by some 19%, compared to about 9% nationally. Even more dramatically, between 1990 and 2000, the Hawaiian 85+ population increased nearly twice as fast as the national average (68.9% vs. 37.6% U.S.).⁶ An estimated 207,001 persons in Hawaii, or 17 percent of the state's population, were 60 years or older in 2000, higher than the national average of 16.3%. Hawaii ranks 20th nationally in the percentage of older persons (60+) residing in the state.⁷ About 17,564 persons, or about 1% of the state's population, were 85 years or older in 2000⁸.

The racial makeup of the state's older population is the most diverse in the nation and differs significantly from that of the United States as a whole, with a minority of older white persons (22.7% vs. 82.4% U.S.) and a predominant Asian population (60.6% vs. 2.5% U.S.). Some 5.5% of the state's 60+ population is Native Hawaiian. Compared to the national average, Hawaii has proportionately fewer older African Americans (0.4% vs. 8.4% U.S.) and older Hispanics (2.6% vs. 5.4% U.S.).⁹

Consistent with the state as a whole, about 75% of Hawaii's total older population (ages 60+) reside in the city and county of Honolulu. On the neighbor islands, about 13% of the state's older population live in the county of Hawaii on the Big Island, 10% in Maui County and about 5% in Kauai County.

An estimated 114,872 family caregivers reside in Hawaii. These family caregivers provide about 107 million hours of caregiving per year at an estimated value in 1997 of about \$875 million.¹⁰

Hawaii has recovered somewhat from a major recession in the mid-1990s. Hawaii's economy, however, depends on tourism, which brought \$10.9 billion to the state in 2000. Thus the state is very concerned about the impact that the economic downturn on the United States mainland will have on tourism to Hawaii.

Housing is expensive in the state because of limited availability and the high price of land. The state ranks 48th nationally in the home ownership rate.¹¹ Hawaii has a relatively low tax burden compared to other states and no state personal property tax. Rather, property taxes are collected through county assessments. The cost of living for a family of four has been estimated to be 27% higher than the U.S. average.¹² Geographic boundaries on neighbor islands pose barriers to getting quality health and social services. Because of the state's antitax sentiments, Hawaii's health and social programs are relatively limited.

Table 1. Selected Characteristics of HAWAII and the UNITED STATES, 2000 ^a

	Hawaii	United States
Total Population Characteristics		
Total Pop. ^b	1,211,537	281,421,906
% African American ^c	1.8%	12.3%
% Hispanic ^d	7.2%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	207,001	45,797,200
% 60+ ^f	17.1%	16.3%
National ranking 60+ ^g	20	NA
Pop. 65+ ^h	160,601	34,991,753
% 65+ ⁱ	13.3%	12.4%
National ranking 65+ ^j	16	NA
Pop. 85+ ^k	17,564	4,239,587
% 85+ ^l	1.4%	1.5%
National ranking 85+ ^m	30	NA
% increase 1990–2000 60+ pop. ⁿ	19.1%	9.4%
% White (60+) ^o	22.7%	82.4%
% African American (60+)	0.4%	8.4%
% Hispanic (60+)	2.6%	5.4%
% Asian (60+)	60.6%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	5.5%	0.1%
% Amer. Indian/Alaska Native (60+)	0.1%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	114,872	25,798,370
Caregiving hours (millions) (1997)	106.9	24,013.1
Value of caregiving (millions) (1997)	\$874.6	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$28,221	\$29,676
% of pop. below poverty (1997) ^r	11.1%	13.3%
Internet		
% of households w/Internet access (2001) ^s	43.0%	41.5%
Nat'l ranking of households w/Internet access	18	NA

a Unless otherwise noted, all data are from 2000.

b MapStats-Hawaii, www.fedstats.gov (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r MapStats-Hawaii.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

Caregiver support services for the elderly and for adults with physical disabilities are administered largely through two state agencies in Hawaii: the Executive Office on Aging (EOA) in the Department of Health and the Department of Human Services (DHS). Several key informants noted that the EOA has been viewed as serving the "well elderly" and non-Medicaid-eligible older population, and the DHS, through the Medicaid and Medicaid waiver programs, has traditionally served the state's more frail and low-income older population.

The EOA is administratively attached to the Department of Health, serving as the State Unit on Aging (SUA) and administering the provisions of the federal Older Americans Act, including the new NFCSP. Programmatically, the EOA executive director reports to the governor. The EOA also administers Hawaii's state-funded home and community-based care program, now known as *Kupuna Care*. In 1999, the program was given this title and reorganized to increase accountability and management of services. Eligibility standards, service authorization and client cost-sharing were developed to promote greater program efficiencies.

