

State of Hawai`i Family Caregiver Needs Assessment

Prepared for the Joint Legislative Committee on
Family Caregiving

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Executive Summary

Introduction

The purposes of this survey, undertaken by the Joint Legislative Committee on Family Caregiving in 2007, are to estimate the prevalence of informal (unpaid) caregiving in Hawai'i, establish the characteristics of caregivers and their care recipients, specify the services used and not used by caregivers, assess the impact of providing care on caregivers' health and well-being, and estimate the costs of care and determine the effects, if any, on employment. Caregivers were also given an opportunity to suggest the degree to which they might support any anticipated public policies designed to assist them.

Methodology

The original version of the instrument used for this survey was developed in 2001 by gerontology researchers from California as part of a national data collection effort for the Family Caregiver Support Project. It was modified in 2007 for data collection in Hawai'i to include additional information on certain areas of interest in this state including service use preferences, the cost of caregiving, more detail on employed caregivers and benefits provided by employers, and opinions about public policy options to support caregivers.

A probability sample was collected of caregivers in the fall of 2007. Potential respondents were identified by random digit dialing, and a set of screening questions was used to identify caregiving households. These included a determination that: (1) this was a caregiving household, (2) at least some assistance with activities of daily living (ADL's) and/or instrumental activities of daily living (IADL's) were needed by the care recipient, and (3) the person providing care was unpaid. Caregivers on neighbor islands were over sampled in order to make between-county comparisons. Sample size was 300 in Oahu and 100 each in Hawaii, Maui, and Kauai counties for a final sample of N=600. Following data collection, files were re-weighted to reflect population data utilizing 2006 Census Data Estimates.

Results

Demographics

In Hawai'i over one quarter (26.1%) of the households contain at least one individual providing care for older adults over 60. Over seventy-three percent (73.6%) of the caregivers are female and the remaining 26.4% male. The average age of the caregivers is 54. Well over half (almost 55.9%) are caring for an aging parent, followed by

16% caring for a spouse. Just over one quarter of caregiving households (27.5%) include children under 18. On average, caregivers in the sample have lived in Hawai'i for 30 years and most (82.5%) are caring for only one person. Median household income is in the \$30,000 to \$35,000 range.

Among care recipients, over half the sample (57.1%) required assistance with personal care, but up to 85% of the sample required assistance with instrumental activities of daily living, such as shopping and transportation. The most common chronic condition was hypertension with arthritis being second, followed by severe memory impairment at third.

Providing Care and Service Use

Caregivers had been caring on average for 1-5 years and provided over 20 hours a week of care, although almost 30% reported providing constant care. Very few (less than 10%) used any paid help, but 7% to 25% of the sample were actively using one of the community services mentioned. Most often mentioned was nursing, followed by training, case management, transportation, and legal services. Among the named reasons for *not* using services were having all the help needed, the cost of services, and the care recipient not wanting the services. Among unmet needs, caregivers cited most often the need for better medical care and respite services. Service utilization varied greatly by county, ethnicity, income, and hours of care provided.

Caregiving Impact

The questions on financial hardship, physical strain, and emotional stress were rated on a five point scale from 1 (no hardship) to 5 (a great deal of hardship). Financial hardship ranked lowest (2.15), next was physical strain (2.36); the highest ranked item was emotional stress (2.80). However, all of the mean scores reflect low levels of negative effects from caregiving.

Just over fifty five percent (55.8%) of the sample were employed and of these, over one quarter (26.8%) said that their employment had been affected by caregiving responsibilities. Among these respondents, over half (55.2%) said they reduced work hours in response to caregiving. Thirty-six percent said that they had turned down a promotion or taken a leave of absence. Among other impacts on employment, almost all respondents (94.3%) said they frequently rearranged their work schedules and over three quarters (77.9%) took time off during work to deal with caregiving responsibilities.

Eldercare benefits were perceived as being minimal. Unpaid leave, a benefit required by law, was mentioned most often, but only by 18% of the sample. The ability to work part time, have flextime options, and dependent care flexible allowances were each mentioned next, but by less than 10% of the employed sample. The most common response was that no eldercare benefits were offered.

Public Policy Opinions

Overwhelmingly, respondents favored changes in public policies to support caregivers; however there were differences in the level of support between groups. Overall, the highest ranked item was that government should provide a state income tax credit for caregiving, followed by a place for obtaining information and support. Women were significantly more likely than men to support most policies. Employed caregivers expressed a greater need than non-employed for more community services as well as expressing greater support for unpaid family leave and training and education. If the caregiver was an adult child, he or she ranked significantly higher the need for government support in nearly all areas including more community services, more respite services, tax credits, and paid and unpaid family leave. Younger caregivers were also more likely to support a paid family leave program and respite programs, as were those who had taken a leave of absence from work. Finally, there were significant differences by county with Hawai`i County significantly more likely on almost every item to say that government should support family caregivers.

Multivariate analysis showed that consistent predictors of emotional stress, physical strain, and financial hardship included: the caregiver having interrupted sleep, the care recipient requiring assistance with personal care, the care recipient having severe memory or behavior problems, and the number of hours per week the caregiver provided care. In turn, each of these types of caregiver burdens were highly predictive of support for public policy interventions to support caregivers. In other words, as levels of burden rose, so did the likelihood of positive endorsement of the measures listed in the survey.

Table of Contents

Introduction.....	5
Background.....	6
Methods.....	8
Results.....	10
Discussion and Conclusions.....	16
Tables.....	21
Bibliography.....	44

Introduction

Act 204, Session Laws of Hawaii 2007, required the Joint Legislative Committee on Family Caregiving to conduct a comprehensive needs assessment of the needs of family caregivers and care recipients who are age 60 and older with physical or cognitive disabilities. A contract to conduct the needs assessment was awarded to Pacific Research and Planning Associates, and second contract was awarded to the University of Hawaii School of Social Work to analyze the data. This report represents Part 1 of a two part series. Part 1 is the analysis of the needs assessment of family caregivers; part 2 is the analysis of the needs assessment of care recipients.

While a small portion of the elderly in the U. S. is cared for in institutional long term care settings, informal (unpaid) caregivers provide the vast majority of the needed care (AARP/NAC, 1997; Robinson, 1997). For many years it was felt that this was a personal issue with costs (physical, financial, and emotional) to be borne by families and elders themselves. However, the way in which the care needs of elders will be met at a time when changes in family structure are occurring through modernization, urbanization, and the changing role of women is a now becoming a very real issue. What should the role of the public sector be in caregiving? This is an issue that legislative bodies are only beginning to address (AARP 2002b; Cooney & Di, 1999; Brewer, 2001; Spitzer, Neufeld, Harrison, Hughes & Stewart, 2003).

Estimates of the prevalence of caregiving in Hawai'i have suggested that between 14% - 21% of Hawai'i's adult population or between 126,598-192,390 people provide care or assistance to a person age sixty or older (Executive Office on Aging, 2006). Approximately 115,000 family caregivers provide personal care to persons aged 15 years old and older, for an estimated total of 107 million hours (Arno and Memmott, 1997). While these estimates include caregiving to persons with disabilities aged 15 and over, they illustrate the extent of informal caregiving.

