

Report to the Twenty-Third Legislature  
State of Hawaii  
Regular Session of 2005

PURSUANT TO HOUSE CONCURRENT RESOLUTION 154  
2004 LEGISLATIVE SESSION  
REQUESTING THE EXECUTIVE OFFICE ON AGING TO PROVIDE  
DATA ON HAWAII'S FAMILY CAREGIVERS AND THE OLDER  
ADULTS TO WHOM THEY PROVIDE ASSISTANCE

PREPARED BY:  
STATE OF HAWAII  
DEPARTMENT OF HEALTH  
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## EXECUTIVE SUMMARY

Family caregivers are the predominant providers of long-term care nationally and in Hawaii, constituting the backbone of the long-term care system.

National estimates of the number of caregivers in the country range widely—between 5.9 and 52 million caregivers—depending on data source and the definition of a caregiver used.

Regardless of the definition of a caregiver used, considerable amount of national data clearly demonstrates the enormous value of the care provided by family caregivers. National data also shows the costs of caregiving to the caregivers themselves, in terms of negative impacts of caregiving responsibilities on caregivers' own health, employment, retirement, and in other aspects of their lives. Thus, there is growing effort nationwide to strengthen support of family caregivers and to better address caregivers' and care recipients' needs to enable persons with disabilities to stay in the communities.

Population-based, representative data on Hawaii caregivers and the older adults for whom they care, their demographics, needs, and financial costs, is virtually non-existent. This has to do with the fact that data on caregiving derives almost exclusively from certain national studies. As is common with other national studies, these national studies fail to represent Hawaii adequately, if at all.

Since 2003 however, the State Executive Office on Aging (EOA) has been sponsoring collection of a limited number of data elements on caregiving through the State's two primary health data surveys, the Behavioral Risk Factor Surveillance System (BRFSS) and Hawaii Health Survey (HHS). This data shows that between 14% and 21% of Hawaii's adults provide regular care or assistance to persons aged 60 years old and older.

Considering that data on caregiving in Hawaii is extremely limited, as well as the sense of urgency to develop and actively pursue strategies to address the needs of Hawaii caregivers, the following data-related recommendations have emerged:

- Future collection of caregiving related data should be centered on the types of data that can have direct applicability to state policy, program, and service planning, implementation, and evaluation.
- Immediate effort should be devoted to collecting reliable data to identify and prioritize needs of caregivers in the State of Hawaii, as well as to develop culturally appropriate ways to address those needs.
- At present, data on aging and long-term care issues is “scattered around.” Immediate effort should be devoted to developing and promoting some form of centralized location for state data and information pertaining to aging and long-term care.

## INTRODUCTION

## BACKGROUND

Family caregivers are the backbone of the long-term care system, with family caregivers providing most of the assistance to persons with disabilities. Many caregivers assist their family members with personal care for a major portion of time each week, often over a period of years. Although caregivers and care recipients value their relationships and find caregiving rewarding, caregiving can come at a significant cost to individuals, communities, and society at large, in terms of foregone resources, health, and opportunities. By reducing this caregiver cost and burden, much can be done to strengthen the ability of caregivers to provide care.

There has been growing awareness nationally as well as locally in Hawaii of the enormous importance of caregivers and the informal care they provide. Last year in Hawaii, the 2004 Legislative Session considered multiple caregiver measures: the Caregiver Data measure (H.C.R. No. 154); the Supportive Services for Caregivers measures (H.B. No. 2114/S.B. No. 2591); the Education and Training measures (H.B. No. 2112 and H.B. No. 2113/S.B. No. 2571); the Respite Services measures (H.B. No. 2113/S.B. No. 2571 and H.B. No. 2708/S.B. No. 3037); the Caregiver Recognition measures (S.C.R. No. 75/S.R. No. 35/H.R. No. 91 and H.B. No. 2016/S.B. No. 2221); the Caregiver Tax credit measures (H.B. No. 2110/S.B. No. 2573); the Caregiver Reimbursement measures (H.B. No. 2015/S.B. No. 2225); the Consumer Direction measures (H.B. No. 2107/S.B. No. 2258); the Grandparents Raising Grandchildren measures (H.B. No. 1868/S.B. No. 2161); and the General Caregiver Support measures (H.B. No. 2113/S.B. No. 2571). All these measures, except the Caregiver Data resolution and the Caregiver Recognition resolution, failed to pass the Legislature.

The Caregiver Data measure, the House Concurrent Resolution No. 154 (HCR No. 154), adopted by the 2004 State Legislature, requested that the State Executive Office on Aging (EOA) provide data on Hawaii's family caregivers and the older adults to whom they provide assistance. This Resolution acknowledged family caregivers as the primary providers of long-term care; that with the aging of the baby boomer population, a growing number of individuals will be in the 60 years of age and older group and thus greater

numbers of families will provide long-term care to frail and disabled older adults, and the impact of caregiving on caregivers. This Resolution stated, "now is the time to provide caregiver support and financial incentives as part of our long-term care system so that older adults can remain at home with their families for as long as possible, and rising costs of long-term care expenditures, particularly for nursing home care, can be controlled." This Resolution requested that the EOA provide data on Hawaii's family caregivers and the older adults to whom they provide assistance, including demographics, needs, and financial costs of Hawaii family caregivers, as well as related findings and recommendations.

## OBJECTIVES

The present report has been prepared in response to House Concurrent Resolution No. 154 and fulfills the following objectives:

- I. Provide national and local data on family caregivers and the older adults to whom they provide assistance, including demographics, needs, and financial costs
- II. Provide and discuss caregiving data related issues, implications, and recommendations, based on review of national and local data as well as the input solicited and obtained from focus groups representing a broad spectrum of stakeholders in the State.

It is intended that, in addition to responding to HCR No. 154, this report serve as a centralized source of data and information, national and Hawaii, on caregivers and the older adults for whom they care, to be used by the agencies, groups and other parties working on caregiving issues in the State.

In accordance with the Resolution's requirements, the present report focuses on family caregivers who care for older adults.

## METHODOLOGY

The present report has been developed using the following two-fold approach:

- I. Review and summarize existing national and local data on family caregivers and the older care recipients to whom they provide assistance, including demographics, needs, and financial costs; as well as provide and discuss data related issues, implications, and recommendations that emerged from review of the available data
- II. Solicit, obtain, and summarize input, via focus group discussions, from a broad spectrum of representatives of Hawaii caregivers, advocacy groups, government agencies, health care, business, service providers, media, and research, regarding their experience with and recommendations on the data they need to help them advance issues in support of Hawaii's caregivers.

## SOURCES OF DATA ON CAREGIVERS AND THE OLDER ADULTS FOR WHOM THEY CARE

### NATIONALLY

National data on caregivers and the care recipients to whom they provide care derive from two main types of data sources:

- Special studies on caregiving sponsored by various government and private agencies
- Behavioral Risk Factor Surveillance System (BRFSS) conducted by the Centers of Disease Control and Prevention (CDC) in partnership with all the states.

Most of the available data on caregivers and care recipients derive from **special studies** that were sponsored and conducted by various government and private agencies to specifically obtain information on caregiving related issues. These studies include:

- Caregiving in the U.S.<sup>1</sup>

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<sup>1</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

- Caregiver Survey, by the National Family Caregivers Association (2000)
- Long-Term Care from the Caregiver's Perspective<sup>2</sup>
- The Characteristics of Long-Term Care Users<sup>3,4</sup>
- Family Caregiving in the U.S.: Findings from a National Survey<sup>5,6,7,8,9,10</sup>
- The Economic Value of Informal Caregiving<sup>11,12</sup>
- Informal Caregiving: Compassion in Action, Parts I and II<sup>13,14,15</sup>
- Characteristics of Caregivers based on the Survey of Income and Program Participation (SIPP)<sup>16</sup>

It is important to recognize that these studies were focusing on different aspects of caregiving, each study had its own methodology and data sources, and thus certain results vary from study to study. Also of note, these studies pertained to different sub-populations of caregivers and differed substantially with regard to the study participant inclusion criteria, such as the ages of care recipients. For example, the *Characteristics of Long-Term Care Users and*

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<sup>2</sup> The Henry J. Kaiser Family Foundation, Harvard School of Public Health, United Hospital Fund of New York, Visiting Nurse Service of New York. *The Wide Circle of Caregiving. Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*. 2002.

<sup>3</sup> Spector, W.D., et al. *The Characteristics of Long-Term Care Users* (AHRQ Publication No. 00-0049). Agency for Healthcare Research and Policy, Rockville, MD. 2000.

<sup>4</sup> Health and Human Services. *Informal Caregiving: Compassion in Action*. Department of Health and Human Services, Washington, DC. 1998.

<sup>5</sup> National Alliance for Caregiving & AARP. *Family Caregiving in the U.S.: Findings From a National Survey*, National Alliance for Caregiving, Bethesda, MD and AARP, Washington, DC. 1997.

<sup>6</sup> Metlife Mature Market Group & National Alliance for Caregiving. *The MetLife Study of Employer Costs for Working Caregivers*. Metlife Mature Market Group, Westport, CT and National Alliance for Caregiving, Bethesda, MD. 1997.

<sup>7</sup> Arno, P.S., Levine, C., & Memmott, M.M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

<sup>8</sup> Alzheimer's Association & National Alliance for Caregiving. *Who Cares: Families Caring for Persons with Alzheimer's Disease*. Alzheimer's Association, Washington, DC & National Alliance for Caregiving, Bethesda, MD. 1999.

<sup>9</sup> Wagner, D.L. *Comparative Analysis of Caregiver Data for Caregivers to the Elderly 1987 and 1997*. National Alliance for Caregiving, Bethesda, MD. 1997.

<sup>10</sup> Ory, M.G., et al. Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers. *The Gerontologist*, 39:177-185. 1999.

<sup>11</sup> Arno, P.S., Levine, C. & Memmott, M.M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

<sup>12</sup> Health and Human Services. *Informal Caregiving: Compassion in Action*. Department of Health and Human Services, Washington, DC. 1998.

<sup>13</sup> Health and Human Services. *Informal Caregiving: Compassion in Action*. Department of Health and Human Services, Washington, DC. 1998.

<sup>14</sup> Arno, P.S., Levine, C. & Memmott, M.M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

<sup>15</sup> Spector, W.D., et al. *The Characteristics of Long-Term Care Users* (AHRQ Publication No. 00-0049). Agency for Healthcare Research and Policy, Rockville, MD. 2000.

<sup>16</sup> Alecxih, L.M.B., Zeruld, S. & Olearczyk, B. *Characteristics of Caregivers Based on the Survey of Income and Program Participation*. The Lewin Group, Falls Church, VA. [National Family Caregiver Support Program: Selected Issue Briefs.] 2001.

*Informal Caregiving: Compassion in Action, Part II* studies focused on caregiving to care recipients ages 65 and older; whereas the two parts of the widely cited Economic Value of Informal Caregiving study examined caregiving to care recipients ages 15+ and 18+. These distinctions are important, as they have implications for generalizability of the studies' findings and any statistics derived from them. (For more detail on these studies, see Appendix.)

Another important source of data on caregivers is the **Behavioral Risk Factor Surveillance System (BRFSS)** conducted by the CDC in partnership with all the states. In 2000, the U.S. Administration on Aging (AoA) sponsored two questions pertaining to caregiving to be included in the BRFSS in each state that year.

The first question aimed at estimating percent and number of adults who are providing care to a person age 60 or older:

*"There are situations where people provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?" [Yes; No]*

The second question was to find out whom people would call if an older friend or relative needed assistance:

*"Who would you call to arrange short or long-term care in the home for an elderly relative or friend who was no longer able to care for themselves?" [Relative/friend; Would provide care myself; Nursing home; Home health service; Personal physician; Area Agency on Aging; Hospice; Hospital nurse; Minister/priest/rabbi; Other; Don't know who to call]*

The BRFSS source of data is of particular importance since it is the only source, of all national ones, that actually has sufficient sample size to compute estimates for Hawaii, Hawaii's four counties, and to compare those to the national estimates obtained following the same methodology.

## IN HAWAII

Data on caregivers in Hawaii is extremely sparse. This scarcity of local information parallels considerable lack of data on caregivers nationally as well. Only in 2000 did the U.S. Administration on Aging add several questions on caregiving to the Behavioral Risk Factor Surveillance System (BRFSS), the nation's primary public health surveillance survey. Other national estimates on caregivers are all based on specific studies, with Hawaii, being the "small" state, not included in these estimates.

To date, there are two sources of population based, representative data on caregivers in Hawaii:

- Behavioral Risk Factor Surveillance System (BRFSS), year 2000
- Hawaii Health Survey (HHS), year 2003

both coordinated by the Hawaii State Department of Health. (See Appendix for more information on these two data sources.)

Also, the Executive Office on Aging is sponsoring an extensive list of questions on caregiving that are included in the Hawaii Health Survey 2004, with these data to be available in Spring 2005.

### **BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS), YEAR 2000**

As described above, in 2000, the U.S. Administration on Aging sponsored two questions pertaining to caregiving that were asked in each state as part of the BRFSS for that year. This source provides population-based, representative data on caregivers in Hawaii and allows comparison with national estimates. (For more detail on the BRFSS, see Appendix.)

### **HAWAII HEALTH SURVEY (HHS), YEAR 2003**

The EOA sponsored three questions on family caregiving in the HHS 2003.

The first question on the HHS 2003 was the same as the question sponsored by the U.S. Administration on Aging on BRFSS 2000, as this is a nationally validated

question, which allows for benchmarking against national statistics as well as comparisons to the estimates for the year 2000:

*"There are situations where people provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?"*

The second question was,

*"Does this person live with you?"*

that was asked of those who answered affirmatively to the first question.

The third question was,

*"What is your relationship to the person you care for?"*

that was asked of those who answered affirmatively to the first question and when the care recipient lived in the same household.

It is important to recognize certain issues in **interpretability of the data** from the caregiver questions that were asked on the BRFSS 2000 and HHS 2003 surveys. It has been recognized nationally that the terms used in the BRFSS question about family caregiving are not clearly defined and are subject to high variability in interpretation. "There are situations where people provide **regular care or assistance** to a family member or friend who is elderly or has a **long-term illness or disability**. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?" The terms "regular care" or "assistance" and the terms "long-term illness or disability" are not defined. Respondents may interpret these terms differently.

Additional data on special topics pertaining to sub-groups of the caregiver population are available from several Hawaii studies, including *Statewide Survey on Caregiving* (2002), *A Framework for Family Caregiver Support in Hawaii* (2001), and *Caring for Elderly Family Members; The Impact on Employed Caregivers* (1990). The methodology, particularly the sampling approach, used in these studies limits the extent to which their findings can be generalized to the entire population.

## FOCUS GROUP DISCUSSIONS

To complement the data currently available on caregiving in Hawaii, the contractor solicited, obtained, and summarized input from a broad spectrum of representatives of Hawaii caregivers, advocacy groups, government agencies, health care, business, service providers, media, and research, regarding their experience with and recommendations on the data they need to help them advance issues in support of Hawaii's caregivers. This information was collected at a series of focus group discussions.

The focus group discussions were conducted using an open-ended methodology to allow focus group participants from various backgrounds and functions to express data related issues and needs that they encounter in their work, and to generate as much information as possible from participants. Six focus groups were conducted over the period July through September 2004.

The sections below contain a review of the available data on caregiving nationally and in Hawaii, as well as data from the input obtained in the focus group discussions.

## CHARACTERISTICS OF CAREGIVERS

### NATIONALLY

### PREVALENCE OF CAREGIVING

**PREVALENCE OF CAREGIVING: NATIONAL ESTIMATES OF THE NUMBER OF CAREGIVERS RANGE FROM 5.9 MILLION TO 52 MILLION CAREGIVERS.**

National estimates of the number of caregivers derived from the most commonly referenced caregiver prevalence studies range from 5.9 million caregivers to 52 million.

The estimated number of caregivers in the U.S. varies widely from study to study because there is no uniform definition of a caregiver.