In addition to the EOA, the infrastructure of Hawaii's aging network is a statewide system of four Area Agencies on Aging (AAAs), all located in county government, and private agencies under contract to EOA and the AAAs. The four AAAs serve Kauai County, the city and county of Honolulu, Maui and Kalawao and Hawaii County on the Big Island. The AAAs are not direct service providers; rather, they subcontract with providers in the community to do case management and deliver services to the older population. The roles of the AAAs vary from county to county. The Honolulu AAA on the Island of Oahu, with about 75% of the state's total older population, is by far the largest AAA and has the most community resources. Because there are many different aging-related agencies in Honolulu, that AAA's primary role is coordination among the programs and services. However, outlying areas of Oahu have some of the same problems as neighbor islands, that

is, few services and relatively long driving distances to get care. On the neighbor islands, which are relatively rural and have few resources, the AAAs are the primary focal points for information and services.

The DHS serves as the “single state agency” for administering the Medicaid program. The department operates two 1915 (c) Aged/Disabled waivers, which were originally approved in 1983. The first, the Nursing Home Without Walls (NHWW) waiver, serves persons of all ages with serious or chronic illnesses or disabilities who want to remain in their own homes. The second, the Residential Alternative Community Care (RACC) waiver, is for eligible adults (ages 18+) who need a residence in an assisted-living facility or in a group family home that provides assistance with care needs. Case management teams of social workers and nurses, employed by the state, deliver services. Six case management teams work on the island of Oahu. One case management team is located on each neighbor island. ^a

In October 2001, the Hawaii DHS was awarded a Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The University of Hawaii, Center on Disability Studies, serves as a subcontractor. Other key state agencies involved include two Department of Health divisions and the EOA. The aim of the three-year grant is to develop a common assessment tool and a website to promote single entry to the long-term care system. Family caregiver issues are not a current focus of the grant.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Long-term care has been a major interest of Hawaii’s lawmakers in recent years. Many bills have been introduced, including some to expand home and community-based care, restructure the administration of aging and long-term care programs and create an affordable method of financing long-term care. Lawmakers have debated legislation for long-term care reform; however, few proposals have been enacted. In 2002, some bills addressing long-term care and the needs of family caregivers were again introduced. Only two were passed, H.B. 2638 and S. 2416. Hawaii Governor Ben Cayetano signed H.B. 2638, creating the Hawaii Long-Term Care Benefits Fund and a board of trustees to pay state residents’ long-term care costs. The Trust Fund would apply to all age groups in the state, regardless of income. The intent of the original legislation was to create a financing system based on a social insurance model, although this component was dropped from the final proposal. Several case study respondents said that lawmakers would be back next year to reintroduce the more comprehensive bill. A second piece of legislation (S. 2416) signed into law by the governor requires the EOA to hold a long-term care summit. Key informants from the EOA said that such a summit would address family caregiver issues.

Several factors constrain Hawaii’s current long-term care system. The first is Hawaii’s relatively low proportion of nursing home beds, the third lowest in the United States for those 65–84 years of age and the lowest ratio in the nation for those 85 years or older.¹³ Traditionally, Hawaii has depended on extended family to provide long-term care at home to address the shortage of nursing home beds.

^a The DHS also administers a Mental Retardation/Developmental Disabilities (MR/DD) waiver, an HIV Community Care waiver and a Medically Fragile waiver for children.

Because of the high cost of living in the state, particularly for housing, extended families most commonly live together in one household. Often, three or four generations live together, creating a high proportion of intergenerational housing in Hawaii. These traditional values have played a significant role in shaping Hawaii's public policies.

The second challenge to Hawaii's long-term care system is the severe shortage of trained long-term care providers, particularly on the neighbor islands. One Medicaid official commented that a lack of trained social workers, nurses and personal care workers on some islands may mean that qualified and trained personnel are not available to provide some home and community-based services even though clients are entitled to the services. Long-term care (i.e., home and community-based services as well as nursing homes) is more available in Honolulu on the island of Oahu, the population center, than anywhere else in the state.

Finally, all respondents talked about the cultural value in Hawaii of taking care of family in one's own home, where the older person is happiest and most cherished. One respondent pointed out that "tradition dictates that among Native Hawaiian families, caregiving for an older person who is ill or disabled is a task that is delegated to a chosen member of the family, generally female." Increasingly, however, family members must work more than one job just to survive and no one is left at home to provide care. In some cultural groups, asking for help to care for a family member is considered shameful. Also still prevalent today, however, is the cultural value of older persons who do not want to be a burden to the family.

Hawaii has no formal state statute recognizing family caregivers as a central component of a comprehensive long-term care system, although respondents believed state law implies such recognition because of the state's tradition of reliance on family care. Some observers expressed the belief that caregiver support services have not been a priority within the long-term care reform debates because "our values are to take care of our own." Others believed that key trends—nursing home bed shortages, limited home and community-based care, aging of the baby boomers and the high proportion of Hawaiian women in the labor force juggling work and caregiving—are causing state leaders to begin shaping public policy to recognize that family caregivers need support services themselves to sustain them in their caregiving role.