The purpose of this survey undertaken by the Joint Legislative Committee on Family Caregiving in 2007 was to estimate the prevalence of caregiving in Hawai'i as well as to gain an assessment of the impact on caregivers' health and well being, the costs of care, and effects on employment. Finally, it was an opportunity for caregivers to express their needs and preferences for community services as well as the degree to which they might support any anticipated public policies designed to support their efforts.

Background

The prevalence, extended length, and commitment to family caregiving have been well documented in the literature (AARP, 1997; Brewer, 2001; Knight, Robinson, Flynn, Longmire, Nakao & Kim, 2002). However, in the 1990's, care patterns began to change, even in Asian countries, where there is a centuries old established system of elder care. Given the unusually high population of Asian and Pacific Islander elders in Hawai'i, these studies are of interest. Recent research indicates in countries as diverse as India, Indonesia, Taiwan, Korea, Japan, and China (including Hong Kong) that the patterns of familial caregiving are beginning to be altered (Liu & Kendig, 2001; Asahara, Momose & Murashima, 2002). These changes can be traced to several different sources.

First, declines in fertility rates have fueled the growth of the elderly population. Second, the availability of pensions and retirement income have increased elder's preferences for independence, and fewer live in intergenerational settings than they did in the past. Another change is that in the past the vast majority of informal caregivers have been women (AARP, 1997; Velkoff & Lawson, 1998; Brewer, 2001; Liu & Kendig, 2001). However, emerging trends, such as the increasing number of women in the workplace, the economic and emotional disincentives for co-residential caregiving, and the increased lifespan of elders, which proportionately increased the years of chronic illness, make it likely that female informal caregivers may be in increasingly short supply (Pezzin, Kemper & Reschovsky, 1996). Finally, the supply of adult children available for caregiving is also decreasing. As the current post WWII cohorts age, fewer children will care for them than is the case with the current group of elders. We are facing an unprecedented period of time (from about 2010 to 2030) with more elders, a changing family structure that does not easily accommodate co-residential caregiving, and a potentially smaller available pool of informal caregivers.

However, this crisis requires addressing not only because there will be elders without care but also because there are major consequences for those people who undertake the role of caregiver.

Burden and Stress

One of the most well documented effects of caregiving is what has come to be termed by researchers as "caregiver burden." This is characterized by a sense of loss of privacy, periods of irritability, a constant sense of demand, and no time for oneself. Early studies on

this topic suggested that up to 50% of caregivers indicated they were under severe strain (Schulz, Williamson, Morycz & Biegel, 1993; Pearlin, Mullen, Semle, Skaff, 1990; Dunkin & Anderson-Hanley, 1998), and caregivers who lived with the person cared-for experienced the highest amount. While there is almost no research on Pacific Islanders and caregiving, research on Asian caregivers report social pressure to retain their role and resultant increases in their sense of burden (Zhan, 2002). The more intense commitment to “familism” (Shin, 1999; Knight, Robinson, Flynn et al., 2002) among Asian caregivers may actually increase, not decrease, their sense of burden. In Asian families parents still expect filial care, including living with their child if they so desire, while their children may express that they are no longer able or willing to accommodate them (AARP, 2001).

High levels of stress are also associated with caregiving. Stress is differentiated from burden in that it relates to those already stressful areas of life that may be made worse by caregiving, such as employment or finances. Caregivers across cultures characterize these feelings as trying to balance the demands of family or job/school with elder care and financial worries (Scharlach, 1994; Janevic & Connell, 2001; AARP, 2001; Youn, Knight, Jeong & Benton, 1999). Among Asian caregivers, there are also reports of physical deterioration, financial strain (expressed as monetary restrictions) as well as negative emotions (Ngan & Chen 1992; Holroyd, & Mackenzie, 1995; Holroyd, 2005).

Physical Strain

The effects of caregiving on the physical health status of caregivers is less well documented than emotional effects; however research indicates that between one-tenth and one-third of informal caregivers report health problems. These studies indicate that the most common physical complaints among caregivers are (1) not getting enough rest; (2) not having enough time to exercise; (3) no time to recuperate from illness; and (4) forgetting to take prescription medications (Cattanach & Tebes, 1991; Schulz, Visintainer & Williamson, 1990; Moritz, Kasl & Ostfeld, 1992; Cooney & Di, 1999). Health consequences such as exhaustion, fatigue, and sleep deprivation are consistently reported especially by caregivers of people with dementia (Moritz, Kasl & Ostfeld, 1992; Teel, 1999). Caregivers also consistently report delaying needed medical treatment due to a lack of options for juggling caregiving responsibilities with a lengthy recovery period (Conway-Giustra, Crowley & Gorin, 2002; Cohen, Miller & Weinrobe, 2001).

Impact on Employment

In recent studies, it is estimated that nine percent of U.S. caregivers quit their jobs to provide care. For adult daughters, this number rises to 12 percent (National Alliance for Caregiving, 1999). Less dramatic effects of caregiving on employment include the utilization of leave and vacation hours for caregiving emergencies, making informal adjustments to work schedules, taking time off during the work day, turning down chances to work on special projects and work related travel (National Alliance for Caregiving, 1999; Max, Arnsberger Webber & Fox, 1995). As the number of male caregivers, especially Asian male caregivers, seems to be on the increase (Arnsberger, 2003; Arnsberger & Sato, 2005) this impact will become greater.

In spite of these negative findings, recent work on the effects of caregiving suggests that caregivers are improving in their abilities to manage care. Braus (1998) and others conclude that many of those caring for elders, even those who were employed, emerged as busy, capable people with an optimistic point of view (Braus, 1998; AARP, 2001; National Alliance for Caregiving, 1999). Similarly, while some subsets of the sample were reporting feelings of burden, more than 70 % of the AARP multicultural survey respondents felt capable of handling all of their family caregiving responsibilities even when it included both elders & children (AARP, 2001).

Methods

Instrument Development

The original instrument utilized in the study was developed in 2001 by a team of gerontology researchers from the University of California at Berkeley and the University of California at San Francisco as part of a national data collection effort for the Family Caregiver Support Project. It was modified in 2003 for a data collection effort in the People's Republic of China and again in 2007 for data collection here in Hawai'i. The instrument covers the following domains:

- Caregiver and care recipient demographics, including gender, age, income, education, marital status, and current living arrangements;
- Care recipient's ADL and IADL impairments and chronic conditions;
- Community service utilization patterns, reasons for not using services, and other services that might be useful;

- Characteristics of the caregiving experience including tasks performed, paid and unpaid support for the primary caregiver, length and intensity of caregiving;
- Effects of caregiving including measures of physical, financial, and mental stress, as well as the cost of caregiving;
- Employment related questions including the impact of caregiving on employment and benefits provided by employers; and
- Opinions about public policy options to support caregivers

Data Collection

The study data were collected in the fall of 2007. A probability sample was collected of caregivers. Potential respondents were identified by random digit dialing. A total of 2,259 calls were needed to identify 600 caregivers who met the study criteria. A set of screening questions was used to identify eligible caregivers. These included a determination that: (1) there was a caregiver for someone 60 or over in the household; (2) at least some assistance with ADL's and or IADL's was needed by the care recipient; and (3) the person providing care was unpaid. Oral consent was obtained over the phone. A decision was made to over sample caregivers on neighbor islands in order to have the ability to make between-county comparisons. Final sample size was 300 in Oahu and 100 each in Hawaii, Maui, and Kauai counties for N=600.