**TABLE 1: NATIONAL ESTIMATES OF THE NUMBER OF CAREGIVERS**

STUDY	ESTIMATED NUMBER OF CAREGIVERS	DEFINITION OF CAREGIVER AND CARE RECIPIENT
The Characteristics of Long-Term Care Users <sup>1</sup>	5.9 million caregivers	Family or friend providing help to a disabled elder (65+) living in the community with a need that has lasted or is expected to last 3+ months.
Informal Caregiving: Compassion in Action, Part II <sup>1</sup>	7 million caregivers	Provided care to an elder (65+) who needed assistance with everyday activities.
Characteristics of Caregivers Based on the SIPP <sup>1</sup>	9.4 million caregivers	"Unpaid care or assistance to someone [of any age] with a long-term illness or a disability during the past month."
Family Caregiving in the U.S., 1997: Findings From a National Survey <sup>1</sup>	22.4 million households (5 million of which provide care to someone with dementia)	Someone 18+ currently providing care or who had at some point in the past 12 months to a relative or friend who is aged 50+ to help them take care of themselves.
The Economic Value of Informal Caregiving <sup>1</sup>	24 million caregivers	Anyone aged 15+ needed or provided assistance with everyday activities due to a condition that lasted or was expected to last 3+ months.
The Economic Value of Informal Caregiving <sup>1</sup>	27.6 million caregivers	Need for or provision of personal assistance due to disability or chronic illness, aged 18+.
Behavioral Risk Factor Surveillance System (BRFSS) <sup>2</sup>	32.6 million caregivers	"There are situations where people provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?"
Family Caregiving in the U.S., 2004: Findings From a National Survey <sup>3</sup>	44.4 million caregivers	Someone 18+ currently providing care or who had at some point in the past 12 months to a relative or friend who is aged 18+ to help them take care of themselves.
Informal Caregiving: Compassion in Action, Part I <sup>1</sup>	52 million caregivers	Aged 20+ providing "informal care" to a family member or friend of any age who is ill or disabled.

Source: <sup>1</sup> National Caregiver Alliance. *Fact Sheet: Side-by-Side Comparison of Family Caregiver Prevalence Studies.*

<sup>2</sup> Centers for Disease Control and Prevention (CDC). *Behavioral Risk Factor Surveillance System (BRFSS), 2000.*

<sup>3</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004.*

## FAMILY CAREGIVERS ARE THE PREDOMINANT PROVIDERS OF LONG-TERM CARE.

Family caregivers provide most of the care to persons needing personal assistance, thus constituting the backbone of the long-term care system. Many family caregivers provide care over extended periods of time, for months and often years.

The majority (over three-quarters) of adults receiving long-term care at home rely exclusively on informal care, i.e., care provided by family members, friends, and volunteers.<sup>17</sup>

Even among adults in the community with substantial disabilities (limitations with three or more Activities of Daily Living), two-thirds rely exclusively on care rendered by family caregivers.<sup>18</sup>

Many family caregivers also provide hands-on assistance with various tasks, such as bathing and eating, to their family members or friends who are living in nursing home and other such settings.<sup>19</sup>

Many caregivers providing care for a family member over the age of 50 underestimate the length of time they will spend as caregivers: only 46% expected to be caregivers longer than two years. However, the average length of time spent on caregiving was close to eight years, with approximately one-third of respondents providing care for 10 years or more.<sup>20</sup>

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<sup>17</sup> Health Policy Institute, Georgetown University, analysis of data from the 1994-1995 National Health Interview Surveys on Disabilities, Phase II. Reported in: Thompson, L. *Issue Brief, Long-Term Care: Support for Family Caregivers*. Georgetown University Long-Term Care Financing Project, March 2004.

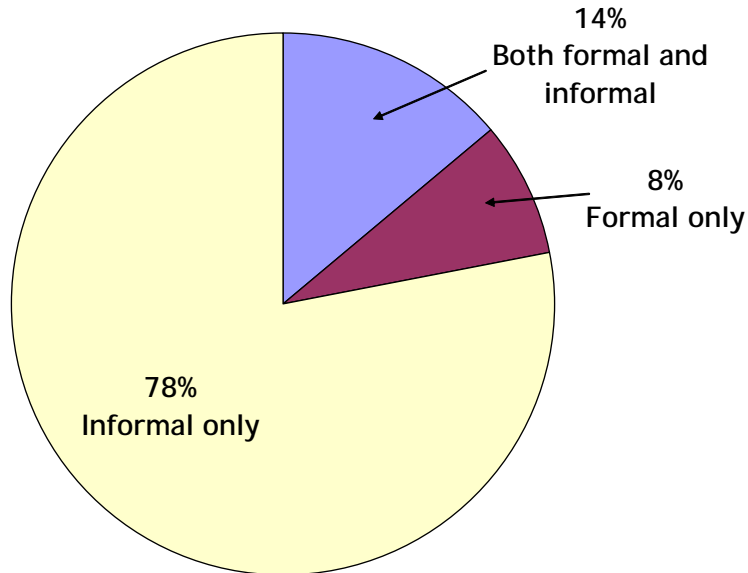
<sup>18</sup> *Ibid.*

<sup>19</sup> Ross, M., Carswell, A., & Dalziel, W. Family Caregiving in Long-Term Care Facilities. *Clinical Nursing Research*, 10:347-363. 2001.

<sup>20</sup> MetLife. *Juggling Act Study, Balancing Caregiving with Work and the Costs of Caregiving*. Met Life Mature Market Institute. 1999.

**FIGURE 1: DISTRIBUTION OF ADULTS RECEIVING LONG-TERM CARE AT HOME, BY TYPE OF CARE**

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Based on national data.

Note: Based on people age 18 and over who, because of disability or health condition, receive help from another person with Activities of Daily Living or Instrumental Activities of Daily Living (see Glossary for explanation of terms).

Source: Health Policy Institute, Georgetown University, analysis of data from the 1994-1995 National Health Interview Surveys on Disabilities, Phase II. Reported in: Thompson, L. *Issue Brief, Long-Term Care: Support for Family Caregivers*. Georgetown University Long-Term Care Financing Project, March 2004.

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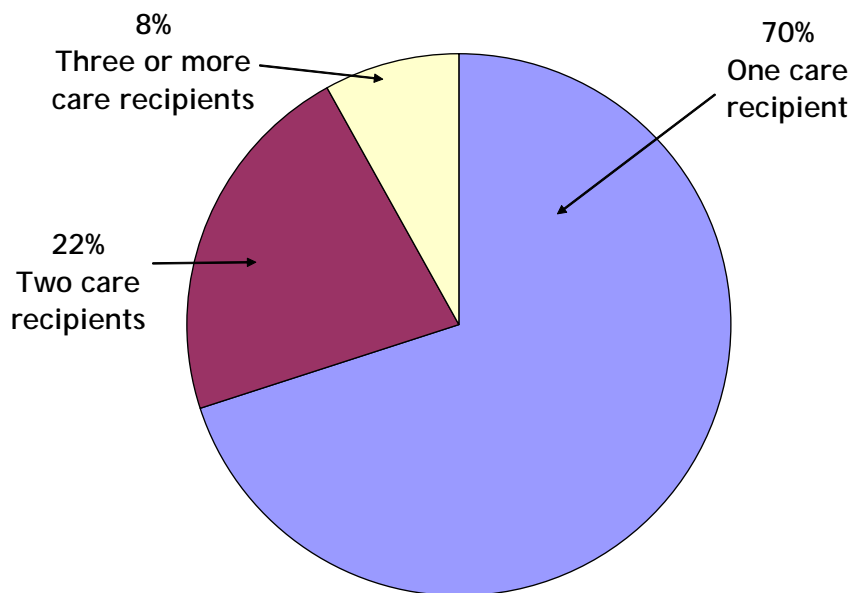
## CHARACTERISTICS OF CAREGIVERS

### MANY CAREGIVERS CARE FOR MORE THAN ONE PERSON.

The majority of caregivers care for one person. However, three in ten caregivers report that they care for two or more persons.<sup>21</sup>

**FIGURE 2: NUMBER OF CARE RECIPIENTS**

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Based on national data.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

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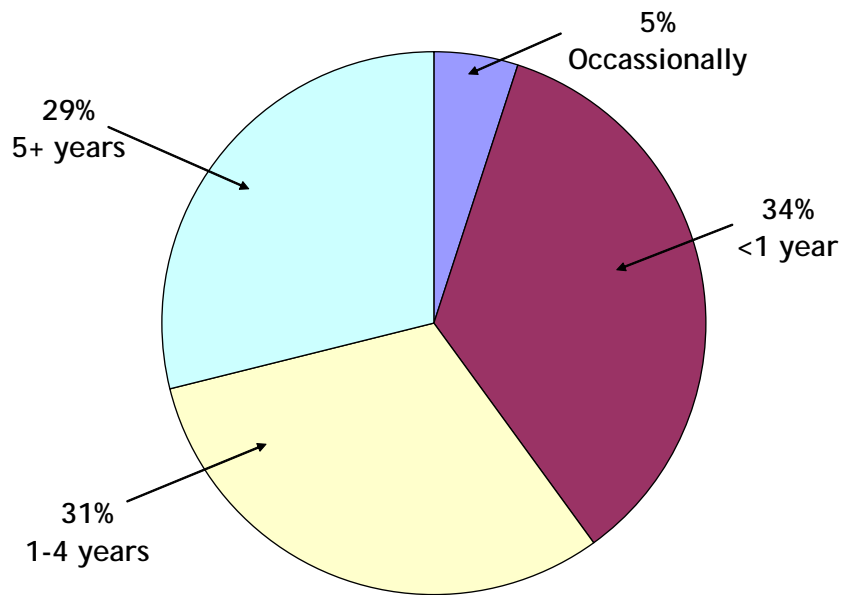
<sup>21</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

## MANY CAREGIVERS PROVIDE CARE FOR SEVERAL YEARS.

According to a recent national study, the average duration of caregiving is over four years. Six in ten caregivers say they have provided care for a year or longer.<sup>22</sup>

**FIGURE 3: DURATION OF CAREGIVING**

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Based on national data. Percentages may not sum to 100% due to rounding.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

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<sup>22</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

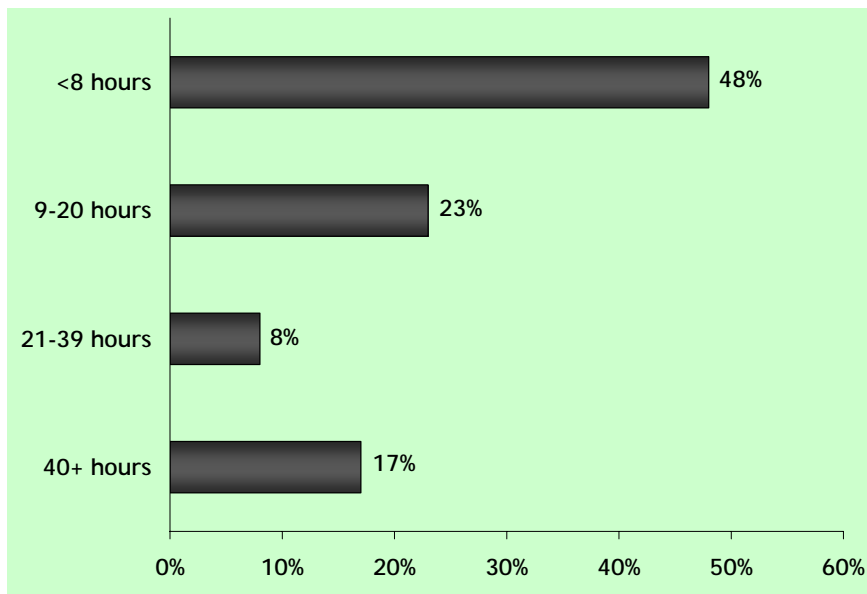
## LEVEL OF INTENSITY OF CAREGIVING VARIES.

Intensity of caregiving varies across caregivers, both in terms of the amount of time spent caregiving and duration and the kinds of care provided.<sup>23</sup>

According to a national study of caregivers providing personal care, more than half of caregivers provide at least eight hours of care a week.<sup>24</sup>

**FIGURE 4: HOURS OF CAREGIVING PER WEEK**

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Based on national data.

Note: The Figure presents data on caregivers providing personal care to persons ages 18+, as presented in *Caregiving in the U.S. 2004*.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

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<sup>23</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

<sup>24</sup> *Ibid.*

## PRIMARY AND SECONDARY CAREGIVERS

Most people who need long-term care rely primarily on one or two key individuals.<sup>25</sup>

At least half of the caregivers identify themselves as primary caregivers, i.e. those who provide most of the care for the person who needs help (70 percent according to one study<sup>26</sup> and 51 percent according to another<sup>27</sup>).

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<sup>25</sup> Stone, R. *Long-Term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-First Century*. New York, NY: Milbank Memorial Fund. 2000.

<sup>26</sup> Alexih, L., Szeruld, S., & Olearczyk, B.A. *Characteristics of Caregivers Based on the Survey of Income and Program Participation, National Family Caregiver Support Program: Selected Issue Briefs*. Washington, D.C. Administration on Aging. 2002.

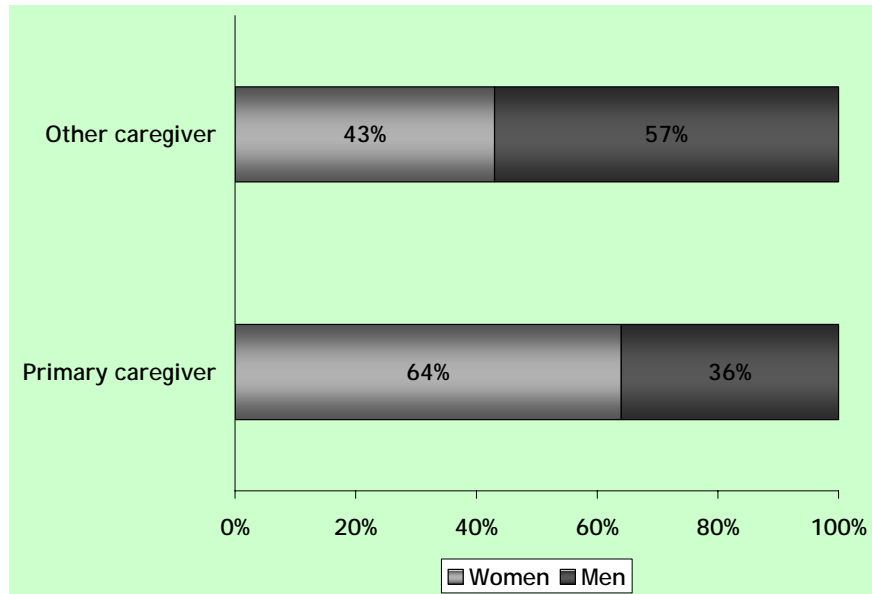
<sup>27</sup> The Henry J. Kaiser Family Foundation. *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998*. 2002.

## WOMEN ARE MORE LIKELY THAN MEN TO BE PRIMARY CAREGIVERS.

Nearly two-thirds of primary caregivers, i.e., those who provide most of the care for the person who needs help, are women; whereas men are more likely to be secondary caregivers.<sup>28</sup>

FIGURE 5: GENDER OF PRIMARY AND OTHER CAREGIVERS

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Based on national data.

Source: The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998.* 2002.

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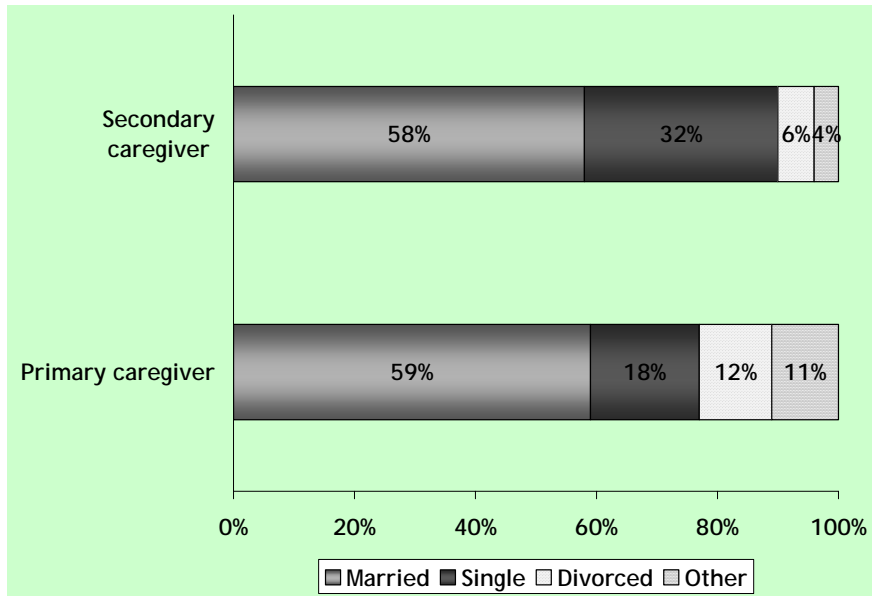
<sup>28</sup> The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998.* 2002.

## THE MAJORITY OF BOTH PRIMARY AND OTHER CAREGIVERS ARE MARRIED.

The majority of both primary and other caregivers are married. A higher proportion of secondary than primary caregivers have never been married.<sup>29</sup>

**FIGURE 6: MARITAL STATUS OF PRIMARY AND OTHER CAREGIVERS**

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Based on national data.