Today, Hawaii is slowly changing its attitudes about family caregivers and recognizing that caregivers have their own needs for support, not just relying on them to provide the bulk of long-term care. In February 2002, in recognition of the new NFCSP funds, the governor joined the mayors of all four of Hawaii's counties to proclaim the year 2002 as "The Year of the Family Caregiver." This proclamation promoted awareness of and support for caregiver issues by recognizing family caregiving as a vital piece in the long-term care of Hawaii's older population and by recognizing the importance of providing support services to sustain family caregivers. On the island of Kauai, the mayor is a family caregiver herself and has spoken about her situation and the need for support numerous times.

Multicultural caregiving initiatives: Two demonstration projects are currently being implemented in Hawaii to address the needs of the state's diverse caregiving population. The projects' goals are to strengthen Hawaii's caregiver support services and to provide effective models and promising practices for replication by other states.

- ❖ Under the leadership of the EOA, Hawaii has a five-year history of work to improve end-of-life care. In 2001, the University of Hawaii's Center on Aging received a three-year NFCSP innovation grant to explore the impact of group-targeted messages and individually tailored support on end-of-life planning by multiethnic caregivers of older persons receiving long-term care services. The Center on Aging will develop a series of four booklets to include messages targeted to caregivers at three stages: (1) prior to self-identification as a caregiver, (2) during active home-based caregiving and (3) after the care recipient's institutionalization or death. Working with community partners, the project aims to provide 600 caregivers with the message booklets and support through either caregiver training or counseling, and to document culturally linked barriers to end-of-life planning and strategies to address them.
- ❖ Alu Like is a primarily federally funded Native Hawaiian service organization. In 2001, the agency received a three-year Native American caregivers grant under the NFCSP to design and test quality standards and assurance mechanisms for multifaceted systems of support for family caregivers.^b The project will provide direct services to Native Hawaiian family caregivers, develop culturally appropriate training manuals, conduct education programs and evaluate results. Part of the project will involve paying family caregivers to provide respite.

PROGRAM BACKGROUND/DEVELOPMENT

In the late 1980s, the EOA developed the first long-term care plan for Hawaii, which implicitly recognized the need to support family caregivers in order to sustain the long-term care system. Over the past 15 years, the main focus of the EOA's caregiver initiatives has been on caregiver education and training. One observer noted that "really good skills training is what family caregivers say they need." A number of projects were developed during this time, including a seven-week program through community colleges to train family caregivers, publication of a booklet on caregiving and a study of state employees to estimate the prevalence of employed caregivers in state government.

Prior to the passage of the NFCSP in 2000, no statewide caregiver support program existed in Hawaii. Respondents pointed out that most of the advocacy efforts over the past two decades have been to expand home and community-based care for the older person, not specifically to address the needs of the family caregiver or to take a "family systems" approach to service delivery.

The EOA began planning for the establishment of the new program in January 2001. To identify innovative models that could be implemented in the state, Hawaii looked at Wisconsin's Alzheimer's disease program, California's caregiver resource centers, Louisiana's respite sitters program, Minnesota's program to pay family caregivers and Pennsylvania's "cash grant" program. The state also reviewed the lessons learned from Hawaii's federal Alzheimer's Disease Demonstration Grant to States. This federal demonstration, undertaken in the early 1990s, provided a stipend to participating caregivers in exchange for training on how to care for their frail family members with dementia. The project also used "low-tech" friendship approach, using volunteers to provide respite care. The EOA and the AAAs also utilized the Administration on Aging (AoA) listserv to stimulate program development and conducted focus groups to better understand the needs of family caregivers.

^b The Hana Community Health Center on Maui also received a Native American caregivers demonstration grant under the NFCSP. Their project will identify and prioritize the needs of Native Hawaiian family caregivers.

Like other small states, Hawaii did not receive any administrative funds to operate the NFCSP at the state level. All of the federal funds were passed through to the four AAAs. The EOA recognized, however, the importance of maintaining a statewide focus on caregiving and in September 2001, hired a caregiver coordinator whose position is state funded. The coordinator heads up the Caregivers Resource Initiative (CRI) project. Although the NFCSP served as the catalyst for the CRI project, it is not directly related to it in terms of services. The intent of the state project is to assist and enhance caregiver support efforts at the state and local level by partnering and collaborating with various stakeholders in the community to develop caregiver resources; increase access to information on caregiver services and issues; and increase support for caregivers throughout the state. A statewide family caregiving network, newsletter and website are being developed to further the intent of the state project.

To ensure that family caregivers are indeed part of the ongoing planning process for the new family caregiver support program, the EOA contracted with the University of Hawaii's Center on Aging to conduct a statewide caregiver survey during the summer of 2002. Results will be used to help shape the state's next four-year state plan on aging (FY 2003–06) and to provide caregiver data to state leaders involved in Hawaii's long-term care reform efforts.