Data Analysis

The first step in the analysis was to establish codes for data fields. Certain variables were summed or recoded for analysis. Raw data were used to generate frequencies for between-county results. This was done in order to have sufficient cell sizes to determine between-county differences. The data file was then weighted using county population estimates from the 2006 U.S. Census Bureau Projections for the State of Hawai'i. Univariate analysis (frequencies for categorical variables, and means, median, and measures of dispersion for continuous variables) provided the first results. All of the outcome variables of interest were then subjected to bivariate statistical analysis (Independent T Tests, Chi Square Tests of Association, and Analysis of Variance) to compare continuous, nominal, and ordinal data respectively by county, gender, employment status, or other category of interest.

Backward stepwise regression was used to generate three regression models to assess the relative importance of variables in the data set in predicting levels of emotional

stress, physical strain, and financial hardship. Several good models were developed for each of three outcome variables; the most parsimonious models (the fewest variables) with the most explained variance in the outcome variable (the highest adjusted R squared value) are presented in the results section.

Qualitative data (comments) were also analyzed with common themes established as well as categories within those themes.

Results

Demographics of Caregivers and Care Recipients

Utilizing U.S. Census Bureau estimates of the total population of Hawaii for 2006 (1,285,500) and U.S. Census Bureau data from the 2000 census of the mean number of people per household (2.9), it was determined that of the 443,275 households in Hawai'i, approximately 118,350 are caregiving households (Note: this does not necessarily mean that the care recipient lives with the caregiver). This number excludes those who are paid caregivers and those who are caring for someone under 60 unless they also were caring for an older adult.

As shown in Table 1, the average caregiver has had some college education. The distribution of gender shows that 73.6% of the caregivers are female and the remaining 26.4% male. The average age of the caregivers is 54. Both of these results are similar to the national averages in these areas. Well over half (55.9%) are caring for an aging parent, followed by spouse (15.7%). Over one quarter (27.5%) of caregiving households include children under 18; 14% specified they are caring for grandchildren. On average, caregivers in the sample have lived in Hawai'i for just under 30 years, and most (85.2%) are caring for only one person. Median household income is relatively low (in the \$30,000 to \$35,000 range), especially when compared to the median household income reported in the 2006 census estimates for Hawai'i of \$51,359.

For care recipients the mean age is approximately 80 years old, which is older than the national average of 77. Almost two-thirds (64.8%) of the care recipients are female; one third (32.8%) live alone, and approximately another quarter (each) live with the caregiver or in the home of another family member or friend. Only three percent reside in a nursing home, which is a reminder that almost all caregiving takes place in the community and not in an institutional setting.

Chronic Conditions and Functional Impairments

As shown in Table 2, over half of the care recipients (57.1%) needed assistance with personal care (bathing, dressing), and up to 85% needed assistance with most IADL's (shopping, transportation, arranging care, and getting medical care). Among chronic conditions, the highest percentage of the sample reported hypertension and heart disease, followed by arthritis and then dementia. An unusually high percentage (27.8%) also reported mental health problems. It is possible that some respondents considered Alzheimer's disease to be a mental health problem and not a type of dementia.

Providing Care

As displayed in Table 3, caregivers' mean scores reflect between one and five years of caregiving. Travel time, a predictor of caregiver burden, was less than 15 minutes for most of the sample. In addition, the caregivers report spending over 20 hours a week on caregiving. However, almost an additional 30% of the sample said they provided constant care. Well over half the sample of caregivers had assistance from other family members for an average of 6.7 hrs a week (in data not shown in the tables it was found that women had a significantly higher number of hours of assistance than men). Almost 70% of the sample said that someone else would help if they could not.

Community Service Utilization

As shown in Table 4, from 7% to 25% of the sample indicated they had used at least one of the named services. This is a much higher rate than other national studies that report service utilization rates across services at fewer than 10%. Most often mentioned as being used were nursing, followed by training, case management, transportation, and legal services.

Among the named reasons for *not* using services, the most often endorsed in the sample was having all the help needed, followed by the cost of services, and the care recipient not wanting the services. This ranking exactly replicates national studies.

Among the services they might wish to have, caregivers mentioned most often better medical care and respite services, followed by wheelchair or accessible transportation services. 'Other' items mentioned included more available and affordable community services, lower taxes, and financial assistance. Only 51 respondents (well under 10%) reported using paid help. Of those who did use paid help, it averaged 8.7 hours a week.

Service utilization patterns varied greatly by county (see Table 4a). In analysis not shown here (using a summed number of services), respondents in Maui County tended to be significantly heavier users of community services across the board ($P < .008$); Hawai'i was next (however, this was largely driven by the doubtful public assistance item – see Table 4), followed by Kauai and Oahu. Table 4b reflects this same analysis by other caregiver characteristics. There were also significant differences in service utilization patterns by ethnicity with Hispanic and Filipino groups ranking highest in service utilization, and Koreans, Chinese, and Samoans the lowest users. However, numbers in most of these groups were very low, so it is difficult to generalize. There were no significant differences in the total amount of services used by caregiver age, employment status, or education. However as income went up, service use went down and as hours of care increased, so did service utilization.

Effects of Caregiving

Physical and Mental Health Effects

As displayed in Table 5, the questions on financial hardship, physical strain, and emotional stress were rated on a five point scale from 1 (no hardship) to 5 (a great deal of hardship). The mean score for financial hardship was 2.12. Ranked second was physical strain (2.36) with the highest ranked item being emotional stress (2.80). However, all of these mean scores still reflect only low-to-not-quite-moderate levels of burden and are in line with recent national results which indicate that most caregivers report few negative effects from caregiving.

This minimal impact is reflected also in the next question which shows that nearly 80% of the sample (79.4%) reported no increase in physical or mental health problems from caregiving. The annual cost of care question was not answered by 81 people, which is often the case when income or financial information is being requested in these surveys. However, it appears that 60.7% of the sample who did respond spent \$5,000 or less on caregiving and the remaining 39.3% spent more than that.

In comparing selected effects of care, as well as caregiver characteristics across counties (see Table 5a), Oahu caregivers have significantly higher emotional and physical measures of stress and also rate very high on financial hardship. They do not stand out from other caregivers in age, income, travel time, employment status, being a spouse, or the hours of care provided. They did have the highest number of hours of paid help (which

is a relationship that has been observed before in the literature, the meaning of which is still unknown), and the highest percentage of caregivers listing themselves as providing 'constant care' but this last item was not a significant difference.