Source: The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998.* 2002.

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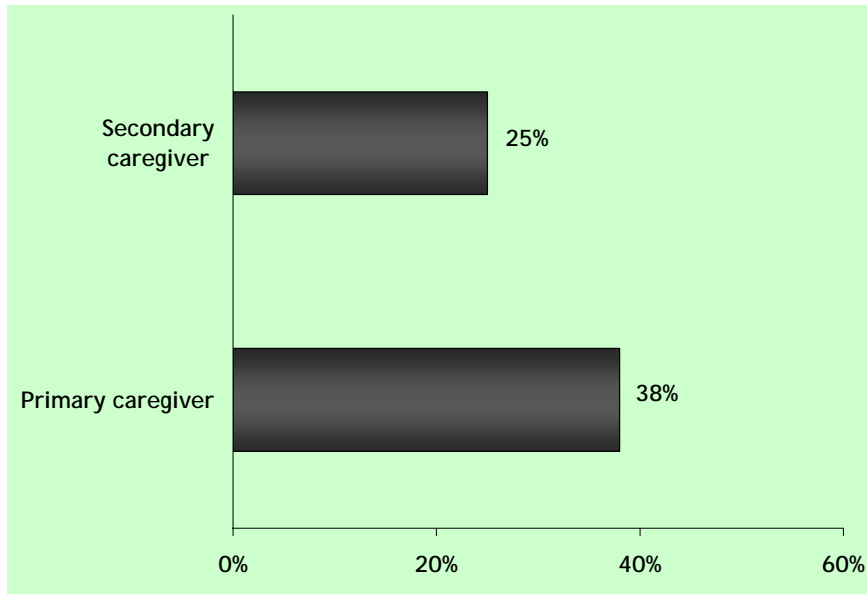
<sup>29</sup> The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998.* 2002.

## MANY PRIMARY CAREGIVERS HAVE SERIOUS HEALTH PROBLEMS THEMSELVES.

Many primary caregivers, who are generally older than other caregivers, have serious health problems themselves.<sup>30</sup>

**FIGURE 7: PRIMARY AND OTHER CAREGIVERS WITH SERIOUS HEALTH PROBLEMS**

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Based on national data.

Source: The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998.* 2002.

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<sup>30</sup> The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998.* 2002.

## **MOST CAREGIVERS ARE EMPLOYED; MANY HAVE CHILDREN AT HOME.**

More than half of caregivers are employed outside of the home.<sup>31,32</sup>

Approximately one in three caregivers has children under age 18 at home, and nearly one in five is both employed and has children at home.<sup>33</sup>

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<sup>31</sup> Alecxih, L., Szeruld, S., & Olearczyk B.A. *Characteristics of Caregivers Based on the Survey of Income and Program Participation, National Family Caregiver Support Program: Selected Issue Briefs*. Washington, D.C.: Administration on Aging. 2002.

<sup>32</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

<sup>33</sup> Alecxih, L., Szeruld, S., & Olearczyk B.A. *Characteristics of Caregivers Based on the Survey of Income and Program Participation, National Family Caregiver Support Program: Selected Issue Briefs*. Washington, D.C.: Administration on Aging. 2002.

## IN HAWAII

### PREVALENCE OF CAREGIVING

In Hawaii, estimates of prevalence of caregiving, i.e., the percent of adult population who are caregivers, and the number of caregivers derive primarily from two data sources:

- Behavioral Risk Factor Surveillance System (BRFSS), year 2000
- Hawaii Health Survey (HHS), year 2003.

(See Appendix for more detail about the BRFSS and HHS. See Glossary for a definition of prevalence.)

Both sources use the definition based on the question that was included in the BRFSS for year 2000 nationally by the U.S. Administration on Aging. Thus, all of the Hawaii estimates presented below are based on this definition (unless stated otherwise):

*“There are situations where people provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?”*

**AN ESTIMATED 14% TO 21% OF ADULTS IN THE STATE OF HAWAII PROVIDE REGULAR CARE OR ASSISTANCE TO A PERSON AGED 60 YEARS OR OLDER.**

**TABLE 2: PREVALENCE OF CAREGIVING IN HAWAII**

	SOURCE OF DATA	
	BRFSS 2000 <sup>1</sup>	HHS 2003 <sup>2</sup>
State	14%	21%
County		
Honolulu	14%	21%
Hawaii	14%	21%
Kauai	13%	21%
Maui	13%	20%

Based on Hawaii data.

<sup>1</sup> Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

<sup>2</sup> Hawaii State Department of Health. *Hawaii Health Survey. 2003.*

**TABLE 3: ESTIMATED NUMBER OF CAREGIVERS IN HAWAII**

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

Based on Hawaii data.

<sup>1</sup> Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

<sup>2</sup> Hawaii State Department of Health. *Hawaii Health Survey. 2003.*

## PREVALENCE OF CAREGIVING IS REMARKABLY SIMILAR ACROSS DEMOGRAPHIC AND SOCIOECONOMIC GROUPS.

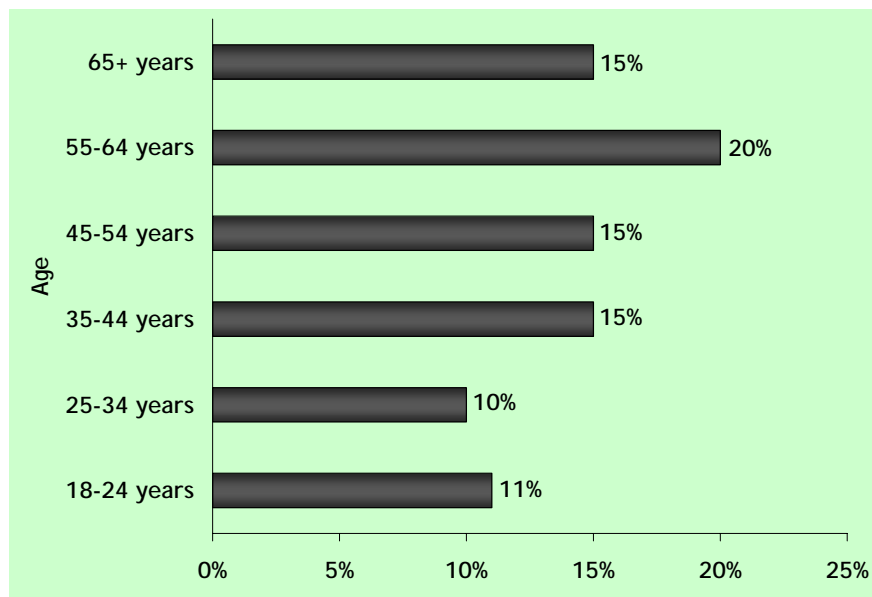
Overall, persons in different demographic groups and with different socioeconomic characteristics exhibit a remarkably similar likelihood of being caregivers.

### PREVALENCE OF CAREGIVING BY AGE

Persons below their mid-30s are least likely to be caregivers. Approximately one in ten Hawaii residents in that age group say that they provide regular care or assistance to someone 60 years old or older. Persons in the 55-64 age group are most likely to be caregivers, with approximately one in five persons saying that they provide care or assistance to someone 60 years old or older.

**FIGURE 8: PREVALENCE OF CAREGIVING BY AGE**

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Based on Hawaii data.

Note: This figure represents the percent of respondents in each age group who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study. Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

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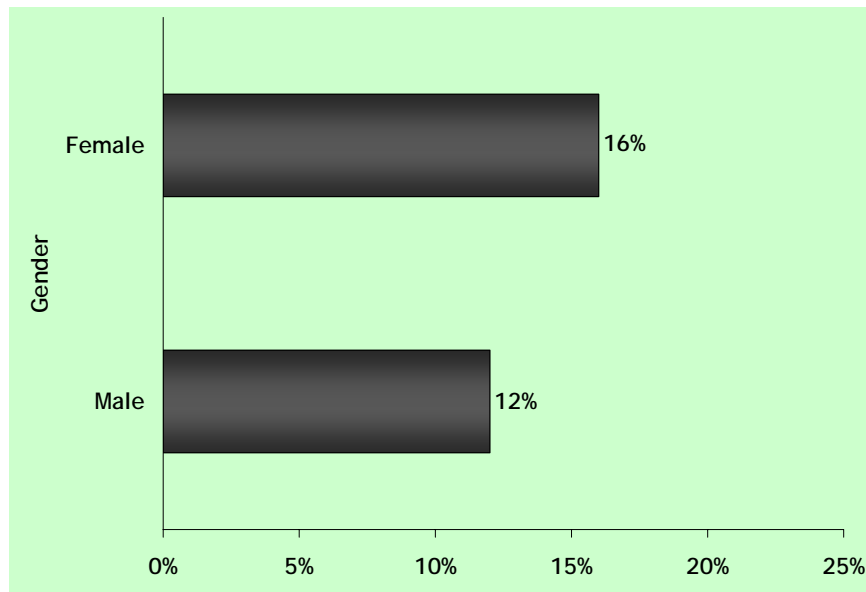
## PREVALENCE OF CAREGIVING BY GENDER

Similar proportions of men and women (12% and 16%, respectively) report that they provide care or assistance to someone 60 years old or older.

Although men are almost as likely as women to report that they provide care or assistance to an elderly person, several national studies have found that women are more likely than men to be primary caregivers rather than secondary caregivers, and that women are more likely than men to provide caregiving of higher intensity and frequency.<sup>34,35</sup>

**FIGURE 9: PREVALENCE OF CAREGIVING BY GENDER**

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Based on Hawaii data.

Note: This figure represents the percent of male and female respondents who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

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<sup>34</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

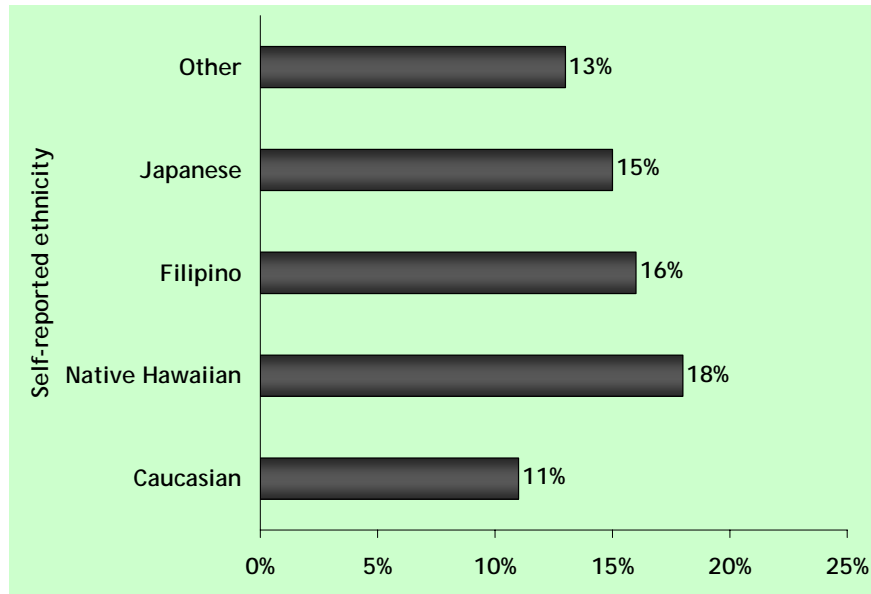
<sup>35</sup> The Henry J. Kaiser Family Foundation, et al. *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998.* 2002.

## PREVALENCE OF CAREGIVING BY ETHNICITY

Among the different ethnic groups in Hawaii, Native Hawaiians are most likely to provide care or assistance to an elderly person (18%); Caucasians are least likely to provide care or assistance to an elderly person (11%).

**FIGURE 10: PREVALENCE OF CAREGIVING BY ETHNICITY**

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Based on Hawaii data.

Note: This figure represents the percent of respondents in each ethnic group who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

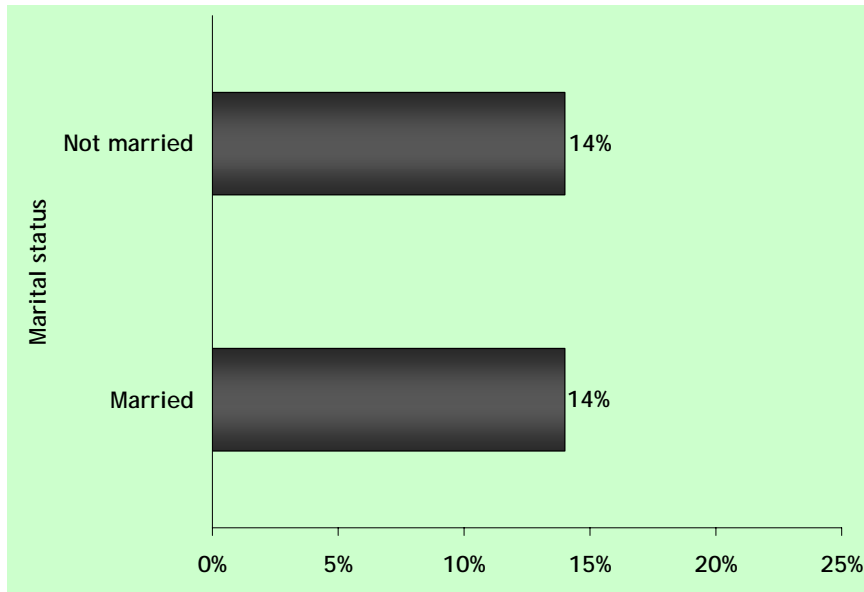
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## PREVALENCE OF CAREGIVING BY MARITAL STATUS

Married persons are as likely to provide care or assistance to an elderly person as their unmarried counterparts (approximately 14% of married and unmarried persons are caregivers).

**FIGURE 11: PREVALENCE OF CAREGIVING BY MARITAL STATUS**

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Based on Hawaii data.

Note: This figure represents the percent of respondents in each marital status group who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

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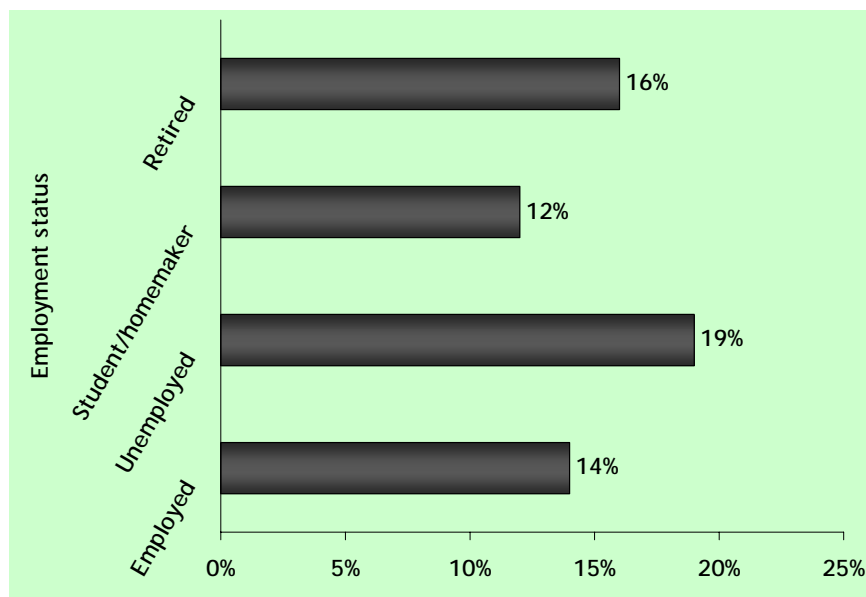
## PREVALENCE OF CAREGIVING BY EMPLOYMENT STATUS

A higher percent of unemployed than employed persons say that they provide care or assistance to an elderly person.

This rate of unemployed caregivers is consistent with findings of national studies that some caregivers resort to quitting their jobs or altering their employment arrangements to accommodate their caregiving responsibilities.<sup>36</sup>

**FIGURE 12: PREVALENCE OF CAREGIVING BY EMPLOYMENT STATUS**

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Based on Hawaii data.