Because of the limited federal NFCSP funds coming to Hawaii, the EOA did not take a centralized or system's development approach during the start-up phase of the new program or require that all the AAAs provide all caregiver support services. Rather, the EOA gave the AAAs much flexibility in designing their caregiver support program so the EOA asked each of the four AAAs to come up with a plan for identifying which services would work best in each county and what outcomes to expect. Each AAA has conducted small-scale needs assessments and focus groups with caregivers. Services were slow to start up and were phased in over several months. The counties of Maui and Kauai started providing services in July 2001. Honolulu's start-up was in September 2001. On the Big Island of Hawaii, service delivery did not begin until March 2002.

Because of the wide disparity in funding for caregiver support at the local level, with the Honolulu AAA receiving nearly two-thirds of the federal NFCSP funds for services in the state (\$410,000 per year) and the other three AAAs receiving NFCSP funds ranging from only \$62,000 to about \$97,000 per year, the EOA did not recommend that each AAA establish a caregiver coordinator or specialist position. Both the Honolulu and Big Island AAAs hired designated caregiver specialists.

Most rewarding: Key informants noted that the most rewarding aspect of the program's development has been the recognition of family caregivers as a "new constituency" in the state. The federal funds, although very limited, have allowed Hawaii to begin focusing specifically on the needs of family caregivers.

Biggest challenge: State officials acknowledged that the program has been hard to "get off the ground" because of the limited federal funds and the "push to spend the dollars so quickly." Respondents expressed frustration in the lack of overall guidance from the federal government, particularly in data collection, program evaluation and outcomes.

FUNDING

In FY 2001, the first year of federal funding under the NFCSP, Hawaii received \$564,300 in federal funds. The majority of the federal funds were carried over to the next fiscal year. In FY 2002, the federal share of the NFCSP was increased to \$639,540, or only about 6% of the EOA's \$12 million budget.

In contrast, Hawaii's expenditures for the state-funded home and community-based care program, Kupuna Care, administered by the EOA, was \$4.4 million in FY 2001 and \$4.9 million in FY 2002. In FY 2001, the total cost of services under the two Medicaid Aged/Disabled waivers administered by the DHS was \$38.3 million. The state Medicaid official was unable to estimate the amount spent overall for respite care under the two waivers.

Hawaii received nearly \$39 million in tobacco settlement funds during FY 2000 and \$42 million in FY 2001. The state elected not to use these revenues to shore up state spending on Medicaid, expand home and community-based care or fund caregiver support services. Rather, the state has used the funds for health promotion and disease prevention activities through the Department of Health, to establish an emergency and budget reserve "rainy day" fund and, more recently, to help pay for the construction of a new medical school at the University of Hawaii.

Key informants generally described Hawaii's current budget situation as stable, with level funding and no impact to date on the new family caregiver support program. Hawaii has used state administrative funds from the EOA budget for the caregiver coordinator position and in-kind contributions from the AAAs to maintain the required 25% state match for the NFCSP funds.

Unlike other states, Hawaii experienced a budget crisis beginning in 1994, and in the mid- to late 1990s, major service cuts were made to health and social service programs. Several state leaders and stakeholders expressed apprehension about next year's budget. The economic downturn on the U.S. mainland will likely adversely affect Hawaii's tourism industry, which is a major source of state revenue. There is real potential for a major economic slump, yet again, in Hawaii.

PROGRAM ADMINISTRATION

The EOA sees its role in the development and implementation of Hawaii's first statewide caregiver support program to be in the areas of oversight, needs assessment and evaluation to ensure that family caregiver support services are integrated into the state's long-term care system. One state official commented that caregiver support is "extremely politically attractive." Respondents noted that during the program start-up phase, policy development has been a joint undertaking between the EOA and the four AAAs. One observer noted that the next phase of program implementation, when the state attempts to implement a systems development approach to caregiver support services, will be more difficult.

The EOA has focused its resources on gathering a range of information on family caregivers to aid in understanding the "big picture" and examining what is possible for Hawaii to accomplish. By partnering with the University of Hawaii's Center on Aging to conduct a statewide caregiver survey, the EOA hopes to better understand "what works and doesn't work for Hawaii's families." Through the state's caregiver coordinator, the EOA has an important presence, serving as a linkage to community groups and agencies throughout the state.

The Medicaid waiver respondent did not identify a role for the DHS with regard to caregiver support services in Hawaii and noted that the department was not involved in the planning process for the new federally funded family caregiver support program. The respondent stated that policies are not developed specifically for family caregivers in the Medicaid waiver programs, because the focus is on the care recipient (i.e., the client).

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Family caregiver support program: Eligibility for Hawaii's caregiver support program is consistent with federal requirements under the Older Americans Act: family or informal caregivers of any age who provide care to persons ages 60 and older, as well as caregivers ages 60 and older who are caring for children ages 18 or younger.^c For respite and supplemental services, the older person (age 60+) must need help with at least two activities of daily living (ADLs) or have cognitive impairment. The family caregiver is considered the client in the new program.