Employment Effects

As displayed in Table 6, over fifty-five percent (55.8%) of the sample was employed. Over one quarter (26.8%) said that employment had been affected by their caregiving responsibilities. The highest ranked main effect was that they reduced work hours (55.2%), followed by turning down a promotion or taking a leave of absence (just over 36% each). Highest ranked among other effects was that they had rearranged their work schedules (94.3%) and had taken time off during work to deal with caregiving responsibilities (77.9%). Despite these adjustments, they named far fewer employer eldercare benefits than the employers themselves mentioned in the 2007 Eldercare Survey of Hawaii's Employers. Unpaid leave was reported by 18% of the sample but for employers with over 50 employees, this benefit is required by law. The ability to work part time was tied with flextime and dependent care flexible allowances for second, but each of the three were mentioned by just under 10% of the sample. The most common response was that no benefits were offered.

Public Policies to Support Caregiving

Overwhelmingly, respondents favored changes in public policies to support caregivers (See Tables 7-7e). Government should provide a 'state income tax credit for caregiving' was ranked first with 94% of the sample endorsing this item. Government should provide a 'place for information and support' was second with 90.7% of the sample in support, and third was government should 'require employers to offer unpaid family leave' (88.9%).

By gender there were significant differences on almost every program or policy. Men ranked highest the unpaid family leave item, followed by support for the state income tax credit and then need for a place for information and support, while women ranked highest the state income tax credit for caregiving, followed by the need for more affordable community services (in other analysis not shown here, women were found to have a significantly lower income level than men), followed by the need for a place for information and support. Overall, women were significantly more likely than men to support six of the

policies mentioned and were close to significance on two more. Male caregivers have fewer expectations of government than do female caregivers.

By employment status, there were many significant differences. Employed caregivers were significantly more likely to endorse the need for more community services as well as support for unpaid family leave, a state tax credit for long term care insurance, training, more affordable services, case management services, a state income tax credit for caregivers, family allowances, and two of the three respite options. In all, employed caregivers endorsed more strongly nearly all of the 'government should' items than did the non-employed. (Note: In an addendum table, this analysis was repeated for those who reported being on a leave of absence from work. One hundred percent of these caregivers supported unpaid family leave, a state income tax credit for caregivers, that government should provide a place for information and support, and a paid family leave program.)

There were also major differences by the relationship of the care recipient to the caregiver. If the caregiver was an adult child, he or she ranked significantly higher the need for government support in nearly all areas, including the government providing a place for information and support, weekend respite services, a state income tax credit, more affordable community survives, a paid family leave program, a state income tax credit for LTC insurance, and unpaid family leave.

There were significant differences by county (see Table 7d). Hawai'i County was significantly more likely on almost every item to say that government should support family caregivers, and Oahu was often second.

There were significant differences by age. Results from this analysis are depicted in Table 7e. Each cell shows the mean age of the people who supported the item as compared to the mean age of those who did not. Almost always, younger caregivers were more supportive of the item than were older caregivers, with significant differences on overnight and weekend respite services, allowance to family members, a paid family leave program, and a state income tax credit for long term care insurance.

The results of the regression analyses are presented in tables 8, 9 and 10. Table 8 presents the results of the best set of variables explaining the variance in financial hardship. One-third of the variance (.331%) is explained by this model. The most significant predictor was the need for assistance with personal care followed by the number of hours the caregiver spent providing care. As this increased, so did the level of

financial hardship. Not surprisingly, the estimated annual cost of caregiving also showed a positive relationship to financial hardship. Of less impact but still significant were the sum of community services used and the care recipient having severe memory problems.

Table 9 presents the results of the best set of variables explaining the variance in physical strain. Well over half (57.9%) of the variance is explained by this model. The most significant predictor here was the care recipient had behavior problems, followed again by the number of hours the caregiver spent providing care. In both cases, as these increased, so did the level of physical strain. Next, in order of significance was the care recipient needed assistance with financial matters, then personal care, and sum of community services. Interrupted sleep was next most important, followed by care recipient needing assistance with medical needs.

Table 10 presents the results of the best set of variables explaining the variance in emotional stress. Over forty percent of the variance (40.5%) is explained by this model. The most significant predictor here is the care recipient having behavior problems, followed by the care recipient requiring assistance with meals and laundry. Number of hours of care provided during the week and being retired or on a leave of absence from work was next, followed by the need for help with financial matters. Interrupted sleep had the next highest impact on stress, followed by the sum of community services used and the need for assistance with personal care. Education approaches significance with more education predictive of higher stress.

Finally, independent T Tests were used to compare each type of burden with opinions on and support for government policies and interventions. In all cases but three, the higher the level of burden in any of the three areas, the more likely was the support for (or endorsement of) the policy change suggested.

Results of Qualitative Analysis

Caregivers were offered the opportunity to make any comments they wished and an estimated two thirds did. The comments tended to provide support for the quantitative results, but several additional themes were also established.

The first and most common theme expressed was a sense that the work was both welcome and demanding. People said things like “We will continue to help as long as is needed” and “Hard but rewarding.” These respondents made it clear that they would continue to provide help no matter what, but as one individual said “I like what I do, but I

need more help.” A subset of these people mentioned cultural and family values as their sustaining reasons for continuing to care; others just spoke about love.

The second most common theme came from people who identified as ‘middle class’ and wondered why they couldn’t get help. It was this group that repeatedly mentioned state income tax credits. One respondent said “People not using the system should get a tax break” and another said simply “Tax credit, tax credit, tax credit.” This group also mentioned that long term care insurance needed to be made more affordable and that better and more understandable medical and drug coverage would be welcomed. They also wanted more services that did not leave them out. One caregiver made a list: “More outpatient services, more community services, more case management, more transportation....”

The next group was probably a lower income group. They spoke about protecting SSI and felt the cost of care was overwhelming. They said even when they could find the services they needed, they couldn’t afford them. One respondent said “If we don’t find some way to deal with the financial burden of caregiving, it’s going to be too late.”

The need for more available information also came up as a major theme. People felt that they needed one place to turn for help. One individual said “I need help to find help!” and another said “I would like to have one state office for {caregivers} to find help.”

The need for a break came up next. These caregivers didn’t always use the word respite, but as one said “This takes a lot of effort! I need a vacation!” Other services mentioned specifically as being needed were better transportation services, interpreters, and the need for a statewide pool of available, affordable well-trained caregivers. Training was also mentioned as needed by family caregivers themselves.

There was also one group of caregivers who were clearly getting desperate. They spoke about the physical strains of caregiving as well as the emotional burden. They made comments like “It’s physically challenging” and “I am surviving so far but don’t know how much longer I can go on.” Another said “I do it for love but am tired and could use support, as the burden is all on me.” One just said “I have nothing more to add; I just need help ASAP.”