Note: This figure represents the percent of respondents in each employment status group who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

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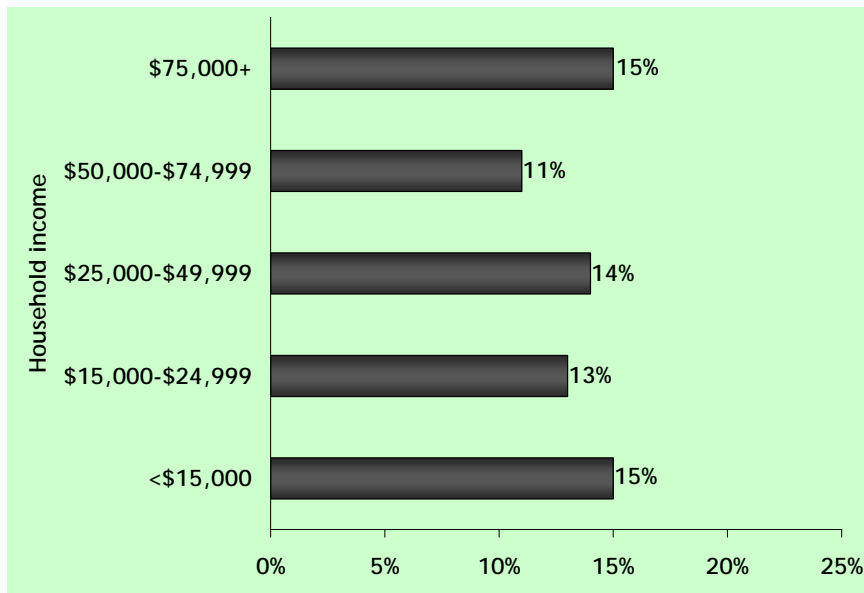
<sup>36</sup> National Alliance for Caregiving/MetLife. *The MetLife Study of Employer Costs for Working Caregivers.* Based on data from Family Caregiving in the U.S.: Findings from a National Survey, 1997.

## PREVALENCE OF CAREGIVING BY HOUSEHOLD INCOME

Adults of any household income in Hawaii have a similar likelihood of providing care or assistance to an elderly person.

**FIGURE 13: PREVALENCE OF CAREGIVING BY HOUSEHOLD INCOME**

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Based on Hawaii data.

Note: This figure represents the percent of respondents in each household income category who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

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## CHARACTERISTICS OF HAWAII CAREGIVERS

To get a clearer picture of Hawaii caregivers and their demographic, socioeconomic, and health characteristics, it is prudent to compare caregivers with non-caregivers. Comparing caregivers with non-caregivers allows answering frequently raised questions about whether caregivers are any different from non-caregivers, such as: Are caregivers older than non-caregivers? Do caregivers have different levels of income? Do they have worse or the same health status as the non-caregivers?

**HAWAII CAREGIVERS ARE REMARKABLY SIMILAR TO THEIR NON CAREGIVING COUNTERPARTS IN THE STATE, IN TERMS OF AGE, ETHNICITY, EDUCATION, INCOME, HOUSEHOLD SIZE, HEALTH, AND OTHER CHARACTERISTICS.**

### AGE

The average age of Hawaii family caregivers caring for someone aged 60 years or older is 47 years old.<sup>37</sup> Twenty-five percent of Hawaii family caregivers caring for someone 60 years or older are themselves ages 60 years or older.<sup>38</sup>

### GENDER

Fifty-seven percent of Hawaii family caregivers caring for someone aged 60 years or older are female.<sup>39</sup>

### ETHNICITY

The ethnic distribution of Hawaii caregivers is very similar to the ethnic distribution of Hawaii adults in general.<sup>40</sup>

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<sup>37</sup> Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

<sup>38</sup> *Ibid.*

<sup>39</sup> *Ibid.*

<sup>40</sup> *Ibid.*

## THE CHARACTERISTICS OF HAWAII CAREGIVERS ARE VERY SIMILAR ACROSS THE FOUR COUNTIES.

Hawaii caregivers are very similar to their non-caregiving counterparts, in terms of age, ethnicity, education, household income, health, and other characteristics. The same holds across the four counties. (For more detail on the characteristics of caregivers in the four counties, see Appendix.)<sup>41,42</sup>

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<sup>41</sup> Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

<sup>42</sup> Hawaii State Department of Health. *Hawaii Health Survey. 2003.*

**TABLE 4: DEMOGRAPHIC CHARACTERISTICS OF HAWAII CAREGIVERS COMPARED TO NON-CAREGIVERS**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	9%	12%
25-34	14%	20%
35-44	22%	21%
45-54	19%	18%
55-64	18%	12%
65+	18%	16%
Total	100%	100%
Gender		
Male	43%	52%
Female	57%	48%
Total	100%	100%
Marital status		
Married/living w/ partner	58%	59%
Not married	42%	41%
Total	100%	100%
County		
Honolulu	75%	73%
Hawaii	11%	12%
Kauai	4%	5%
Maui	9%	10%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	21%	29%
Native Hawaiian	20%	15%
Chinese	6%	5%
Filipino	17%	15%
Japanese	24%	22%
Other	12%	14%
Total	100%	100%

Based on Hawaii data. The Table compares demographic characteristics of Hawaii caregivers and non-caregivers. For example, 43% of caregivers were male; 52% of non-caregivers were male. Among caregivers, 21% were Caucasian; among non-caregivers, 29% were Caucasian.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health, *Behavioral Risk Factor Surveillance System, 2000*.

**TABLE 5: SOCIOECONOMIC CHARACTERISTICS OF HAWAII CAREGIVERS COMPARED TO NON-CAREGIVERS**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	7%	8%
High school graduate	34%	32%
Some college/technical school	28%	29%
College graduate	31%	30%
Total	100%	100%
Household income		
Under \$10,000	5%	5%
\$10,000 to \$14,999	6%	5%
\$15,000 to \$19,999	5%	5%
\$20,000 to \$24,999	6%	8%
\$25,000 to \$34,999	13%	13%
\$35,000 to \$49,999	16%	17%
\$50,000 to \$74,999	11%	15%
\$75,000 and over	15%	15%
Don't know/not sure/refused	22%	18%
Total	100%	100%
Employment status		
Employed	65%	68%
Retired	21%	18%
Other	14%	14%
Total	100%	100%

Based on Hawaii data. The Table compares socioeconomic characteristics of Hawaii caregivers and non-caregivers. For example, 7% of caregivers had some high school or less; 8% of non-caregivers had some high school or less. Among caregivers, 65% were employed; among non-caregivers, 68% were employed.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health, *Behavioral Risk Factor Surveillance System, 2000*.

**TABLE 6: HEALTH CHARACTERISTICS OF HAWAII CAREGIVERS COMPARED TO NON-CAREGIVERS**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	8%	7%
General health status		
Excellent	17%	22%
Very good	31%	33%
Good	36%	34%
Fair	11%	9%
Poor	4%	2%
Total	100%	100%

Based on Hawaii data. The Table compares health characteristics of Hawaii caregivers and non-caregivers. For example, 8% of caregivers had no health insurance; 7% of non-caregivers had no health insurance.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

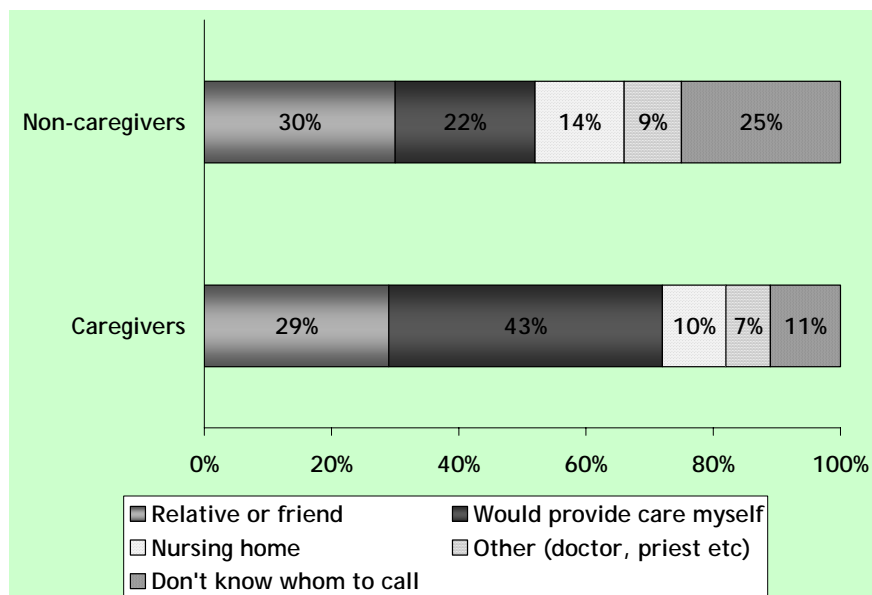
## MANY HAWAII ADULTS HAVE NO ONE TO CALL ON TO ASSIST WITH LONG-TERM CARE.

Almost one-third of Hawaii adults, both caregivers and non-caregivers, say that they would call on relatives and friends to help them arrange for long-term care.

More caregivers than non-caregivers say that they would provide long-term care themselves rather than seek assistance.

One in four non-caregivers and approximately one in ten caregivers report that they do not know whom to call on for assistance with arranging long-term care.

**FIGURE 14: “WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?”**



Based on Hawaii data.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 7: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?"**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	29%	30%
Would provide care myself	43%	22%
Nursing home or home health service	10%	14%
Doctor or nurse	3%	5%
Area Agency on Aging	2%	2%
Other	2%	2%
Don't know whom to call	11%	25%
Total	100%	100%

Based on Hawaii data.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

## CHARACTERISTICS OF CARE RECIPIENTS

### NATIONALLY

Nationally, among persons ages 18 years old and older receiving personal care, the typical care recipient is female, widowed, and approximately 66 years of age. The majority of care recipients live in the same household or less than an hour away.<sup>43</sup>

### **MOST CARE RECIPIENTS ARE RELATIVES OF CAREGIVERS.**

Eighty-five percent of caregivers providing personal care to persons ages 50 years old and older say they care for relatives, most commonly for mothers (34%), grandmothers (11%), fathers (10%), mothers-in-law (8%), spouses (6%), siblings (4%), and daughters/sons (1%).<sup>44</sup>

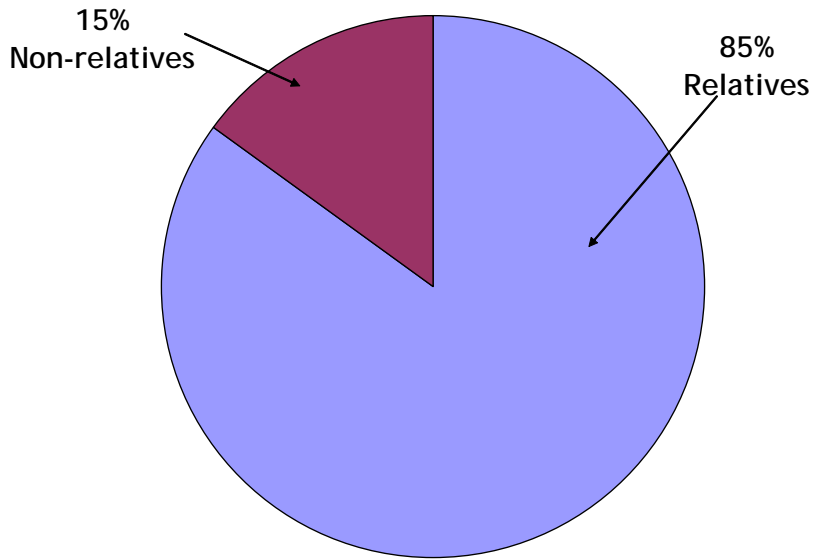
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<sup>43</sup> Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

<sup>44</sup> *Ibid.*

**FIGURE 15: RELATIONSHIP BETWEEN CAREGIVER AND CARE RECIPIENT**

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Based on national data.

Note: Data represents caregivers providing personal care to persons aged 50 years old and older.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

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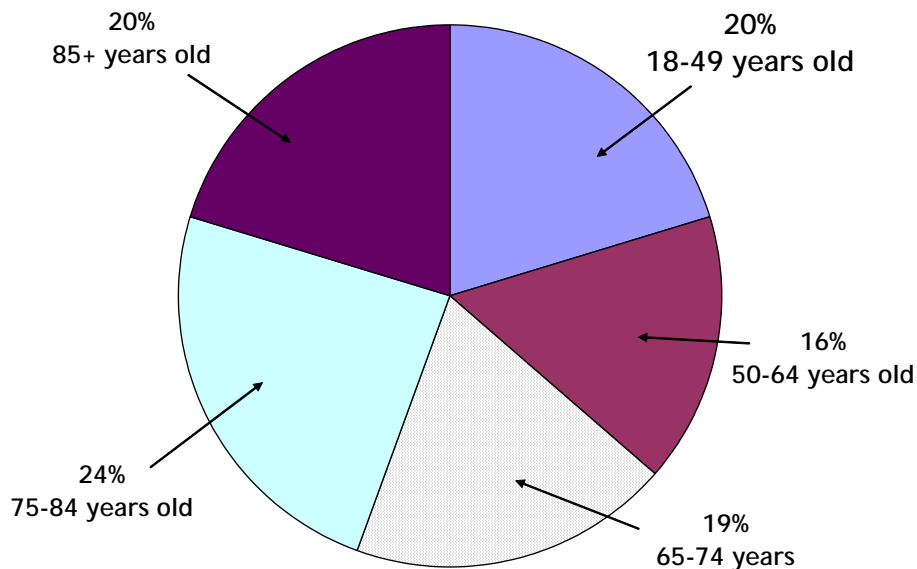
## AGE OF CARE RECIPIENTS

The majority (80%) of caregivers providing personal care say that they care for a person aged 50 years old or older.<sup>45</sup>

Among care recipients aged 50 years old or older receiving personal care, the average age of a care recipient is 75 years old.<sup>46</sup>

**FIGURE 16: AGE DISTRIBUTION OF CARE RECIPIENTS**

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Based on national data.

Note: Data represents a study of caregivers providing personal care, as presented in *Caregiving in the U.S. 2004*.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

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<sup>45</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

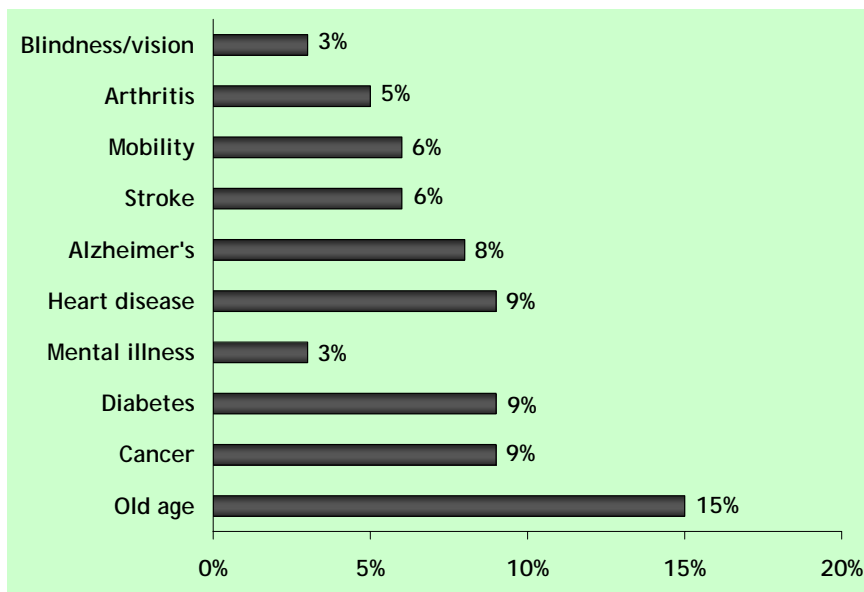
<sup>46</sup> *Ibid.*

## HEALTH OF CARE RECIPIENTS

The primary illness or health problem of care recipients varies a lot, particularly by the age of the care recipient.

Among care recipients below the age of 50, the most commonly identified health problem is mental illness or emotional health. In contrast, among the care recipients aged 50 years old or older, the most commonly identified health problems are aging, being old, and the chronic conditions associated with aging.<sup>47</sup>

**FIGURE 17: MAIN PROBLEM OR ILLNESS OF CARE RECIPIENTS AS IDENTIFIED BY CAREGIVERS**



Based on national data.

Note: Data represents a study of caregivers providing personal care to persons aged 50 years old and older, as presented in *Caregiving in the U.S. 2004*.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

<sup>47</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

## IN HAWAII

Reliable, population-based data on care recipients in the State of Hawaii is practically non-existent.

No population-based data, such as the characteristics of care recipients, their health status, the type or intensity of care they receive, or any other related data, is available regarding Hawaii's elderly who receive informal care and assistance from their relatives or friends.

This lack of data regarding Hawaii's elderly who receive informal care and assistance stems primarily from the fact that data on care recipients derive from national caregiving studies. As is frequently the case with other national studies, Hawaii receives extremely limited or no representation in these studies.

## PLACE OF RESIDENCE OF HAWAII CARE RECIPIENTS

One-fifth (20%) of Hawaii caregivers, who provide care to a person aged 60 years old or older, care for a person who lives in the same household. This pattern is similar in all four counties.