State officials noted that the EOA's caregiver coordinator is developing a family caregiver network across Hawaii to develop a coordinated system of information on caregiver issues. There will be no age requirement to participate. Using its state funds, Hawaii will thus be able to go beyond the federal age restrictions and involve family caregivers who are caring for adults under the age of 60.

While Hawaii's Kupuna Care program has a uniform intake/assessment process, the EOA has not yet established uniform assessment standards for Hawaii's AAAs or required the AAAs to utilize a common intake form for the caregiver support program. The EOA has encouraged all AAAs to use the Kupuna Care common intake form more broadly for family caregivers as well, but few AAAs have adopted this approach. Because of the small level of funding overall and the very early stage of program development, respondents noted each AAA is utilizing its own methods and forms. The county of Hawaii is currently developing an automated caregiver assessment tool.

Kupuna Care: To be eligible for Hawaii's state-funded home and community based services program, Kupuna Care, a person must meet the following requirements:

- ❖ Be age 60 or older
- ❖ Not be covered by a comparable government or private service
- ❖ Not reside in an institution
- ❖ Have two or more ADL/IADL (instrumental activities of daily living) limitations or substantive cognitive impairment
- ❖ Need help with one or more identified limitations in activities of daily living

Each AAA contracts with locally based case managers to make eligibility determinations and develop care plans for clients. The AAAs also contract with service providers who deliver direct services. The intake and assessment tool focuses on the care recipient. As part of the assessment process, the extent of informal care and the ability of the family caregiver to provide care are taken into account in the authorization of paid services for the care recipient.

^c Including caregivers 60+ who are caring for children who are affected with mental retardation or who have developmental disabilities.

Medicaid waivers: Eligibility for the two Aged/Disabled waivers are based on income level (supplemental security income, or SSI), functional criteria (Medicaid nursing home level of care) and age (18+ for the RACC waiver and all ages for the NHWW waiver). Consistent with Medicaid policy, the care recipient is the identified client in the program. The case management team includes a social worker and a nurse who are employed by the DHS. The case managers reassess every six months and call the client monthly. One observer noted that even though the focus is on the care recipient, the family caregiver is oftentimes part of the assessment process.

The state has no uniform assessment standards for the waiver programs. Some waiver programs are using a common assessment tool, such as the NHWW waiver, and include questions about the family caregiver's ability to provide care. Consistent with Medicaid policy in general, respondents noted that the extent of informal care is always taken into account in the authorization of paid services for the care recipient. The assessment tool for the NHWW waiver focuses on both the care recipient and the family caregiver. It includes questions about informal support in general and about the primary family caregiver in particular. For example:

- ❖ Data are collected about the type of help provided to the care recipient by family, friends and neighbors; name and age of the caregiver; relationship to the care recipient and employment status and number of days and hours the caregiver works.
- ❖ Data are collected about the primary family caregiver, including name, age, relationship to care recipient, ability to read, ability to work and employment status and work hours.
- ❖ The primary family caregiver is asked 12 yes/no questions to assess his or her ability to provide care, regarding such things as whether the caregiver has other family responsibilities, has health problems that impact caregiving or has difficulty making decisions.
- ❖ The primary family caregiver is asked the open-ended question, "What would you do if you were unable to care for the care recipient?"

SERVICES

Hawaii offers limited home and community-based services and support for family caregivers through its state-funded Kupuna Care program and the Aged/Disabled Medicaid waivers, as well as through the new federally funded family caregiver support program.

Family caregiver support program: Given the very limited federal NFCSP funds in Hawaii, the state did not mandate that each AAA provide all caregiver support services. Each AAA has the flexibility to provide a different package of caregiver support services based on local needs and resources. Limited respite care, individual counseling and supplemental services are available in every AAA region, however. According to several stakeholders, family caregivers' access to support services varies widely from county to county (i.e., island to island), with services unevenly distributed across Hawaii. Statewide, all five categories of services are funded: information, assistance, counseling/support groups/training, respite care and supplemental services.

At the time of the site visit, Hawaii's AAAs were utilizing diverse approaches to provide caregiver support services. The Hawaii AAA on the Big Island is developing a family consultation program to provide information and support to family caregivers and assist them through the long-term care system, for example. On Kauai, a series of caregiver training programs is being developed. In Honolulu and on Maui, case management is being offered to family caregivers.

Supplemental services are a key component of Hawaii's caregiver support program and are, according to several state officials and stakeholders, filling an important gap in service delivery. On the Big Island, the Hawaii AAA has paid for the installation of lifeline emergency response equipment in one home, for example, so that a family caregiver could return to work and have peace of mind that her loved one was safe. In another case, the AAA has paid for bookkeeper services for a caregiver who needed help in managing day-to-day household finances. In Honolulu, the AAA is providing transportation services for a caregiver that are not related to the care recipient's medical needs.

The state and the AAAs have generally taken a low-key approach to publicizing the program because of the limited federal funds in the start-up year. There are no waiting lists for services at this time. Unlike other "new" states that are providing explicit caregiver support for the first time, Hawaii elected not to require the AAAs to pool a proportion of their base allocation for joint activities with statewide impact. State officials expressed interest in pursuing this option if Hawaii receives additional federal funds under the NFCSP to provide caregiver support.