Discussion and Conclusions

While caregivers in Hawai`i are doing well overall in their ability to provide care, there are certain impacts on physical and mental health, finances, and employment, for up

to 30% of all caregivers. Although many of the findings are in line with national estimates, there are some exceptions.

First, caregivers tended to be lower income than expected, especially given the high cost of living in Hawai'i. The average annual household income in Hawai'i is \$10,000 to \$15,000 higher annually than the caregivers' median income. There is also a relatively high cost of care reported. These costs may be paid at least partially, however, by the elder's income or assets, and that must be taken into account. Still, in regression analysis, cost of care contributed to the caregiver's sense of financial burden. Therefore, although the financial hardship reported is not great, there may be more of an issue in Hawai'i than elsewhere to relieve the burden of the cost of care. Two other findings that support this are how often the need for more affordable community services was ranked highly (especially by women caregivers), and the item 'services cost too much' ranked second as a reason for not using services.

Second, there is a higher rate of service utilization in Hawai'i than has been reported in previous studies. The analysis shows that there is an inverse relationship between income and total units of services used. This analysis may mean that lower income caregivers are appropriately accessing community services for which they are income eligible in order to continue providing care in the community. If so, this access to services is a good trend, probably ensuring both a better quality of life for the care recipients as well as ensuring more cost effectiveness for society.

Third, there are few caregiver surveys that have asked direct questions about public policies. A much higher percentage than those greatly burdened by caregiving expressed the need for government support and assistance. Generally, three quarters or more of all caregivers surveyed would tend to support any efforts in this area and this was made doubly apparent by the qualitative results. While this support is across the board, there appear to be several groups who are differentially affected by caregiving. Adult children who are caregivers, women, and people who live on Oahu (in terms of caregiver burden, but Hawai'i ranks higher in public policy support), those who are employed, and those who are younger are more supportive of government help.

Further analysis showed no difference between male and female caregivers in financial, emotional, or physical burden from caregiving, hours of care provided, or impact on employment. The one difference is that women had a significantly lower income than

men ($P < .001$). Adult children may express a need for more assistance due to their employment status or younger age. For between-county differences, there are two possible driving factors. As noted above, Oahu does have more caregivers reporting constant care and Hawai'i County has a significantly younger caregiver population, a fact that is related to unmet needs.

Most highly endorsed across groups is a state income tax credit for caregivers. Close behind that is the need for government to provide a place for information and assistance, which is particularly relevant in terms of the current Aging and Disability Resource Center statewide implementation effort. Third is enforcing with employers a requirement to provide unpaid family leave. Few employed caregivers seemed to realize that this was a benefit they were entitled to if they worked in a medium to large size business. In addition, the need for more available and more affordable community services is repeated in several places.

The regression models tell us that those who provide more hours of care, including constant care, are experiencing more stress on every level. Additionally, the need to provide personal care and have one's sleep interrupted also produced negative effects. The estimated annual cost of care also increases financial hardship. Finally, the presence of severe memory impairment, and the behavior problems probably associated with it, is also significant predictors of negative outcomes. Caregivers who provide virtually constant care and caregivers of those with dementia may need special programs or assistance. (Note: The higher amount of community services used in each case is probably the result of higher levels of burden, not the cause)

Finally, the comparison of burden levels with endorsement of specific eldercare policies reveals that the measures of burden are valid predictors of support for change and are probably of use as part of any assessment of need for particular programs.

The results of the qualitative analysis revealed more fully the overwhelming level of support for government interventions of any kind. This sample of caregivers wants "the government to do something and soon". Another caregiver said "It's about time someone is trying to help us" and another respondent summed up his opinions by saying "Now that the legislature has asked what they can do, let's hope they do something good."

Paid Family Leave, Respite Care, Cash and Counseling

Three areas were subjected to further examination: paid family leave, respite care, and cash and counseling. Paid family leave is ranked in the bottom third (9th out of 13th) on the list of “government should...” items. However, opinions on this item did vary widely. Younger caregivers were significantly more likely than older caregivers to support paid family leave ($p < .001$), as do women (79.5% vs 75.5% of men), those who were employed (82% vs 74%), adult children by a huge margin (81.8% vs. 61.6%), and those who reside in Hawai`i county ($P < .011$).

Although tending to be ranked low in terms of government “should do” items, respite care also deserves more attention. As with paid family leave, age also matters in terms of respite care. All three type of respite (daytime, overnight, and weekend) were supported more strongly by younger caregivers ($P < .114$, $P < .043$, and $P < .021$ respectively). In addition, more burdened caregivers differentially supported respite care, as did those on leaves of absence. Caregivers also cited respite first (tied with better medical care) as something they needed and this was a volunteered response, not a pre-coded category. Finally, in the comments section the ‘need for a break’ was mentioned repeatedly by caregivers. Whether they would cite this as a need for ‘respite’ needs to be further explored.

Finally, while no questions were asked specifically about consumer directed care, there was support by most caregivers for paid family allowance (80.7%) as well as case management (77.6%) which would both be related to cash and counseling. The need for both of these was also differentially supported by the caregivers who expressed the highest degrees of burden. Furthermore, the items about the need for available and affordable community services are also ranked consistently highly and again mentioned repeatedly in the comments section. Another indicator of the need for cash and counseling could also be suggested by the relatively low income level of caregivers and the not insignificant amounts spent on care. One service that cash and counseling could provide that would be useful to middle class caregivers might be to recruit and train an available pool of home health, respite, and companion personnel. Many caregivers in this income category seemed willing to pay for these services if they could find them.

Overall this survey reveals that caregivers across ethnicities, of spouses and parents, employed or not, with low or moderate incomes, would appreciate legislative

efforts on their behalf and would be grateful for a sense that the State recognizes their contribution to family and society and supports them in their efforts.

Table 1
Selected Care Recipient (CR) and Caregiver (CG) Demographics

Variable	Percentage or Mean
Caregiver Primary Ethnicity	
Japanese	30.8%
Caucasian	27.2%
Hawaiian/Part Hawaiian	20.7%
Filipino	8.8%
Hispanic	2.1%
Chinese	2.0 %
Samoan	2.0%
African American	1.3%
Native Am/Alaskan native	1.0%
Indian	0.5%
Korean	0.6%
Other (mixed, Tongan, Thai)	4.0%
CG Educational level (1=<HS to 7= post graduate)	4.78 (some college)
CG Gender	
Female	73.6%
Male	26.4%
Relationship to care recipient	
Mother	38.1%
Father	17.87%
Spouse	15.7%
Grandmother	8.3%
Friend	5.3%
Aunt	3.3%
Mother in law	3.3%
Uncle	3.3%
Other (includes siblings, other in-laws grandfather)	4.0%
CG age	54.08
Children under 18 living at home	27.5%
Caregiver length of time living in Hawaii	29.8 yrs
Caregiver raising grandchildren	14.1%
Number of adults being care for	
One	85.2
Two	12.2
Three	2.1
Four or more	0.5
CG total household income 2006 (N=477)	12.1%