**TABLE 8: PERCENT OF CAREGIVERS LIVING IN THE SAME HOUSEHOLD WITH THE CARE RECIPIENT**

PERCENT OF CAREGIVERS WHO REPORTED THAT THE PERSON THEY CARE FOR LIVES IN SAME HOUSEHOLD	HONOLULU	HAWAII	KAUAI	MAUI	STATE
	20%	22%	22%	20%	20%

Based on Hawaii data.

Source: State Department of Health. *Hawaii Health Survey. 2003.*

## RELATIONSHIP BETWEEN HAWAII CAREGIVERS AND THEIR CARE RECIPIENTS

In Hawaii, among caregivers and care recipients living in the same household, the person most likely to provide care to an older person is a spouse or partner (29% of caregivers), a child (21%), or other relative (22%).

**TABLE 9: RELATION TO OLDER PERSON WHO RECEIVES CARE**

RELATION TO OLDER PERSON WHO RECEIVES CARE	% OF CAREGIVERS LIVING WITH CARE RECIPIENT				
	HONOLULU	HAWAII	KAUAI	MAUI	STATE
Spouse or partner	31%	29%	28%	22%	29%
Child	19%	27%	31%	27%	21%
Grandchild	10%	4%	6%	9%	9%
Other	40%	40%	35%	42%	41%
Total	100%	100%	100%	100%	100%

Based on Hawaii data. Source: State Department of Health. *Hawaii Health Survey. 2003.*

## IMPACTS OF CAREGIVING

### ECONOMIC VALUE OF CAREGIVING

#### THE VALUE OF FAMILY CAREGIVING IS HIGH AND FAR SURPASSES WHAT IS SPENT ON HOME HEALTH CARE AND NURSING HOME CARE.

According to the *Economic Value of Informal Caregiving* study estimates, approximately 26 million family caregivers provided personal care to persons aged 15 years old and older, for a total of approximately 24 billion hours, resulting in an economic value of caregiving of \$196 billion a year nationally.<sup>48</sup>

A more recent estimate valued family caregiving at \$257 billion a year nationally.<sup>49</sup> The economic value of care provided by family members and friends far surpasses what is spent on home health care and nursing home care.<sup>50</sup>

The same study estimated that approximately 115,000 family caregivers in Hawaii provided personal care to persons aged 15 years old and older, for a total of approximately 107 million hours, resulting in an estimated economic value of caregiving of approximately \$875 million per year.<sup>51</sup>

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<sup>48</sup> Arno, P., Levine, C., & Memmott, M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

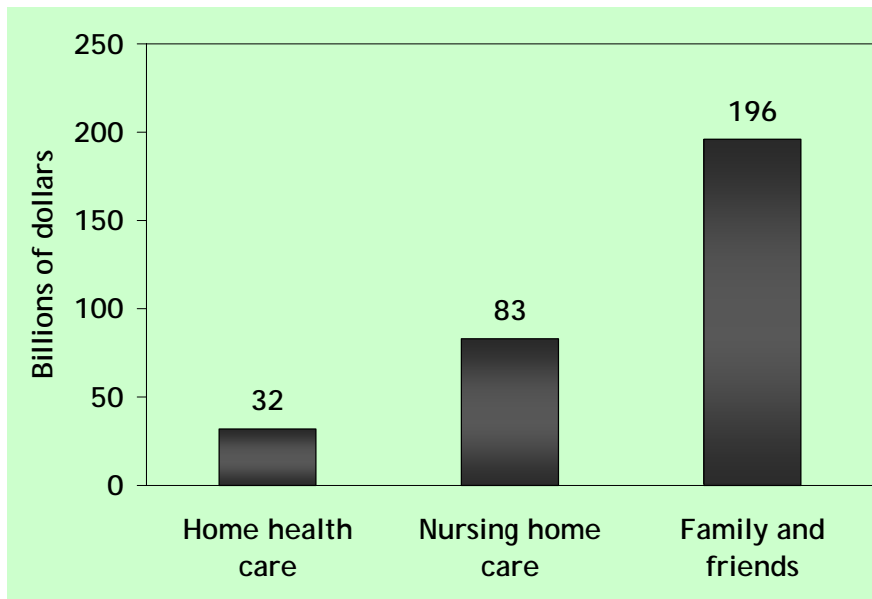
<sup>49</sup> Arno, P. *Economic Value of Informal Caregiving*. Presented at the American Association of Geriatric Psychiatry, February 24, 2002.

<sup>50</sup> Arno, P., Levine, C., & Memmott, M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

<sup>51</sup> *Ibid.*

**FIGURE 18: ESTIMATED ECONOMIC VALUE OF FAMILY CAREGIVING, PER YEAR**

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Based on national data.

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

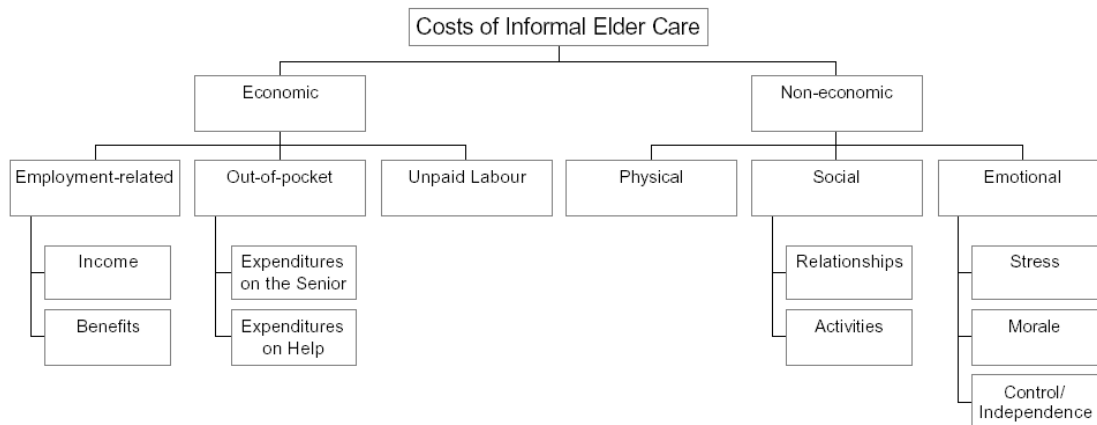
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# ECONOMIC AND NON-ECONOMIC COSTS OF CAREGIVING

It is increasingly recognized that the “free” care provided by caregivers to their family members and friends often comes at a high cost to caregivers themselves, in terms of impacts on their own health, well-being, employment, and other aspects of their lives.

**FIGURE 19: ECONOMIC AND NON-ECONOMIC COSTS OF INFORMAL ELDER CARE**

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Source: Fast, J.E., & Keating, N.C. *Informal Caregivers in Canada: A Snapshot*. 2001.

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## HEALTH IMPACT OF CAREGIVING

Elderly spouses, who are caregivers with a history of chronic illness themselves and who experience caregiving-related stress, have a 63% higher mortality rate than their non-caregiving peers.<sup>52</sup>

Research has shown that the stress of family caregiving for persons with dementia impacts a person's immune system for up to three years after their caregiving ends. Thus, this stress for caregivers increases their chances of developing a chronic illness themselves.<sup>53</sup>

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<sup>52</sup> Schulz, R. & Beach, S.R. Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282. 1999.

<sup>53</sup> Glaser, J.K. & Glaser, R. Chronic Stress and Age-related Increases in the Proinflammatory Cytokine IL-6. *Proceedings of the National Academy of Sciences*, June 30, 2003.

## IMPACT OF CAREGIVING ON EMPLOYMENT AND RETIREMENT

One of the caregivers in our focus group discussions shared the following story from her personal experience:

*"I've been a caregiver for my mother for about three years. My mother has mild dementia and she moved to live with me and my husband because there was no way she could live by herself. Unfortunately, my job and my employer would not allow any flexibility in my work schedule to accommodate my caregiving needs, not even changing my lunch hour from noon to 1 to 12:30 to 1:30 when needed. I had to finally give up that job and accept another job that would allow for flex time, with a \$28,000 cut in salary..."*

There was clear consensus among participants in the focus group discussions that:

- Caregiving responsibilities have an impact on caregivers' professional lives; many caregivers, including women in particular, quit their jobs in order to accommodate their caregiving responsibilities.
- No population-based, representative data is available on the impact of caregiving on the employment and retirement of Hawaii caregivers.

Participants also expressed clear consensus that:

- Easing the burden of caregiving on caregivers' professional lives should be one of the priority areas in supporting caregivers.
- Further effort should be devoted to assessing factors that would make it easier for caregivers to remain employed, including:
  - Working with employers to help caregivers stay in the workplace despite their caregiving responsibilities
  - Providing financial planning advice to help caregivers understand the consequences of early retirement so that they can make long-term, informed decisions.

## **COST OF CAREGIVING TO BUSINESS AND EMPLOYERS**

There is a growing awareness that caring for older relatives is not just a family matter, but is something that exacts a cost on businesses and employers. Several studies have documented costs of caregiving to businesses, particularly in terms of the:

- Replacement costs for employees who quit due to their caregiving responsibilities
- Absenteeism costs
- Costs due to workday interruptions
- Costs due to eldercare crises
- Costs associated with supervising employed caregivers
- Costs associated with the detrimental impact of caregiving responsibilities on caregivers' health.

According to the 1997 National Alliance for Caregiving/MetLife study of employer costs for working caregivers:<sup>54</sup>

- The majority of caregivers are employed;
- many caregivers quit or change their jobs due to their caregiving Responsibilities; and
- It is estimated that U.S. businesses lose between \$11 billion and \$29 billion each year due to employees' need to care for loved ones 50 years of age and older.

### **THE MAJORITY OF CAREGIVERS ARE EMPLOYED.**

One in four U.S. households, or estimated 22,411,200 households, are involved in caregiving. The majority of these of these caregivers are employed. This data translates into 14.4 million full and part-time employed caregivers who are balancing work with their caregiving roles.

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<sup>54</sup> National Alliance for Caregiving/MetLife. *The MetLife Study of Employer Costs for Working Caregivers*. Based on data from Family Caregiving in the U.S.: Findings from a National Survey. 1997.

Note: This study focused on caregivers who were employed full-time and who were providing personal care. These caregivers were, on average, providing assistance with 2 or more Activities of Daily Living (bathing, feeding, toileting, transferring from chair or bed, or walking), and 4 or more Instrumental Activities of Daily Living (financial management, transportation, help with medications, shopping, preparing meals, etc.) for an average of at least 9 hours of care each week. This study based its estimates of the costs of caregiving to businesses upon the estimated 5.7 million of such caregivers.

## **MANY CAREGIVERS QUIT OR CHANGE THEIR JOBS DUE TO THEIR CAREGIVING RESPONSIBILITIES.**

According to the 1997 MetLife Study of Employer Costs for Working Caregivers (Metlife Study), one-tenth of caregivers permanently left the workforce; of these caregivers, 4% took early retirement and another 6% left work without any retirement benefits. Another 11% of caregivers reported that they took a leave of absence; 7% of caregivers changed from full-time work to part-time work or took a less demanding job.

## **IT IS ESTIMATED THAT U.S. BUSINESSES LOSE BETWEEN \$11 BILLION AND \$29 BILLION EACH YEAR DUE TO EMPLOYEES' NEED TO CARE FOR LOVED ONES 50 YEARS OF AGE AND OLDER.**

### **REPLACEMENT COSTS FOR EMPLOYEES WHO QUIT IN ANY YEAR**

Seventeen percent of caregivers who were employed when they began providing personal care reported in the Metlife study that they quit their jobs or took early retirement because of their caregiving responsibilities.

Replacement costs, including recruiting, relocation, training, the temporary inefficiency of new hires and vacant positions, have been estimated to cost employers as much as \$5 billion annually.<sup>55</sup>

### **WORK HOURS LOST DUE TO ABSENTEEISM**

One in ten employed caregivers providing personal care were absent a minimum of three or more days in a six months period previous to the Metlife study (or a minimum of 6 days per year) due to caregiving responsibilities.

Fifty-nine percent of caregivers providing personal care who are employed reported that they had to adjust their work schedules, including changing their lunch hour, leaving work early, and so forth. On average, these caregivers lost a minimum of 1 hour per week for an aggregate annual loss of 50 hours per caregiver that could not be made up.

### **WORK HOURS LOST DUE TO WORKDAY INTERRUPTIONS**

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<sup>55</sup> National Alliance for Caregiving/MetLife. *The MetLife Study of Employer Costs for Working Caregivers*. Based on data from Family Caregiving in the U.S.: Findings from a National Survey. 1997.

Many caregivers reported in the Metlife study that they experienced interruptions during the day due to the performance of caregiving tasks, such as making phone calls to the care recipient or to service providers, receiving phone calls, and so forth. The total lost work time due to these interruptions were estimated at 1 hour per week for 50 weeks for those employed caregivers providing personal care.

### **WORK DAYS LOST DUE TO ELDERCARE CRISES**

Sixty percent of employed caregivers reported experiencing an eldercare crisis in the six months prior to the Metlife study (e.g., the person receiving care was hospitalized.) The Metlife study estimated the time lost to additional phone calls, loss of concentration and partial absenteeism in dealing with such crises at 3 days per year.

## KEY TRENDS AFFECTING CAREGIVING

### NATIONALLY

#### **THE U.S. POPULATION IS AGING.**

The population aged 65 years old and older is expected to double, from 35 million persons in 2000 (representing 12% of the population) to an estimated 70 million person by 2030 (representing 20% of the population).<sup>56</sup>

The very old, aged 85 years old or older—those most in need of long-term care—are the fastest growing segment of the U.S. population. This age group is expected to grow from approximately 4 million persons in 2000 to an estimated 9 million persons in 2030.

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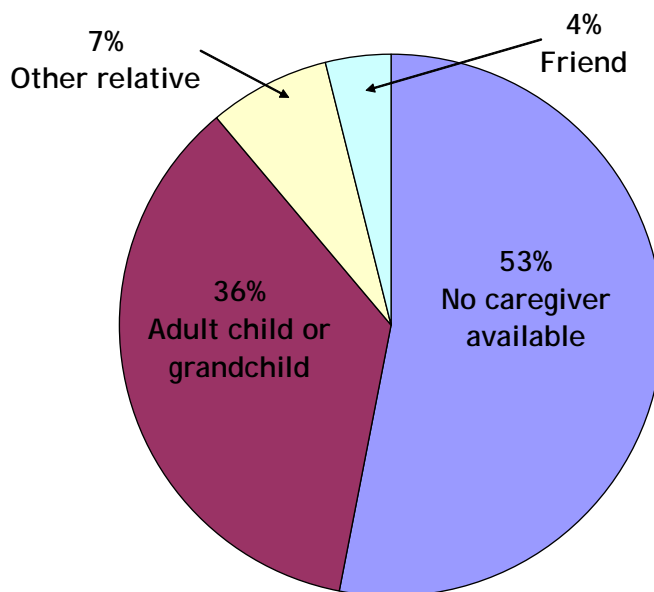
<sup>56</sup> U.S. Administration on Aging. *A Profile of Older Americans: 2003*.

## MILLIONS OF ELDERLY ARE PROJECTED TO NEED CARE.

The majority of people who do not have caregivers do not expect to have a caregiver in the future. Among older adults aged 70 years old and older who were not receiving help at the time of the study, more than half (53%) reported that they did not expect to have a caregiver available in the future; whereas approximately one-third (36%) reported their belief that their child or grandchild would be available to provide them needed care.<sup>57</sup>

**FIGURE 20: AVAILABILITY OF CAREGIVERS IN THE FUTURE AS PERCEIVED BY PERSONS AGED 70 YEARS OLD AND OLDER WHO DO NOT CURRENTLY RECEIVE HELP**

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Based on national data.

Source: National Academy on an Aging Society analysis of data from the 1993 study of Assets and Health Dynamics Among the Oldest Old (AHEAD) or persons aged 70 years old and older. Reported in: National Academy on an Aging Society. *Caregiving: Helping the Elderly with Activity Limitations*. Number 7, May 2000.

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<sup>57</sup> National Academy on an Aging Society analysis of data from the 1993 study of Assets and Health Dynamics Among the Oldest Old (AHEAD) or persons age 70 and older. Reported in: National Academy on an Aging Society. *Caregiving: Helping the Elderly with Activity Limitations*. Number 7, May 2000.