Kupuna Care: This state-funded program served about 5,300 older persons in Hawaii in 2001, with a waiting list of nearly 500 older persons. According to state respondents, the waiting list has since been reduced because of the new federal funding for family caregiver support services. In the Kupuna Care program, services are designed to be "client centered and family supportive," allowing older adults to live at home with independence and dignity.¹⁴ Each AAA contracts with local private sector providers for the delivery of eight core services: adult day care, assisted transportation, attendant care (i.e., companion assistance), case management, chore services (e.g., yard work), home-delivered meals, homemaker services, and personal care. Interestingly, although the program is intended to be "family supportive" and implicitly assists family caregivers by offering them relief through adult day services and personal care, etc., respite care is not an explicit, covered service.

Medicaid waivers: Hawaii's Medicaid NHWW waiver does not differentiate between personal care, nursing and respite. Thus, Hawaii likely provides more respite care under the NHWW Medicaid waiver than is reflected in reports. The waiver program used to cap the amount of respite for family caregivers but stopped doing so about five years ago. When hours of benefits are assessed, a care recipient who has good family support will likely get fewer hours of service. Key informants noted that Hawaii's NHWW Medicaid waiver also covers other services that can help the family caregiver, such as home modifications and adult day services. There are 1,055 clients served under the NHWW waiver.

Under the state's RACC Medicaid waiver, respite is also a covered service. Care recipients may be served in an assisted living facility or in a family home that provides personal care, homemaking services and transportation as needed. Individuals may also receive private-duty nursing services, respite care and/or adult day health services as needed. This waiver, which serves 845 clients, is the most popular in Hawaii and has a waiting list for program authorization.

Major services needed by caregivers: State officials and stakeholders viewed respite care—in a variety of formats (e.g., overnight, weekend options) and in sufficient amounts to make a difference in the quality of life for the caregiver—as a major need of caregivers. Counseling was another major need identified by both state officials and stakeholders. Stakeholders noted several other service needs, including information and access to services to help caregivers navigate the long-term care system

(particularly in rural areas and for Native Hawaiians) and financial relief. Stakeholders also believed that the supplemental services allowable under the NFCSP were critical to the well-being of family caregivers. Last, state officials also identified the ongoing need for caregiver education and training, specifically for skills-based training.

Findings from a 1995 Alu Like survey conducted among Native Hawaiian family caregivers indicated that caregivers were generally knowledgeable about available services in the community but were reluctant to use services, primarily because of cultural values. Service utilization was low because of attitudes that such home and community-based services were “not for Hawaiians” and also because of the stigma and shame attached to asking for help and using services. Further affecting service utilization was the notion of “family members being neglectful of their *kupuna* [elder] by having them turn to strangers to meet their needs.”

Table 2. Family Caregiver Support Services in Hawaii

Program	Family Caregiver Support Program	Kupuna Care	Aged/Disabled Medicaid waivers ^a
State Administrative Responsibility	Executive Office on Aging, Department of Health	Executive Office on Aging, Department of Health	Department of Human Services
Local Service Delivery	AAAs ^b Subcontractors for case management Service providers/contractors	AAAs Subcontractors for case management Service providers/contractors	State nurses & social workers for assessment & case management Service providers/contractors
Funding Source	Older Americans Act, Title III-E State General Fund ^c	State General Fund	Medicaid 1915 (c) waivers
Expenditures FY 2001	\$564,300—federal (for all caregiver support services) \$113,000—state (Caregivers Resources Initiative Project)	\$4.4 million	\$38.3 million
Client Population	Family & informal caregiver	Care recipient	Care recipient
Eligibility Criteria:			
Age	60+ care recipient Family caregivers of persons 60+	60+ care recipient	NHWW: all ages RACC: 18+
Income	None	Cost sharing for clients about 150% of poverty	SSI level 100% of poverty
Functional Ability	For respite & supplemental services only—at least two ADLs or cognitive impairment for care recipient	2+ ADLs/IADLs or significantly reduced mental capacity 1+ unmet ADL/IADL need	Nursing home level of care
Uniform, Statewide Caregiver Assessment	No	No (uniform intake/assessment for care recipient only)	No (uniform care recipient assessment only)

a Two Aged/Disabled Waivers: Nursing Homes Without Walls (NHWW) and Residential Alternative Community Care (RACC).

b AAAs = Area Agencies on Aging.

c For EOA Caregivers Resources Initiative Project, including the EOA Caregiver Coordinator position.

Table 2. Family Caregiver Support Services in Hawaii (continued)

Program	Family Caregiver Support Program	Kupuna Care	Aged/Disabled Medicaid waivers
Service Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies) ^d	None ^e	Respite care Home modifications
Respite Care	None	None	None
Consumer Direction	Not formally. Some elements of consumer direction are offered. Family caregivers can purchase goods & services (e.g., consumable supplies, home repairs) under the supplemental services category.	No	Yes
Family Caregivers Paid as Respite Providers	No	No	Yes

^d All services provided in Hawaii, however, each AAA does not offer all services.