<\$20,000	12.7%
\$20,000- \$24,999	15.1%
\$25,000- \$29,999	13.2%
\$30,000- \$34,999	9.9%
\$35,000- \$39,999	8.8%
\$40,000- \$44,999	11.3%
\$45,000- \$49,999	7.0%
\$50,000- \$59,999	2.4%
\$60,000- \$69,999	2.2%
\$70,000- \$79,999	1.2%
\$80,000- \$89,999	1.6%
\$90,000- \$99,999	0.9%
\$100,000- \$119,999	0.2%
\$120,000- \$149,999	1.5%
> \$150,000	
CR Gender	
Female	64.8%
Male	35.2%
CR Age	80.4%
CR current living arrangement	
Alone	32.8%
In the home or apt of other family member or friend	26.9%
With CG only	25.6%
With spouse or partner only	5.4%
Retirement community/residential care	6.3%
Nursing care facility	3.0%

Table 2
Care Recipient (CR) ADL and IADL Impairments and Chronic Conditions

Variable	Mean or Percentage
CR needs help IADL's – shopping/ transportation	84.9%
CR needs help IADL's meal prep, laundry	82.8%
CR needs help IADL's finances	65.5%
CR needs help medical needs	58.8%
CR needs help with ADL's-bathing dressing, eating	57.1%
CR needs help arranging for own care	52.1%
Chronic Conditions	
CR has ASHD/ hypertension	60.1%
CR has arthritis	53.1%
CR has dementia	40.6%
CR has hearing impairment	33.4%
CR has diabetes	32.4%
CR has mental health problem	27.8%
CR has cancer	22.8%
CR has CVA/paralysis	24.3%
CR has vision problem	21.3%
CR has behavioral problem	20.9%
CR has emphysema /lung disease	12.4%
CR has HIV/AIDs	1.1%

**Table 3
Providing Care**

Variable	Mean or Percentage
Length of caregiving period	
< 6 mo's	8.4%
6-12 mo's	9.4%
1- 5 yrs	55.0%
6-10 yrs	15.3%
>10yrs	11.9%
Travel time	
Live together	53.6%
< 15 minutes	26.9%
16 to 30 minutes	9.2%
31 to 60 minutes	7.9%
>60 minutes	7.4%
Who provides most of care	
Self	57.8%
Someone else	24.5%
Shared	15.5%
Other arrangement	2.0%
Primary CG /hrs per week	20.82
Constant care	29.5%
Other unpaid help/hrs per week	6.72 hrs
If you were unable someone else would help	69.0%

**Table 4
Community Service Utilization**

Variable	Mean or Percentage
Has public assistance (e.g. Medicaid)*	50.1%
Used nursing services	25.2%
Used training services	24.6%
Has assigned case manager	22.0%
Used transportation	19.8%
Used legal services	19.1%
Used end of life care (hospice)	18.9%
Used Meals on Wheels	16.0%
Used health maintenance services	14.7%
Used companion services	13.1%
Used bathing/personal care services	13.9%
Used adult day health service	12.0%
Used light housekeeping	8.8%
Used heavy cleaning/yard work	7.2%
Used mental health services	7.0%
Used financial services	5.6%
# of hrs provided by paid services (N=51)	8.71 hrs
Other types of assistance that would be helpful (N=141)	
Better medical	3.5%
Respite care	3.5%
Handivan/wheelchair transport	2.2%
Companion services	1.8%
Housecleaning	1.8%
Adult or senior day care	1.8%
Transportation	1.3%
Nurses	1.0%
Other (more affordable services, general community services, lower taxes and financial assistance, etc)	7.5%
Problems getting services you need	17.7%
Other services used (may have been provided by informal (unpaid) or formal sources)	
Daytime Respite	29.6%
Overnight respite	11.9%
Weekend respite	9.5%
Reasons for non use of outside help	
Have all help needed	61.7%
Services cost too much	48.7%
CR doesn't want them	44.4%

No time to get help	36.2%
Services not available	35.4%
Not available when needed	27.8%
No one to stay while you get help	26.9%
Service quality poor	26.2%
Not people like you	25.5%
Long waiting list	24.5%
No transportation	18.8%
Providers don't speak language	5.8%

*It appears likely that this item may been misunderstood by respondents and may include any public payments, such as Medicare.

Table 4a
Service Utilization Patterns
By County¹

Variable	Oahu	Hawaii	Maui	Kauai	Sig.
Used adult day health service	10.8%	12.5%	21.0%	9.0%	P<.038
Used transportation	19.1%	20.0%	28.0%	13.7%	NS
Used Meals on Wheels	7.19%	20.0%	16.0%	31.0%	P<.001
Used mental health services	8.1%	0%	8.4%	8.0%	P<.033
Used bathing/personal care services	13.8%	16.0%	11.2%	15.0%	NS
Used nursing services	25.8%	20.0%	27.1%	27.0%	NS
Used light housekeeping	7.0%	12.0%	12.0%	19.0%	P<.008
Used heavy cleaning/yard work	6.4%	4.0%	14.3%	13.0%	P<.011
Used health maintenance services	15.3%	4.2%	17.7%	27.0%	P<.001
Has assigned case manager	20.4%	29.2%	31.0%	9.4%	P<.001
Has public assistance (Medicare Medicaid)	44.6%	62.5%	68.0%	61.5%	P<.001
Used training services	27.3%	12.5%	16.0%	31.0%	P<.002
Used legal services	16.5%	24.0%	34.4%	12.6%	P<.001
Used financial services	6.3%	0%	6.1%	9.5%	P<.032
Used end of life care (e.g. hospice)	20.9%	20.0%	11.3%	13.35%	NS

¹ Unweighted data used for all between-county comparisons

Table 4b
Total Amount of Community Services Used*
By Caregiver Characteristics

Characteristic	Mean Number of Services Used (if applicable)	Sig. Differences Between Groups
Ethnicity		
African American	1.4	Lower than Hisp, Fili
Hispanic	3.5	Higher than Chin, Kor
Caucasian	2.4	Sam
Indian	5	NS
Chinese	1	Higher than all others
Filipino	3.8	Lower than Sam, Kor
Japanese	2.5	Higher than Haw, Sam
Korean	1	Higher than Haw, Sam
Hawaiian	2.12	Lower than Hisp
Samoan	0	Lower than Hisp, Fili Lower than all others except Chin and Kor
Age		NS
Employment status		NS
Education		NS
Hours of care		Significant relationship (as hours increase so does the number of services used)
Income		Significant inverse relationship (as income <i>decreased</i> so did the number of services used)

* Summed list of all community services

Table 5
Caregiving Impact
Emotional, Physical, and Financial

Variable	Mean or Percentage
Suffered emotional stress as a consequence of c'giving*	2.80
Exp'd financial hardship as a consequence of c'giving *	2.15
C'giving caused physical strain*	2.36
C'giving increased physical or mental health problems	
Physical	7.2%
Mental	1.4%
Both	12.0%
(No increase)	(79.4%)
Interrupted sleep	31.5%
Estimated annual cost of caregiving (N=509)**	
<\$1,999	31.0%
\$2,000-\$4,999	29.7%
\$5,000-\$9,999	15.3%
\$10,000-\$49,000	18.0%
>\$50,000	6.1%