**MANY ELDERLY WITH ACTIVITY LIMITATIONS EXPECT TO MOVE. EXPECTATIONS ABOUT CARE IN THE FUTURE VARY BY GENDER.**

Approximately one in four persons ages 70 and older with activity limitations report that they are likely to move in the next five years.<sup>58</sup>

Of those who expect to move in the next five years, a higher proportion of men than women expect to buy or rent a residence. Women are more likely to expect that they will live in a setting where care may be available, such as a retirement home/community, another person's home, or nursing home.<sup>59</sup>

**TABLE 10: WHERE DO PEOPLE AGE 70+ WITH ACTIVITY LIMITATIONS WHO EXPECT TO MOVE THINK THEY WILL LIVE IN THE NEXT FIVE YEARS?**

	% OF MEN WHO EXPECT TO MOVE	% OF WOMEN WHO EXPECT TO MOVE
Would buy or rent	64%	38%
Another person's home	10%	17%
Nursing home	7%	15%
Retirement home/community	19%	30%
Total	100%	100%

Based on national data.

Source: National Academy on an Aging Society analysis of data from the 1993 study of Assets and Health Dynamics Among the Oldest Old (AHEAD) or persons age 70 and older. Reported in: National Academy on an Aging Society. *Caregiving: Helping the Elderly with Activity Limitations*. Number 7, May 2000.

<sup>58</sup> National Academy on an Aging Society analysis of data from the 1993 study of Assets and Health Dynamics Among the Oldest Old (AHEAD) or persons age 70 and older. Reported in: National Academy on an Aging Society. *Caregiving: Helping the Elderly with Activity Limitations*. Number 7, May 2000.

<sup>59</sup> *Ibid.*

## IN HAWAII

### SEVERAL KEY TRENDS AFFECT HAWAII'S LONG-TERM CARE SYSTEM

Available data and literature, as well as discussions with various stakeholders and the focus group participants identified several key trends affecting long-term care system nationally and in Hawaii.

#### PERCENT AND NUMBER OF HAWAII'S OLDER ADULT POPULATION CONTINUES TO GROW

Hawaii's older adult population (60 years of age or older) continues to grow in number and as a percent of the State's total population. In 1980, there were 113,944 adults aged 60 years old or older, which represented 12% of the total population. By 2000, there were 207,001 individuals aged 60 years old or older, which represented 17% of State's total population. With the aging of the baby boomer generation, it is projected that, by 2020, one in four persons will be aged 60 years old or older.

Between 1980 and 2000, Hawaii's older adult population increased by 82%, while the State's total population increased by 26%.

The population aged 85 years old or older increased even more dramatically. While the total population increased by 26% from 1980 to 2000, the population aged 85 years old or older increased by 216%.<sup>60</sup>

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<sup>60</sup> U.S. Census Bureau, Hawaii data.

## HAWAII OLDER ADULT POPULATION IS INCREASING FASTER THAN IN THE REST OF THE U.S.

The older adult population in Hawaii is increasing considerably faster than in the rest of the country. While Hawaii's older adult population increased by 19% between 1990 and 2000, the U.S. as a whole saw a 9% increase in individuals aged 60 years old or older over the same time period. Between 1990 and 2000, Hawaii's population aged 85 years old or older grew 69%, while the same population group grew 38% nationally.

**TABLE 11: HAWAII'S OLDER ADULT POPULATION**

	1980 <sup>1</sup>	1990 <sup>1</sup>	2000 <sup>1</sup>	2010 <sup>2</sup>	2020 <sup>2</sup>
60+ population % of total population	113,944 12%	173,733 16%	207,001 17%	272,378 21%	361,549 26%
85+ population % of total population	5,561 0.6%	10,397 0.9%	17,564 1.4%	31,187 2.4%	38,867 2.8%
Total population	964,691	1,108,229	1,211,537	1,291,058	1,406,248

Based on Hawaii data.

Source: <sup>1</sup> U.S. Census Bureau.

<sup>2</sup> Hawaii Department of Business, Economic Development and Tourism, Research and Economic Analysis Division, DBEDT 2025 Series. *Population and Economic Projections for the State of Hawaii 2025*. February 2000.

## LIFE EXPECTANCY CONTINUES TO INCREASE.

Life expectancy continues to increase, with Hawaii enjoying one of the highest life expectancies in the nation.

**TABLE 12: U.S. AND HAWAII LIFE EXPECTANCY, IN YEARS**

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	1910	1920	1930	1940	1950	1960	1970	1980	1990	2000
U.S.	50.0	54.1	59.7	62.9	68.2	69.7	70.8	73.7	75.4	76.9
Hawaii:										
Men	44.0	45.6	52.7	59.9	67.8	70.4	72.1	74.5	75.9	77.2
Women	43.8	45.8	55.9	64.9	71.7	74.8	76.4	81.5	82.1	82.7
Total	44.0	45.7	54.0	62.0	69.5	72.4	74.2	77.8	78.9	79.9

Source: Centers for Disease Control and Prevention. *National Vital Statistics Reports. 2003*; and Hawaii Department of Business, Economic Development and Tourism. *The State of Hawaii Data Book. 2003*.

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Even though Hawaii residents enjoy high life expectancy, there are major differences in life expectancy across the race/ethnicity groups in the State.

**TABLE 13: HAWAII LIFE EXPECTANCY BY RACE/ETHNICITY, IN YEARS**

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YEAR	CAUCASIAN	CHINESE	FILIPINO	NATIVE HAWAIIAN	JAPANESE	OTHER
1970	73	76	73	68	77	77
1980	76	82	79	72	81	79
1990	76	83	79	74	82	80

Based on Hawaii data.

Source: Hawaii Department of Health, Office of Health Status Monitoring.

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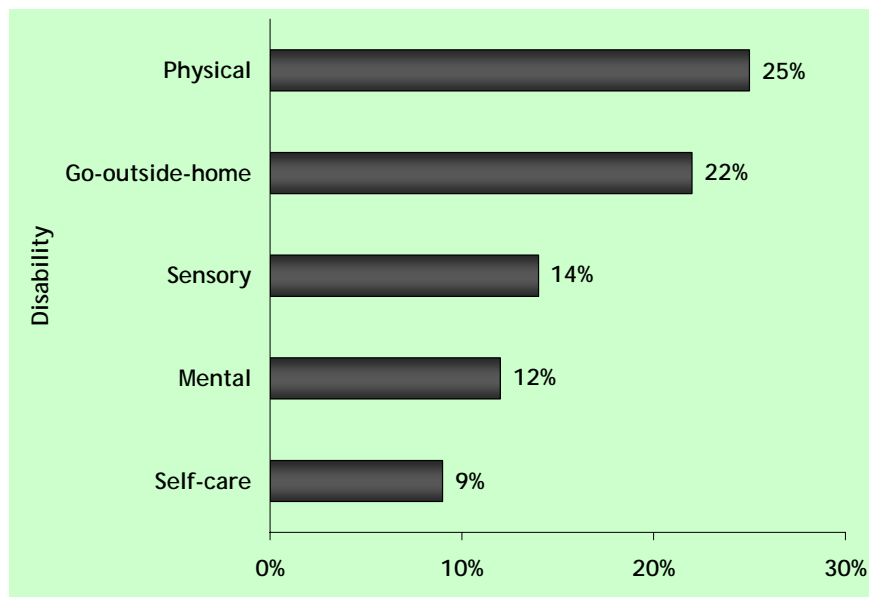
## WOMEN OUTNUMBER MEN.

As in the U.S. (and also as a whole in the world and in other countries), women have higher life expectancy than men and, thus, outnumber men. With advancing age, the differences in life expectancy become greater. For example, , women in Hawaii comprised 55% of the population aged 60 years old or older, 56% of the population aged 65 years old or older, and 59% of the population aged 60 years old or older.<sup>61</sup>

## MANY OLDER ADULTS HAVE AT LEAST ONE DISABILITY.

Approximately four out of ten persons aged 65 years old or older have a disability, defined as having one or more of the following disabilities: sensory, physical, mental, self-care, and/or go-outside-the-home-alone. Over half of these persons have at least two of these disabilities.<sup>62</sup>

**FIGURE 21: PERCENT OF ADULTS AGED 65 YEARS OLD OR OLDER WHO HAVE SPECIFIC DISABILITIES**



Based on Hawaii data.

Source: U.S. Census Bureau. *Census 2000*.

<sup>61</sup> U.S. Census Bureau. *Census 2000*.

<sup>62</sup> *Ibid.*

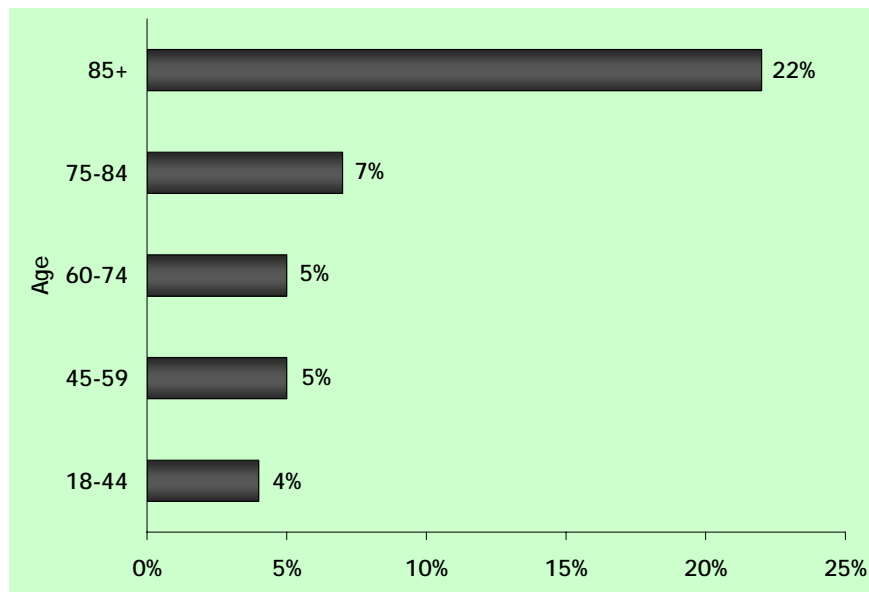
The most common type of disability among older adults is a physical disability, which includes difficulty walking, climbing stairs, reaching, lifting, or carrying, and which affects approximately one in four adults ages 65 and over. Approximately one in five adults ages 65 and over have a disability that inhibits them from going outside the home alone (e.g., to shop, run errands, go to a doctor appointment, etc.). Other common disabilities include sensory limitations (blindness, deafness, or a severe vision or hearing impairment), cognitive or mental disabilities (learning, remembering, or concentrating), and self-care disabilities (dressing, bathing, getting around the house).<sup>63</sup>

### NEED FOR ASSISTANCE WITH PERSONAL CARE INCREASES WITH AGE.

As may be expected, the need for personal care increases with age. Approximately 5%, 7% and 22% of adults in the 60-74, 75-84 and 85+ age groups respectively, report that they need help with personal care.<sup>64</sup>

**FIGURE 22: PERCENT OF ADULTS WHO NEED HELP WITH PERSONAL CARE**

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Based on Hawaii data.

Source: Hawaii Department of Health. *Hawaii Health Survey. 2000.*

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<sup>63</sup> U.S. Census Bureau. *Census 2000.*

<sup>64</sup> Hawaii Department of Health. *Hawaii Health Survey. 2000.*

## **SEVERAL FACTORS CONSTRAIN HAWAII'S LONG-TERM CARE SYSTEM.**

Available data and literature, as well as discussions with various stakeholders and focus group participants, identified several factors that constrain Hawaii's current long-term care system.

### **HAWAII HAS A VERY LIMITED AVAILABILITY OF NURSING HOME BEDS.**

Hawaii is faced with low availability of nursing home beds: the State has fewer than half the national average of long term care beds per 1,000 population aged 65 or over.<sup>65</sup>

### **HAWAII IS FACED WITH A MAJOR SHORTAGE OF TRAINED LONG-TERM CARE PROFESSIONALS.**

Participants in the focus group discussions expressed uniform consensus that the State is faced with a severe shortage of trained long-term care professionals, and that "it is only going to get worse."

### **HAWAII HAS A LONG TRADITION OF CARE RECIPIENTS DEPENDING UPON EXTENDED FAMILY TO PROVIDE LONG-TERM CARE.**

Hawaii has a long tradition of depending on extended family to provide long-term care at home.

A 1995 Alu Like survey of Native Hawaiian family caregivers found that caregivers were reluctant to use services, mainly because of cultural values, attitudes that home and community-based services were "not for Hawaiians," and the notion of "family members being neglectful of their kupuna [elder] by having them turn to strangers to meet their needs"<sup>66</sup>

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<sup>65</sup> Healthcare Association of Hawaii.

<sup>66</sup> Family Caregiver Alliance. *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since Passage of the National Family Caregiver Support Program*. 2002.

## HAWAII CAREGIVER NEEDS

Discussions with various stakeholders and participants in the focus groups revealed that:

- There is a clear consensus that family caregivers constitute the “backbone” of the State’s long-term care system, and that family members are the primary providers of long-term care.
- There was clear perception and consensus that the State’s support of family caregiving is rather limited and not sufficient.
- There is a lack of data on the prioritized needs that the State should address to increase its support of family caregiving in Hawaii, with a range of suggestions and indicated priorities depending on the stakeholder perspective and/or personal family experiences.

The following themes arose with regard to alternative approaches to support Hawaii caregivers:

- Affordable respite care—in a variety of formats (e.g., overnight, weekend options), in sufficient amounts
- Financial measures
- Counseling/support services for caregivers
- Information on services available to caregivers within the State and on how to access these services
- Caregiver education and training, especially for skills-based training.

## DATA ISSUES, IMPLICATIONS, AND RECOMMENDATIONS

### INTERPRETING NATIONAL AND HAWAII DATA ON CAREGIVERS

Data on caregivers and the persons for whom they care come from a wide variety of sources and studies. These various studies and sources:

- Follow different methodologies
- Focus on different aspects of caregiving
- Ask questions on different topics and/or on similar topics but use differently-worded questions, and
- Most importantly, often use varying definitions of a caregiver and a care recipient.

As a result, certain statistics often vary widely from source to source. Thus, national statistics derived from the most commonly referenced caregiver studies—all of which are conducted by highly reputable agencies that follow rigorous methodologies—produce estimates of the number of caregivers ranging from as low as 5.9 million caregivers to as high as 52 million caregivers in the U.S. These variances illustrate the need to exert great care in interpreting those statistics and placing them in the proper context.

This same caution should be used when interpreting Hawaii data on caregivers as well. Even though the estimates of the number of caregivers in the State derive from the same survey question, these caregiver surveys, the BRFSS and HHS, are conducted using different sampling methodologies.

## WHO IS A CAREGIVER?

**“THE TERM ‘CAREGIVER’ MEANS DIFFERENT THINGS TO DIFFERENT PEOPLE.”**

In general usage, the term “caregiver” refers to anyone who provides assistance to someone else that is in some degree incapacitated and needs help. But—“The term means different things to different people.”

As one participant in the focus groups expressed it,

*“Everybody talks about a caregiver, but maybe not everybody is talking about the same phenomenon. The definition of a caregiver varies. Does being a caregiver depend on frequency, intensity (time spent each contact), duration (length of real time involvement) or degree of difficulty of assistance? Does the person live in-home, live out of home, or live out of state? Can a person be a caregiver to an older adult living in a licensed setting? The term means different things to different people.”*

Discovering just how multifaceted the term “caregiver” is, depending on stakeholder perspective and/or personal experiences, was one of the most important revelations in the focus group discussions. This variance in the meaning of the term echoes the wide spectrum of definitions of a “caregiver” used nationally.

The wide spectrum in the definitions of a “caregiver” reflects diversity in the type and amount of care provided by each caregiver, and the varying consequences and impact of the type of care provided. Some caregivers provide only occasional care, while certain caregivers provide care 24 hours a day and 7 days a week; some are “long-distance” caregivers, while others live with the care recipient in the same household. Not every caregiver provides “hands-on” care. Some caregivers are primary caregivers, i.e., they provide most of the care, while others are secondary caregivers and supplement care provided by others.

## **THE NEED FOR SEVERAL DEFINITIONS OF A CAREGIVER, DEPENDING ON "DEFINITION FOR WHAT PURPOSE?"**

Participants in the focus group discussions stated that the way "caregiver" is defined and the level of specificity of the term may and probably should depend on the purposes and usage of the definition. Specifically, we may need to have at least three definitions of a "caregiver," depending on the definition's purpose and usage:

- **"Caregiver" definition for general purposes**, such as estimates of number of caregivers in the State, obtaining demographic characteristics of caregivers and so forth;
- **"Caregiver" definition for the purpose of defining eligibility criteria for services and programs**; estimating number of people that would be eligible for those services and programs, and budget projections;
- **"Caregiver" definition for the purpose of defining eligibility criteria for any proposed financial assistance for caregivers**; estimating number of people that would benefit from financial assistance, and fiscal projections.