^e Although respite isn't a covered service, the care recipient does have access to limited adult day services.

CONSUMER DIRECTION

Neither the new NFCSP in Hawaii nor the state-funded Kupuna Care program offers a formal consumer-directed option, nor do these programs pay family caregivers to provide care. Respondents commented that there has been a perception in the state, slowly changing, that quality control would be lost if consumer direction were allowed and if clients could hire, manage and fire their own workers, including family members.

Key informants noted that the state has not adopted any policy on payment to family caregivers for respite care under the NFCSP. Even so, the AAAs, for the time being, are not offering this option. All of Hawaii's AAAs contract for respite services with local agencies and providers only; families cannot hire their own respite provider and serve as the employer, except in Honolulu, where respite subsidies are available. The EOA observers acknowledged that some elements of consumer direction are available through the provision of NFCSP supplemental services, which allow families to purchase goods and services that they need to keep their relative at home.

Hawaii is in the early stages of considering consumer direction as an option in its home and community-based service system. The EOA is planning to implement a state-funded demonstration on consumer direction in Kupuna Care, beginning in July 2003, to allow family members to be paid to care for their older relatives at home. One EOA respondent commented that "we have to be able to pay family caregivers. Not every family member can afford to quit a job to give care. It may mean the difference [between] keeping someone at home or placing them in a nursing home. This is particularly important in rural areas where there simply are no providers."

Consumer direction *is* offered under the Aged/Disabled Medicaid waivers, allowing care recipients to hire their own personal care attendant or respite worker, including neighbors, friends or family. Because of severe workforce shortages in the state, consumer-directed services, including the hiring of family members, are becoming more widely used. Respondents noted that under the consumer-directed option, family members provide about 90% of care. In Hawaii, the state serves as the fiscal intermediary for the consumer-directed component. Checks are issued in the worker's name but are delivered to the care recipient's home.

Family members can also be paid to provide personal care under Hawaii's Medicaid waivers. Consistent with federal policy, spouses or parents of minor children cannot be paid under the waiver programs. No formal training is required for family members, and criminal background checks for family caregivers are not required either.

QUALITY ASSURANCE AND EVALUATION

Hawaii is utilizing the AoA's minimum data collection requirements for the family caregiver support program: type of service to caregiver (e.g., information, assistance), number of caregivers served by type of service, units of service provided (e.g., information contact, respite hours) and expenditures per service type. Caregiver demographics are also collected, but not consistently across all four AAAs. At this early stage of program start-up, each AAA is collecting different caregiver information based on its interests and resources. The Honolulu AAA, which has by far the largest funding, for example, conducts psychosocial caregiver assessments. In contrast, the Maui AAA, with very limited funding, collects only basic demographic information on the caregiver (e.g., age, gender). The EOA will be working with the AAAs to standardize data collection across the state.

EOA respondents expressed frustration that their current data collection practices under the new family caregiver support program are not as standardized or complete as they would like. Without a consistent, outcomes-oriented data set for all AAAs, state officials acknowledged that they will be hampered in their efforts to advocate for caregiver issues in the larger context of long-term care reform. Currently, the EOA and the AAAs are in the process of automating data collection with both SAMS 2000 and Beacon software that will allow all EOA-administered programs to utilize a uniform service utilization and client tracking system. At the time of the site visit, the Hawaii AAA on the Big Island was the only AAA to have implemented the automated tracking system. All the AAAs and the EOA had purchased the software and received training.

Outcome measures vary from AAA to AAA, and there are no statewide standards. Some AAAs focus on caregiver outcomes; others do not. The Honolulu AAA plans to examine caregiver outcomes through its assessment process. Caregivers who receive services through their AAA will be pre- and post-evaluated on level of well-being and stress. The University of Hawaii's Center on Aging has evaluated the state-funded Kupuna Care program through a client satisfaction survey and plans to assist the EOA by conducting a caregiver satisfaction survey.

Under Hawaii's Aged/Disabled Medicaid waivers, family caregiver information is not specifically tracked. Although the case managers collect caregiver information as part of the assessment process of the care recipient, the data are not aggregated by DHS. The waiver programs use a paper format to collect information; reporting is not yet automated, but this is planned.

SYSTEMS DEVELOPMENT

Respondents, both state officials and stakeholders, commented that the first year of start-up and implementation of the new caregiver support program has been one of "testing" and experimentation to determine what works and what does not work, particularly in providing culturally appropriate services on each island. One stakeholder commented that the challenge "is to integrate the NFCSP into the wider Older Americans Act so that we don't have one program focusing on the older person and one on the family." Several respondents noted that there has been much confusion statewide about "who is the client—the older person or the family caregiver—and with limited resources, who is the priority"?