* From 1 = not at all to 5 = a great deal

** (81 people did not know or refused)

Table 5a
Selected Caregiving Differences by County¹

Variable	Oahu	Hawaii	Maui	Kauai	Significant Differences?
Number of adults cared for	1.19	1.12	1.11	1.25	Maui and Kauai (.026)
Caregiver age	54.4	49.7	57.3	54.6	Haw and all others (.005)
Care recipient age	79.9	78.3	78.7	78.8	No
CG educational level*	4.46	4.36	4.23	5.43	Kauai and all others (.001)
CG length of time in Hawaii	30.8	25.6	27.8	34.2	Hawaii and Kauai (.007)
Primary CG /hrs per week	21.5	20.5	24.8	26.7	Oahu, Haw and Kauai (.051-.055)
Paid help/hrs per week	9.62	7.00	6.65	7.00	Oahu and Maui (.032)
Other help/hrs per week	6.88	8.07	6.02	7.01	Oahu, Haw and Maui (.002-.021)
Annual household income*	4.87	5.06	4.74	4.17	No
Suffered emotional stress as a consequence of c'giving*	3.01	2.52	2.94	2.40	Oahu, Haw and Kauai (.001-.007)
Financial hardship as a consequence of c'giving *	2.31	1.92	2.32	1.99	Oahu, Hawaii and Kauai (.018-.056)
C'giving caused physical strain*	2.62	2.24	2.46	2.57	Oahu and Haw (.028)
Length of caregiving period*	3.13	3.24	2.98	3.08	No
Travel time*	1.79	2.54	2.12	2.04	Oahu, Haw and Maui (.0001-.026)
Estimated annual cost of caregiving* (N=509)	2.35	2.52	2.52	2.22	No
Employed (FT or PT)	55.3%	64.0%	53.0%	47.0%	Hawaii and Kauai (.032)
Spousal caregiver	15.3%	8.0%	25.0%	33.0%	Maui, Kauai from Hawaii (.004)
Constant care	31.3%	28.0%	22.0%	22.0%	No

¹ Unweighted data

* Ordinally coded (ranked) variables; categories listed previously

Table 6
Effects on Employment

Variable	Mean or Percentage
Percent employed	55.8%
(Of those employed)	
FT	78.4%
PT	19.9%
Both	1.7%
(Of those not employed)	
Retired	96.2%
On leave of absence	3.8%
(Of those employed) Did you have changes in work situation due to caregiving?	26.8%
(Of those w/changes N= 98)	
Reduced # wk hrs	55.2%
Leave of absence	36.9 %
Turned down promotion	36.3%
Quit job	29.2%
Changed job	28.5%
Took less demanding job	23.3%
Took 2 nd job	19.7%
Retired	17.1%
Other impacts on employment	
Rearranged wk schedule	94.3%
Took time off during day	77.9%
Arrive early or leave late	56.3%
Exp work day interrptns for crisis care	52.7%
Exp scheduling difficulties	52.2%
Exp stress related health problems	48.1%
Exp stress related health problems	41.8%
Did personal business on wk hrs	41.6%
Missed meetings/app'ts	34.0%
Exp difficulty w/management	26.9%
Exp mental prbs/little concentration	14.6%
Exp resentment coworkers	
(Of those employed) What eldercare benefits does employer offer?	
Unpaid family leave	18.0%
PT work	9.7%
Dependent care flex spend acc	9.7%
Flextime	9.7%
Brown bag lunches	8.5%

CG support group	8.5%
EAP program	8.5%
Compressed wk schedule	7.5%
Paid sick leave for eldercare	7.4%
Leave sharing	7.3%
Paid family leave	7.3%
Eldercare referral	6.3%
Legal	6.3%
LTC Insurance	5.2%
Job sharing	5.2%
Leave w/out pay	5.0%
Paid bereavement leave	4.7%

Table 7
Opinions/Preferences for Government Intervention

Variable	Mean or Percent
Government should provide state income tax credit for caregiving	94.0%
Government should provide a place for information and support	90.7%
Government should require employers to offer unpaid family leave	88.9%
Government should make community services more affordable	88.3%
Government should provide training and education for caregivers	86.4%
Government should provide a state income tax credit for LTC insurance	84.3%
Government should increase the availability of community services	82.3%
Government should provide an allowance to family members	80.7%
Government should create a paid family leave program	78.6%
Government should provide case management services	77.6%
Government should provide daytime respite services	66.8%
Government should provide weekend respite services	66.6%
Government should provide overnight respite services	61.0%

Table 7a
Opinions/Preferences for Government Intervention
By Gender

Variable	Male	Female	Significance
Government should provide state income tax credit	88.0%	96.1%	P<.001***
Government should provide a place for information and support	86.1%	92.2%	P<.037*
Government should provide a state income tax credit for LTC insurance	77.2%	89.6%	P<.069
Government should require employers to offer unpaid family leave	79.4%	85.9%	P<.NS
Government should make community services more affordable	75.5%	92.8%	P<.001***
Government should provide an allowance to family members	74.8%	82.8%	P<.038*
Government should increase the availability of community services	66.7%	87.4%	P<.001***
Government should provide training and education for caregivers	75.4%	86.6%	P<.001**
Government should create a paid family leave program	75.5%	79.5%	NS
Government should provide case management services	72.3%	79.4%	P<.086
Government should provide daytime respite services	67.1%	66.3%	NS
Government should provide weekend respite services	63.0%	67.9%	NS
Government should provide overnight respite services	57.2%	62.6%	NS

NS = not significant; *P<.05 ** P<.01 ***P<.001

Table 7b
Opinions/Preferences for Government Intervention
By Employment Status

Variable	Unemployed or Retired	Employed (FT or PT)	Significance
Government should provide state income tax credit	90.9%	96.2%	P<.011**
Government should require employers to offer unpaid family leave	83.0%	93.0%	P<.001***
Government should provide a place for information and support	89.3%	91.8%	NS
Government should make community services more affordable	82.7%	92.3%	P<.001***
Government should provide training and education for caregivers	78.0%	92.3%	P<.001*
Government should provide a state income tax credit for LTC insurance	78.7%	88.3%	P<.002**
Government should increase the availability of community services	73.4%	88.4%	P<.001***
Government should provide an allowance to family members	75.1%	84.7%	P<.005
Government should create a paid family leave program	74.1%	82.0%	P<.027*
Government should provide case management services	71.5%	81.5%	P<.007**
Government should provide weekend respite services	61.6%	70.2%	P<.034*
Government should provide daytime respite services	64.5%	68.5%	NS
Government should provide overnight respite services	55.4%	65.0%	P<.021*

NS= not significant; *P<.05 ** P<.01 ***P<.001

Table 7c
Opinions/Preferences for Government Intervention
By Spousal vs All Other Caregivers