All of the definitions regardless of the purpose or usage should explicitly state:

- Types of care provided (e.g., personal care, with how many Activities of Daily Living, etc.)
- Ages of care recipients (e.g., caring for a person aged 60 years old or older)
- Timeframe to which the question refers (e.g., currently, in the last month, in the last 12 months, ever).

## CAREGIVERS GO THROUGH STAGES OF CAREGIVING.

Another issue closely related to the issue of defining the term “caregiver” is the issue related to defining the stages of caregiving. To capture the diversity of the “caregiver” phenomenon, several focus group participants and the EOA staff pointed to the nationally recognized conceptual framework of stages of caregiving (the so-called Montgomery stages of caregiving framework<sup>67,68</sup>).

The Stages of Caregiving framework is based on the premise that caregiving is a dynamic process which unfolds over time. This framework outlines the following key stages in the “caregiver career” that mark significant shifts in caregiving experiences (see Appendix for details):

- I. Performing caregiving tasks
- II. Self-definition as a caregiver
- III. Performing personal care
- IV. Seeking assistance and formal service use
- V. Institutionalization
- VI. Termination of the caregiving role

Acknowledging several distinct stages of caregiving, as conceptualized in the above-described framework, has major implications for planning and delivery of caregiver support services, and, thus, data collection and interpretation:

- Caregivers may need a range of caregiver support services. For example, certain caregivers simply need information; certain caregivers may need emotional support; certain other caregivers may need assistance with direct care tasks and respite.
- Caregivers may need different types of support, depending upon the “stage of caregiving.” For example, respite is not really needed in the early stages of caregiving, but may be desperately needed in later stages.
- Caregiver support needs are likely to be different for different cultural groups, as different cultures experience the stages of caregiving differently and have different community and family resources to draw on.
- If services are not available at certain stages of caregiving, caregivers may prematurely consider nursing home placement.

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<sup>67</sup> Montgomery, R.J.V., & Hatch L. *The Feasibility of Volunteers and Families Forming a Partnership for Caregiving*. In Brubaker T (Ed.), *Family and Long-term Care* (pp. 143-161). 1997. Beverly Hills, CA: Sage Publications.

<sup>68</sup> Pearlin, L.I. The Careers of Caregivers. *The Gerontologist*, 32:647. 1992.

- Without proper services and support, many caregivers disrupt their employment, change jobs, or quit them altogether, often with major consequences for the caregiver's retirement and financial resources.

**MANY CAREGIVERS DO NOT SELF-IDENTIFY THEMSELVES AS CAREGIVERS.**

As one caregiver who participated in the focus group discussions shared her experience:

*"What is a caregiver?!... I have been taking care of my father who has dementia for the last eleven years. This year I got to the point of feeling on the edge all the time, with never enough sleep, always worried. Can hardly leave home... I went to talk to my doctor, asking him what to do. He said, "You are a caregiver. There are some services and support groups that you may use to help."*

*What is a caregiver?!... This was the first time I heard the term, learned that what I have been going through has a name, and that there are services out there... Eleven years... What's a caregiver?! I am a daughter, that's what I am!"*

There was a clear consensus among a broad spectrum of participants in the focus groups that:

- Many Hawaii caregivers would not necessarily call themselves "caregivers." Instead, they think of themselves as "wife," "husband," "daughter," "neighbor," etc.
- Many Hawaii caregivers would feel uncomfortable "labeling" themselves as "caregivers," performing "caregiving." They feel, "It is my duty as a daughter/son to take care of my parents," "It is my duty as a wife/husband to take care of my spouse."
- Not self-identifying as caregivers may be one of the factors why many Hawaii caregivers are not willing or may not be able to seek outside help and services.
- Hawaii, with its long-standing tradition of placing great value on family values and on taking care of one's family members in the home, may have many more "un-self-identified" caregivers than on the mainland.

This consensus echoes very closely growing awareness nationally that "self-identified" caregivers are only "the tip of the iceberg."

High prevalence of caregivers who do not self-identify themselves as such has major implications for program and service planning and delivery, as well as data collection and interpretation:

- High numbers of caregivers that do not self-identify themselves as such imply that estimates of the number of people who are caregivers are likely to be underestimated.
- Self-identifying as a caregiver has important implications: according to national studies, family caregivers who acknowledge their role are more proactive in reaching out for resources.<sup>69</sup>
- Not “self-identifying” may foster relative invisibility of caregiver issues at the state level.
- Not “self-identifying” may impede with caregivers’ empowerment in the communities and limit opportunities for their recognition in the state.

Participants in our focus groups expressed consensus that considerable effort should be directed at raising the awareness of caregiving issues within the caregivers themselves, emphasizing that they are not alone in caring for their family members in need, as well as at the community and state level.

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<sup>69</sup> National Family Caregivers Association. *Survey of Self-Identified Family Caregivers, 2001*.

**CAREGIVERS AND CARE RECIPIENTS:  
WHO IS THE FOCUS? WHO IS THE CLIENT?  
CAREGIVERS HAVE THEIR OWN NEEDS ABOVE AND BEYOND  
WHAT CARE RECIPIENTS NEED.**

Although obviously the “caregiver” and “care recipient” phenomena cannot exist without each other, they are very distinct. As one participant in the focus groups stated,

*“Caregivers have their own needs above and beyond what care recipients need.”*

*“There is a push-pull between the needs of older adults and the needs of caregivers.”*

In Hawaii’s system of support, only the National Family Caregiver Support Program administered by the EOA explicitly focuses on serving caregivers, whereas Kupuna Care administered by the EOA and the Medicaid Waiver and Nursing Home Without Walls programs administered by the Department of Human Services focus on care recipients.

Discovering the importance of this distinction and explicitly acknowledging it was one the major revelations of the focus group discussions.

## DATA NEEDS ON CAREGIVING IN HAWAII

There was consensus among focus group participants, particularly among participants representing advocacy groups, that:

- Data on caregiving in the State are extremely limited
- Lack of credible, useful information on caregiving issues in the State constitutes one of the key obstacles in developing and implementing mechanisms for addressing caregiver needs, via, for example, data-based advocacy efforts and potential financial assistance
- Available data on aging are "scattered around," and difficult to access.

**PARTICIPANTS SUGGESTED THAT COLLECTING AND DISSEMINATING DATA ON THE FOLLOWING CAREGIVING ISSUES WOULD BE PARTICULARLY HELPFUL IN SUPPORTING EFFORTS TO ADDRESS CAREGIVER ISSUES IN THE STATE:**

**DATA ON UTILIZATION OF SERVICES FOR CAREGIVERS AND CARE RECIPIENTS:**

To what extent are the caregivers using services available to them?

Are caregivers aware of the services available to them?

What are the barriers to utilization of services available to caregivers?

Data is needed to justify need to allocate resources.

To help decision makers and planners, data is needed regarding the characteristics and geographic locations of the population to be served.

**DATA ON RETIREMENT CONSEQUENCES TO CAREGIVERS:**

What percent of caregivers quit their jobs or make other job-related adjustments because of their caregiving responsibilities?

What would help caregivers keep their jobs?

## **DATA ON CURRENT AND PROJECTED SHORTAGES OF FORMAL CARE PROFESSIONALS:**

Participants in several focus groups emphasized that Hawaii faces a serious shortage of workers trained to provide formal care to the elderly needing personal assistance, in part due to the limited educational opportunities for training as a nurse and in other similar fields in Hawaii. Focus group participants emphasized that having data on current and projected shortages of direct care workers may help raise awareness of this issue.

One of the focus group participants shared her experiences based on her work with many families,

*"There may be a need for more trained long-term care providers. If they were available, would the facilities hire enough to overcome the current negative comments from families who have patients in those facilities? "Not enough nurses aides to feed patients." "Unless I changed my mother's wet diaper, the staff would not come for hours even when I asked them." "The staff took my mother's hearing aide and now they think she has dementia. She can't hear them." "I am not keeping my husband in a nursing home. They are so short of staff. Nobody will see him unless I am there.""*

There seems to be consensus that the shortage is a long-term problem, especially in light of the aging of the baby boomer generation that will result in many professionals retiring and at the same time aging. Participants in our focus groups representing the State's higher education system expressed that data documenting shortage of formal care professionals and projected future needs for such professionals will help mount State's support of growing local educational capacities.

## **DATA COLLECTION AND DISSEMINATION:**

Focus group discussions highlighted many important experiences, concerns, and questions that caregiver data users in the State have regarding data collection and dissemination:

"Relationships count," i.e., the need to recognize culturally appropriate approaches to collecting and disseminating data and information.

Issues of data credibility; consistency; and quality and integrity of data collected across the communities.

Who should pay for collecting certain data?

How could the cost of data collection be shared?

Need to partner with multiple agencies (e.g., DOH, DHS, other agencies) for collecting, disseminating and using data.

Identify partners who need data on aging. Establish collaboration to share costs, effort, resources, and results.

Integrate State agencies' collection, dissemination, and use of data; current integration is impeded by the fact that different programs are funded by different agencies, and thus have different data reporting requirements.

Report at community levels to facilitate using data by the communities  
When discussing data collection and usage, need to have representation from funding sources (e.g., to facilitate communication of priorities, etc.).

Assure that the data is available and is used for planning purposes.

### **DATA ON NATIONAL AND LOCAL BEST PRACTICES FOR CAREGIVER PROGRAMS:**

Need best practices data on what other states are doing for caregivers; what works, what does not work, and what can be "borrowed," keeping in mind the cultural specifics of Hawaii.

Need to consider the best practices data from other related subject matter studies; for example, from advocacy efforts aimed at childcare and persons with developmental disabilities.

### **BEST PRACTICES IN REPORTING DATA:**

Participants in several focus groups mentioned the *KidsCount* data program as a possible effective approach to reporting data on aging in general and caregiving in particular in Hawaii.

### **PARTICIPANTS IDENTIFIED THE FOLLOWING CHALLENGES TO BE ADDRESSED:**

Participants in several focus groups expressed their perception that caregiver issues do not receive sufficient attention outside the aging network, and that a public awareness campaign may be need.

Caregivers are often overextended and have no time to be active in advocacy efforts.

Participants in several focus groups noted that multiple organizations and individuals in the State coordinate the actions of the multiple organizations in the State share a concern about caregiver issues and need data on caregiving-related issues. However, there is a lack of coordination, which seems to constitute a major barrier to action.

## **PARTICIPANTS IDENTIFIED STEPS THAT THEY BELIEVE WOULD BENEFIT HAWAII CAREGIVERS:**

Recommend increased recognition of the importance of family caregivers.

Develop a public awareness campaign.

Address the State's shortage of trained care professionals and the looming imbalance between the growing number of chronically ill elderly and available caregivers.

Review and assess what other states are doing to support caregivers; identify best practices, and determine whether these best practices may be utilized in this State given Hawaii's unique features.

Build a framework for data-based advocacy strategies that can generate public support for caregivers in Hawaii.

Create a central repository of information about caregiving-related services and programs, and store information that is in a current, user-friendly format and language, and that is well publicized. Ensure consumers know what is available.

Develop a State legislative framework on caregiving, with input and consensus from all the stakeholders. Establish a single champion to lead and facilitate this effort.

Create a "body" in which caregiver organizations may participate and which major functions will include, but not be limited to, coordination and steering of actions to support Hawaii caregivers; exploration of different models for a mechanism of action; and speaking with a single voice about caregiver issues. However, participating organizations will not and should not abandon their own issues and agendas, and will instead focus on partnering with the other

participating organizations to achieve a single, uniform voice for caregiver issues.

Develop a media strategy.

Investigate and assess different models of addressing caregivers' needs.

Consider creating a single data place with valid and reliable indicators on aging issues in Hawaii, including caregiving.

Define "family caregiving" and "caregiver" so that efforts will have correct focus, recognizing, however, that there may be a need to develop several definitions of a "caregiver," depending upon the definition's purpose and usage (e.g., as a general definition, definition for service eligibility criteria, and/or definition for any considered financial assistance).

## **DATA ON GRANDPARENTS RAISING GRANDCHILDREN:**

Although outside the scope of the present Resolution, another issue that has consistently been identified as a high priority is the issue of grandparents raising grandchildren.

## CONCLUSIONS AND RECOMMENDATIONS

It is recognized nationally, and there is a strong consensus locally in Hawaii as well, that family caregivers are the primary providers of care and assistance to older persons. Thus, family caregivers constitute the backbone of the national and State's long-term care system.

Considerable amount of data from a number of national sources and studies clearly demonstrates the enormous value of the care provided by the family caregivers and the extent of informal caregiving that far exceeds formal caregiving. However, national data also reflects the cost of caregiving to the caregivers themselves, in terms of negative impacts of caregiving responsibilities on caregivers' own health, employment, retirement, and other aspects of their lives. Thus, there is growing effort nationwide to strengthen support of family caregivers and to better address caregivers' and care recipients' needs to enable persons with disabilities to stay in the communities.

National data on caregiving comes almost exclusively from a few, discrete national studies that specifically address caregiving. As is commonly the case with other national studies, Hawaii has not been represented in these studies or has received extremely limited representation in these studies. As a result, population-based, representative data on caregiving in the State of Hawaii comes almost exclusively from a couple of State studies. The Hawaii State Executive Office on Aging has sponsored and coordinated a collection of State data on caregivers since 2003 via the State's two primary sources of population health data—the Behavioral Risk Factor Surveillance System (BRFSS) and Hawaii Health Survey (HHS). Both studies are collected by the Hawaii State Department of Health.

To develop and actively pursue strategies to address the needs of Hawaii caregivers, the following recommendations have emerged for the collection, use, and dissemination of data on caregivers in Hawaii:

- Future collection of caregiving-related data should be focused on the types of data that can have direct applicability to State policies and programs and to service planning, implementation, and evaluation. For example, for the State to consider and evaluate feasibility and expected impact of any Legislative caregiver support measures, clear definitions of a caregiver should be developed, with attention to the definition's intended purpose and usage (e.g., for service eligibility or eligibility for

any financial assistance). Data should then be collected on the number of people who fit within those definitions and thus would be eligible for existing or proposed services and programs in order to calculate the expected costs of such measures.

- Immediate efforts should be devoted to collecting reliable data to identify and prioritize the needs of caregivers in the State of Hawaii and to develop culturally appropriate ways to address those needs. Considering the cultural uniqueness of Hawaii, this type of information is not easily extrapolated from the national studies. Thus, this information should be collected locally, and in close partnership with the State's caregivers, advocacy groups, and other stakeholders.
- At the present, there is a common perception that data on aging, including data on long-term care issues, is "scattered around." Thus, immediate effort should be devoted to developing and promoting some form of centralized place for State data and information pertaining to aging. In addition, because many groups and agencies in the State share common concerns and interests in aging issues, efforts should be devoted to coordinating a partnership (and possibly a cost-sharing relationship) between these groups and agencies with regard to aging data collection and dissemination.

## APPENDIX

### MAJOR NATIONAL STUDIES AND REPORTS ON CAREGIVING

#### CAREGIVING IN THE U.S. (1997)

"Caregiving in the U.S." is a landmark report that was published in 1997 by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP). This report is based on data from a random sample of households.

This widely referenced report estimated that **22.4 million households** involved in caregiving in the U.S. at that time.

This study used the following **definition of caregiving**:

- Caring for persons over the age of 50
- Care occurring some time within the past 12 months
- For persons with limitations in their ADL's (Activities of Daily Living) and/or IADL's (Instrumental Activities of Daily Living)

#### THE ECONOMIC VALUE OF CAREGIVING (1998)

In 1998, Peter Arno, Ph.D., and his colleagues published results of their analysis on the economic value of caregiver services. They estimated that caregiver contributions for unpaid labor and services amount to approximately \$196 billion a year, which is an estimate that is widely quoted.

To develop this estimate, Dr. Arno calculated the number of individual caregivers, as opposed to households in the US. He based his mid-range estimate of **25.8 million caregivers** on data from the National Survey of Families and Households (NSFH) for 1987 and 1988 and the Survey of Income and Program Participation (SIPP) for 1986. These data were projected forward to 1997.

This study used the following **definition of caregiving**:

- Caring for persons at least 15 years of age (SIPP) or 18 years of age (NSFH)
- Providing personal care
- For persons needing assistance because of a health condition (SIPP) or disability or chronic illness (NSFH).

## **INFORMAL CAREGIVING: COMPASSION IN ACTION (1998)**

"Informal Caregiving: Compassion in Action," which was published in 1998 by the Assistant Secretary for Planning and Evaluation (ASPE) and the Administration on Aging of the U.S. Department of Health and Human Services, is another landmark report on caregiving.