The state has taken a decentralized approach to program development, allowing Hawaii's AAAs much flexibility to shape their caregiver support services to meet the local needs of family caregivers and to integrate service delivery with Kupuna Care. After the first full year of implementation, the EOA and AAAs will identify "best practices" to shape statewide policy. The Hawaii AAA on the Big Island intends to regionalize services and establish caregiver resource centers in nine rural areas of the island, for example. State officials noted that they will look closely at this model to see if it could be replicated on the neighbor islands.

The EOA caregiver coordinator is taking a lead role in coordinating caregiver information and support at the state level and is serving as a resource to the AAAs. She is also examining what other states are doing to support families to help shape Hawaii's policies and programs, reviewing caregiver training curricula for replication and building a broad-based caregiver coalition throughout the state.

Hawaii does not have a body whose mission is coordination of family caregiver support services across state departments. Through the efforts of the caregiver coordinator, the EOA is taking the lead to develop a roundtable coalition to involve key stakeholders from other state departments (e.g., DHS) and the private sector. The Medicaid waiver respondent acknowledged the need to increase coordination across state departments as well as at the local level. Several other stakeholders noted that, although there has been minimal communication between aging and Medicaid services, this is beginning to change as Hawaii works to expand home and community-based services.

The state’s intent is to integrate caregiver support services into Hawaii’s other long-term care programs and to build on the infrastructure already in place. The challenge in Hawaii, commented several respondents, is that the home and community-based care system has few resources to meet the needs of the family—be it the older person or the caregiver.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

In May 2000, the Hawaii legislature passed a concurrent resolution to establish an *Olmstead* planning task force. In response, the state set up a planning committee chaired by the directors of the Departments of Human Services and Health and the executive director of the Center for Independent Living.¹⁵ The EOA executive director is a member of the planning committee. Family caregivers are involved in the planning process, primarily representing families in the Mental Retardation/ Developmental Disabilities system. Key informants noted that family caregiver issues for the elderly have not been a focus of the planning discussions.

The committee’s top priority is information management: to increase awareness of what resources are available and to develop a single point of entry for the long-term care system. Hawaii’s planning effort, through its Systems Change grant noted earlier in this report, is also focusing on developing a uniform assessment tool to better identify who is eligible for what services and to link assessment to the information management system being developed.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, “Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?” As shown here, respondents disagreed in their assessment of caregiver support as a state priority. EOA officials generally felt the priority was “low,” although the Medicaid official gave “high” priority to caregiver support in the state. Stakeholders, on the other hand, tended to express either “low” or “medium” priority.

Number of Key Informants	Priority on Caregiver Support
4	→ Low
2	→→→ Medium
2	→→→→→ High

Benefits and challenges: Hawaii's key informants identified four aspects of their program that are most beneficial to family caregivers:

- ❖ Respite care—to give families a break, particularly for family caregivers not eligible for respite under the Medicaid waivers
- ❖ A broad menu of caregiver support—to provide information, assistance and caregiver training designed specifically to meet the needs of family caregivers
- ❖ Flexibility—to design caregiver support services to meet the individual and culturally appropriate needs of Hawaii's diverse families
- ❖ Under the Medicaid waivers, personal care and nursing—to relieve the family caregiver

The following challenges were reported:

- ❖ Very limited funding to develop a statewide caregiver support program
- ❖ A severe labor shortage; a lack of trained direct-care workers, particularly on the more rural and isolated neighbor islands
- ❖ The need to develop a new program with a “new constituency”
- ❖ Lack of a uniform service package across the state; some neighbor islands don't have all the support services; not all islands have the same capacity and trained staff

Major lesson learned: The view of Hawaii's state leaders is “don't make assumptions that we know what caregivers want.” Respondents emphasized the importance of conducting caregiver assessments and developing services that are individually driven and culturally appropriate, rather than “menu driven.”

Opportunity for expanding caregiver support: Hawaii's state respondents were split on their views on expansion of caregiver support over the next three to five years. At the EOA, state leaders were generally optimistic and expressed the view that “the economy will improve and we will have successes. The legislature will be compelled to fund caregiver support programs as the baby boomers age.” At the DHS, on the other hand, the respondent was more cautious and pessimistic, commenting that “Hawaii has no money. The state is heavily dependent on tourism, and the legislature won't tax.”

Recommendations for other states: State respondents offered several recommendations, based on their experience to date:

- ❖ Have adequate funding and staff before you advertise the program and services.
- ❖ Address the issue that caregivers don't self-identify and often don't recognize the term “caregiver” as applying to their family situation.
- ❖ Collaborate with other groups and form partnerships to meet the needs of the caregiver.
- ❖ Develop targeted training to meet the individual and culturally appropriate needs of families.
- ❖ Ensure flexibility in service design and delivery at the local level by offering a wide service package with options to meet caregiver's individual needs.
- ❖ Conduct caregiver assessments and ask caregivers what they need.

NOTES

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