Variable	Adult Children (And Other Relatives)	Spousal CG's	Sig. Level
Government should provide state income tax credit	94.9%	88.4%	P<.020*
Government should provide a place for information and support	92.2%	82.6%	P<.004**
Government should require employers to offer unpaid family leave	90.1%	81.8%	P<.018*
Government should make community services more affordable	89.6%	81.0%	P<.024*
Government should provide training and education for caregivers	87.1%	82.8%	NS
Government should provide an allowance to family members	80.5%	81.6%	NS
Government should increase the availability of community services	83.3%	75.6%	P<.093
Government should provide a state income tax credit for LTC insurance	86.8%	68.8%	P<.001***
Government should provide case management services	77.6%	78.4%	NS
Government should create a paid family leave program	81.8%	61.6%	P<.001***
Government should provide daytime respite services	67.5%	62.7%	NS
Government should provide weekend respite services	68.1%	57.5%	P<.053*
Government should provide overnight respite services	61.2%	59.5%	NS

NS = not significant; *P<.05 ** P<.01 ***P<.001

Table 7d
Opinions/Preferences for Government Intervention
By County¹

Variable	Oahu	Hawaii	Maui	Kauai	Sig.
Government should provide state income tax credit	94.9%	96.0%	91.7%	80.2%	.001***
Government should provide a place for info and support	92.5%	95.8%	80.2%	72.8%	.001***
Government should make community services more affordable	89.2%	95.5%	83.0%	67.0%	.001***
Government should require employers to offer unpaid family leave	87.0%	95.8%	94.4%	85.9%	.024*
Government should provide a state income tax credit for LTC insurance	82.6%	92.0%	88.4%	77.9%	.028*
Government should provide training and education for caregivers	86.9%	92.0%	88.9%	62.0%	.001***
Government should provide allowance to family members	81.4%	84.0%	81.9%	61.1%	.001***
Government should provide case management services	76.3%	91.3%	74.5%	65.6%	.001***
Government should increase the availability of community services	83.1%	87.5%	79.3%	59.3%	.001***
Government should create a paid family leave program	77.9%	87.0%	78.9%	66.3%	.011*
Government should provide daytime respite services	66.2%	80.0%	62.2%	49.0%	.001***
Government should provide weekend respite services	65.2%	83.3%	60.4%	53.3%	.001***
Government should provide overnight respite services	61.8%	72.0%	49.0%	45.0%	.001***

¹ Unweighted (raw data); *P<.05 ** P<.01 ***P<.001

Table 7e
Opinions/Preferences for Government Intervention
By Mean Age of Respondents

Variable	Mean Ages Compared	Sig. Level
Government should provide state income tax credit for caregiving	Yes 54 yrs No 54.5 yrs	NS
Government should provide a place for information and support	Yes 54 yrs No 52 yrs	NS
Government should require employers to offer unpaid family leave	Yes 53 yrs No 58 yrs	P<.06
Government should make community services more affordable	Yes 53.4 yrs No 56.1 yrs	NS
Government should provide training and education for caregivers	Yes 53.8 yrs No 56 yrs	NS
Government should provide a state income tax credit for LTC insurance	Yes 52.8 yrs No 57 yrs	P<.044*
Government should increase the availability of community services	Yes 53.3 yrs No 54.2 yrs	NS
Government should provide an allowance to family members	Yes 52.6 yrs No 58.3 yrs	P<.001***
Government should create a paid family leave program	Yes 52.5 yrs No 58 yrs	P<.001***
Government should provide case management services	Yes 53.5 yrs No 53 yrs	NS
Government should provide daytime respite services	Yes 53 yrs No 55 yrs	NS
Government should provide weekend respite services	Yes 53 yrs No 56 yrs	P<.021*
Government should provide overnight respite services	Yes 53 yrs No 55.6 yrs	P<.043*

NS = not significant; *P<.05 ** P<.01 ***P<.001

Table 8
Financial Hardship
Results of Linear Regression Analysis

Variable	Standardized Coefficient	Sig. Level
CR needs help dressing, eating etc	.246	.000
Sum of community services used	.192	.001
# of hrs/wk CG provides care	.219	.001
Care recipient has severe memory problems	.128	.029
Est annual cost of caregiving	.196	.001

F=23.03; Sig =.000; Adjusted R squared value = .331

Table 9
Physical Strain
Results of Linear Regression Analysis

Variable	Standardized Coefficient	Sig. Level
CR needs help dressing, eating, etc.	.195	.001
# of hrs/wk CG provides care	.263	.000
CR needs help/financial matters	.205	.000
CR needs help with medical needs	.102	.085
CR has behavior problems	.286	.000
Sum of community service used	.181	.000
Interrupted sleep	.097	.039

F=44.92; Sig. = 000; Adjusted R squared value = .579

Table 10
Emotional Stress
Results of Linear Regression Analysis

Variable	Standardized Coefficient	Sig. Level
CR needs help meals laundry	.177	.002
CR needs help with personal care	.114	.064
CR needs help/financial matters	.172	.003
Retired or on a leave of absence	.233	.004
Caregiver education	.074	.083
CR has behavior problems	.265	.000
# of hrs per wk caregiver provides care	.187	.002
Sum of community services used	.110	.051
Interrupted sleep	.132	.021

F=28.06; Sig. = 000; Adjusted R squared value = .405

Table 11
Relationship of Each Type of Caregiver Stress to
Opinions/Preferences for Government Intervention

Variable	Emotional Stress	Physical Strain	Financial Hardship
Government should provide state income tax credit	Yes	Yes	NS
Government should provide a place for info and support	Yes	NS	NS
Government should make community services more affordable	Yes	Yes	Yes
Government should require employers to offer unpaid family leave	Yes**	Yes	Yes
Government should provide a state income tax credit for LTC insurance	Yes	Yes	Yes**
Government should provide training and education for caregivers	Yes	Yes	Yes
Government should provide allowance to family members	Yes	Yes	Yes
Government should provide case management services	Yes	Yes	Yes
Government should increase the availability of community services	Yes	Yes	Yes
Government should create a paid family leave program	Yes	Yes	Yes
Government should provide daytime respite services	Yes**	Yes**	Yes**
Government should provide weekend respite services	Yes**	Yes**	Yes
Government should provide overnight respite services	Yes	Yes	Yes

** Highly significant $P < .001$, otherwise $P < .01$; NS= not significant

Addendum Table
Those on Leave of Absence
N=9

Variable	Percent Agreeing
Government should provide state income tax credit for caregiving	100%
Government should provide a place for information and support	100%
Government should require employers to offer unpaid family leave	100%
Government should create a paid family leave program	100%
Government should provide case management services	75%
Government should provide training and education for caregivers	62.5%
Government should provide a state income tax credit for LTC insurance	62.5%
Government should increase the availability of community services	62.5%
Government should provide an allowance to family members	62.5%
Government should make community services more affordable	62.5%
Government should provide weekend respite services	62.5%
Government should provide overnight respite services	37.5%
Government should provide daytime respite services	25%

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