The data analysis in this study had two parts. Part I analyzed data on "informal" care from the National Survey of Families and Households, NSFH (1987 and 1992). This analysis resulted in an estimate of **52 million caregivers** (31% of the adult population age 20-75) who during the course of any year provide unpaid care to a family member or friend who is ill or disabled.

Part I of the study used the following **definition of caregiving**:

- Caring for persons ages 20 or older
- Providing "informal care" to a family member or friend of any age who is ill or disabled.

Part II looked at a more specific population of caregivers, namely caregivers caring for persons ages 65 and older who needed assistance with everyday activities. This analysis resulted in an estimate of **7 million caregivers** who during the course of any year provide care to a persons aged 65 years old or older.

Part II of the study used the following **definition of caregiving**:

- Caring for persons ages 65 or older
- Providing assistance with everyday activities to a care recipient.

## **NATIONAL FAMILY CAREGIVERS ASSOCIATION SURVEY (2000)**

In 2000, the National Family Caregivers Association (NFCA) published a report which stated that, during the year prior to the study, **54 million people** had been a caregiver and provided some level of caregiving. This number, which was slightly greater than a U.S. government estimate, was based on random sample survey research.

The **definition of caregiving** used in this research effort, which asked questions of adults over the age of 18, included:

- Caring for persons of all ages
- Providing care (interpretation of the term care was left to the respondent)
- Care occurring some time within the 12 months prior to the study
- Care was provided to the care recipient because of a disability or chronic illness or because of the consequences of old age.

## **CAREGIVING IN THE U.S. (2004)**

“Caregiving in the U.S., 2004” is the most recent landmark report that was put together and published by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP), based on data from a random sample of households.

This report estimates that there are **44.4 million caregivers** (21% of the adult population), residing in 22.9 million households (21% of U.S. households) provided unpaid care to an adult ages 18 or older.

The study used the following **definition of caregiving**:

- Caring for persons ages 18 or older
- Care occurring some time within the past 12 months
- For persons with limitations in their ADL's (Activities of Daily Living) or IADL's (Instrumental Activities of Daily Living).

## SOURCES OF HAWAII DATA ON CAREGIVING

### **HAWAII BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS)**

The Behavioral Risk Factor Surveillance System (BRFSS) is a random telephone survey of adults living in private households, conducted yearly in all states of the United States. The BRFSS is a cooperative agreement with the federal Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services and all states, the District of Columbia, and three U.S. territories. It is designed and conducted to collect information about health status, health behaviors and use of health services. The core questions are developed by the CDC and are asked each year by all states. The optional questions are sponsored by different federal and state agencies and may vary from state to state and year to year. Data are used to determine priority health issues, develop strategic plans, and identify appropriate target populations, monitor the effectiveness of interventions, and support appropriate policies. The Hawaii BRFSS is the annual survey conducted by the State of Hawaii, Department of Health.

### **HAWAII HEALTH SURVEY (HHS)**

The Hawaii Health Survey (HHS) was developed by the Hawaii Department of Health (DOH) as a cost-effective way to improve the availability of useful information to State health policy makers. The principal objective of the survey is to provide statewide estimates of population parameters that describe: (1) the current health status of the population; (2) access to and utilization of health care; and (3) the distribution of the population by age, sex, and ethnicity. The Hawaii Health Survey is administered by the State of Hawaii, Department of Health, Office of Health Status Monitoring (OHSM). The HHS is a telephone interview survey administered to adult residents in more than 4,000 households each year.

The current survey instrument is modeled after the National Household Interview Survey (NHIS) conducted by the National Center for Health Statistics (NCHS). All survey respondents are adult residents of the State of Hawaii. Data are collected on all members of sample households, and analysis systems include provisions for handling hierarchical files, including complex data

weighting. The survey has been expanded over the years, in size and content, to serve additional clients including the DOH Family Health Services Division, Papa Ola Lokahi, the DOH Mental Health Division, the University of Hawaii School of Medicine, Queen's Health Systems, Kamehameha Schools, and many others.

## CHARACTERISTICS OF CAREGIVERS BY COUNTY

**TABLE 14: DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; HONOLULU COUNTY**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	8%	13%
25-34	14%	20%
35-44	22%	20%
45-54	20%	18%
55-64	19%	12%
65+	17%	16%
Total	100%	100%
Gender		
Male	41%	52%
Female	59%	48%
Total	100%	100%
Marital status		
Married/living w/ partner	59%	60%
Not married	41%	40%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	18%	27%
Native Hawaiian	19%	14%
Chinese	7%	6%
Filipino	18%	15%
Japanese	26%	24%
Other	12%	14%
Total	100%	100%

Based on Hawaii data. The Table compares demographic characteristics of Honolulu caregivers and non-caregivers. For example, 41% of Honolulu caregivers were male; 52% of Honolulu non-caregivers were male. Among Honolulu caregivers, 18% were Caucasian; among Honolulu non-caregivers, 27% were Caucasian.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 15: SOCIOECONOMIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; HONOLULU COUNTY**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	6%	8%
High school graduate	34%	31%
Some college/technical school	27%	28%
College graduate	33%	32%
Total	100%	100%
Household income		
Under \$10,000	4%	4%
\$10,000 to \$14,999	6%	5%
\$15,000 to \$19,999	4%	4%
\$20,000 to \$24,999	5%	7%
\$25,000 to \$34,999	14%	12%
\$35,000 to \$49,999	17%	17%
\$50,000 to \$74,999	10%	15%
\$75,000 and over	17%	16%
Don't know/not sure/refused	22%	19%
Total	100%	100%
Employment status		
Employed	65%	68%
Retired	22%	17%
Other	13%	15%
Total	100%	100%

Based on Hawaii data. The Table compares socioeconomic characteristics of Honolulu caregivers and non-caregivers. For example, 65% of Honolulu caregivers were employed; 68% of Honolulu non-caregivers were employed.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 16: HEALTH CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; HONOLULU COUNTY**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	8%	6%
General health status		
Excellent	17%	22%
Very good	32%	33%
Good	35%	34%
Fair	11%	9%
Poor	5%	2%
Total	100%	100%

Based on Hawaii data. The Table compares demographic characteristics of Honolulu caregivers and non-caregivers. For example, 8% of Honolulu caregivers had no health insurance; 6% of Honolulu non-caregivers had no health insurance.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 17: DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; HAWAII COUNTY**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	12%	10%
25-34	14%	18%
35-44	19%	22%
45-54	23%	18%
55-64	16%	13%
65+	16%	20%
Total	100%	100%
Gender		
Male	47%	50%
Female	53%	50%
Total	100%	100%
Marital status		
Married/living w/ partner	57%	60%
Not married	43%	40%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	31%	36%
Native Hawaiian	31%	22%
Chinese	0%	2%
Filipino	8%	9%
Japanese	22%	19%
Other	8%	12%
Total	100%	100%

Based on Hawaii data. The Table compares demographic characteristics of Hawaii County caregivers and non-caregivers. For example, 47% of Hawaii County caregivers were male; 50% of Hawaii County non-caregivers were male. Among caregivers, 31% were Caucasian; among non-caregivers, 36% were Caucasian.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 18: SOCIOECONOMIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; HAWAII COUNTY**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	9%	7%
High school graduate	36%	36%
Some college/technical school	30%	29%
College graduate	26%	27%
Total	100%	100%
Household income		
Under \$10,000	8%	7%
\$10,000 to \$14,999	6%	7%
\$15,000 to \$19,999	11%	6%
\$20,000 to \$24,999	8%	8%
\$25,000 to \$34,999	10%	15%
\$35,000 to \$49,999	13%	16%
\$50,000 to \$74,999	14%	13%
\$75,000 and over	13%	10%
Don't know/not sure/refused	17%	17%
Total	100%	100%
Employment status		
Employed	68%	64%
Retired	18%	20%
Other	14%	16%
Total	100%	100%

Based on Hawaii data. The Table compares socioeconomic characteristics of Hawaii County caregivers and non-caregivers. For example, 68% of Hawaii County caregivers were employed; 64% of Hawaii County non-caregivers were employed.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 19: HEALTH CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; HAWAII COUNTY**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	8%	9%
General health status		
Excellent	19%	21%
Very good	26%	33%
Good	44%	31%
Fair	10%	11%
Poor	2%	3%
Total	100%	100%

Based on Hawaii data. The Table compares health characteristics of Hawaii County caregivers and non-caregivers. For example, 8% of caregivers had no health insurance; 9% of non-caregivers had no health insurance.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 20: DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; KAUAI COUNTY**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	14%	10%
25-34	11%	19%
35-44	22%	22%
45-54	18%	17%
55-64	20%	12%
65+	16%	20%
Total	100%	100%
Gender		
Male	43%	51%
Female	57%	49%
Total	100%	100%
Marital status		
Married/living w/ partner	54%	59%
Not married	46%	41%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	27%	33%
Native Hawaiian	17%	15%
Chinese	2%	1%
Filipino	20%	20%
Japanese	13%	13%
Other	21%	18%
Total	100%	100%

Based on Hawaii data. The Table compares demographic characteristics of Kauai caregivers and non-caregivers. For example, 43% of Kauai caregivers were male; 51% of Kauai non-caregivers were male. Among Kauai caregivers, 27% were Caucasian; among Kauai non-caregivers, 33% were Caucasian.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 21: SOCIOECONOMIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; KAUAI COUNTY**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	4%	13%
High school graduate	32%	32%
Some college/technical school	32%	28%
College graduate	32%	28%
Total	100%	100%
Household income		
Under \$10,000	2%	9%
\$10,000 to \$14,999	8%	10%
\$15,000 to \$19,999	5%	5%
\$20,000 to \$24,999	9%	8%
\$25,000 to \$34,999	8%	13%
\$35,000 to \$49,999	17%	16%
\$50,000 to \$74,999	15%	12%
\$75,000 and over	14%	10%
Don't know/not sure/refused	23%	17%
Total	100%	100%
Employment status		
Employed	71%	68%
Retired	16%	21%
Other	13%	11%
Total	100%	100%

Based on Hawaii data. The Table compares socioeconomic characteristics of Kauai caregivers and non-caregivers. For example, 71% of Kauai caregivers were employed; 68% of Kauai non-caregivers were employed.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 22: HEALTH CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; KAUAI COUNTY**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	7%	11%
General health status		
Excellent	19%	18%
Very good	32%	32%
Good	39%	38%
Fair	10%	9%
Poor	0%	2%
Total	100%	100%

Based on Hawaii data. The Table compares health characteristics of Kauai caregivers and non-caregivers. For example, 7% of Kauai caregivers had no health insurance; 11% of Kauai non-caregivers had no health insurance.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 23: DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; MAUI COUNTY**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	12%	10%
25-34	11%	20%
35-44	23%	23%
45-54	12%	19%
55-64	19%	11%
65+	23%	16%
Total	100%	100%
Gender		
Male	49%	51%
Female	51%	49%
Total	100%	100%
Marital status		
Married/living w/ partner	64%	57%
Not married	36%	43%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	33%	38%
Native Hawaiian	19%	16%
Chinese	1%	2%
Filipino	21%	17%
Japanese	16%	16%
Other	10%	11%
Total	100%	100%

Based on Hawaii data. The Table compares demographic characteristics of Maui caregivers and non-caregivers. For example, 49% of Maui caregivers were male; 51% of Maui non-caregivers were male. Among Maui caregivers, 33% were Caucasian; among Maui non-caregivers, 38% were Caucasian.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 24: SOCIOECONOMIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; MAUI COUNTY**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	8%	10%
High school graduate	38%	33%
Some college/technical school	32%	33%
College graduate	22%	24%
Total	100%	100%
Household income		
Under \$10,000	5%	6%
\$10,000 to \$14,999	4%	5%
\$15,000 to \$19,999	3%	6%
\$20,000 to \$24,999	11%	8%
\$25,000 to \$34,999	14%	14%
\$35,000 to \$49,999	13%	20%
\$50,000 to \$74,999	19%	14%
\$75,000 and over	7%	11%
Don't know/not sure/refused	24%	16%
Total	100%	100%
Employment status		
Employed	62%	72%
Retired	25%	18%
Other	13%	10%
Total	100%	100%

Based on Hawaii data. The Table compares socioeconomic characteristics of Maui caregivers and non-caregivers. For example, 62% of Maui caregivers were employed; 72% of Maui non-caregivers were employed.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 25: HEALTH CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS; MAUI COUNTY**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	12%	8%
General health status		
Excellent	16%	24%
Very good	29%	34%
Good	36%	30%
Fair	17%	9%
Poor	2%	3%
Total	100%	100%

Based on Hawaii data. The Table compares health characteristics of Maui caregivers and non-caregivers. For example, 12% of Maui caregivers had no health insurance; 8% of Maui non-caregivers had no health insurance.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

**TABLE 26: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?"  
HONOLULU COUNTY**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	30%	31%
Would provide care myself	44%	22%
Nursing home or home health service	8%	13%
Doctor or nurse	3%	4%
Area Agency on Aging	2%	2%
Other	2%	3%
Don't know whom to call	11%	25%
Total	100%	100%

Based on Hawaii data. The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

**TABLE 27: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?"  
HAWAII COUNTY**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	29%	25%
Would provide care myself	43%	25%
Nursing home or home health service	11%	14%
Doctor or nurse	5%	5%
Area Agency on Aging	2%	2%
Other	2%	4%
Don't know whom to call	8%	25%
Total	100%	100%

Based on Hawaii data. The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

**TABLE 28: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?"**  
**KAUAI COUNTY**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	14%	25%
Would provide care myself	42%	19%
Nursing home or home health service	11%	11%
Doctor or nurse	2%	7%
Area Agency on Aging	9%	3%
Other	2%	3%
Don't know whom to call	20%	32%
Total	100%	100%

Based on Hawaii data. The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

**TABLE 29: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?"**  
**MAUI COUNTY**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	26%	24%
Would provide care myself	36%	20%
Nursing home or home health service	22%	16%
Doctor or nurse	3%	4%
Area Agency on Aging	1%	3%
Other	5%	4%
Don't know whom to call	7%	29%
Total	100%	100%

Based on Hawaii data. The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System, 2000.*

## GLOSSARY OF CAREGIVING TERMS<sup>70</sup>

**ACTIVITIES OF DAILY LIVING (ADLs)** - personal care activities necessary for daily living, such as oral hygiene, dressing, toileting, transferring between bed and chair, eating and bathing.

**ADULT DAY CARE/SERVICES** - a respite care service provided outside the home, designed to meet individual needs and support independence and abilities.

**ADVANCED DIRECTIVES** - written documents, signed while a person is competent to make decision(s) about instructions stated in the document.

**AGING IN PLACE** - meeting a person's increasing needs in his/her preferred familiar residence.

**ANXIETY** - feelings of worry, fear, uneasiness, or helplessness possibly caused by many factors.

**ASSISTED LIVING FACILITIES** - residential care settings combining housing, personalized supportive services and health care.

**ASSESSMENT** - the evaluation, usually of mental, emotional and social status to determine an individual's abilities. Its objectives may be diagnostic—to update a care plan or solve a particular situation.

**AUTONOMY** - the ability to make independent decisions or choices, hopefully retained or involved by a care recipient as one's ability permits.

**BURNOUT** - the feeling of becoming overly frustrated and negative often experienced by some caregivers.

**BURDEN** - the impact or consequence of having the responsibility of caring for someone (most frequently with dementia).

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<sup>70</sup> Many of these terms and definitions have been adopted with modifications from: Alzheimer's Disease and Related Disorders Association, Inc.; Patient and Family Services. *Terms and Tips*. 1995.

**CAREGIVER** - person(s), often one or more relative(s), who provide assistance (in activities and interaction within the environment) to those who are dependent on others for such assistance.

**CARE PLAN** - a written action plan which contains the strategies for delivering care to address individual's needs and problems.

**CASE/CARE MANAGEMENT** - a formal service usually consisting of assessment, arrangement, and coordination of services. Care management and coordination are informal terms. However, case management usually implies a comprehensive assessment, the development of a care plan, evaluating the services, and reassessing the situation. A social worker, nurse, or gerontologist may provide such services.

**CARE RECEIVER/RECIPIENT** - a person who may be dependent on another(s) for care in activities and interaction within the environment.

**CHRONIC ILLNESS** - an illness which lasts over an extended period of time and is treated by management rather than with the expectation of a cure.

**CO-EXISTING ILLNESS** - a medical condition or illness that occurs simultaneously with another condition or illness, which may complicate or obscure diagnosis or treatment of each.

**COGNITIVE FUNCTION** - describes the way information is processed in the brain with such functions as judgment, memory, perception, etc.

**COMPETENCE** - usually used in a legal sense, refers to a person's ability to understand information, make an informed choice based on the information and values, and communicate that decision.

**CONTINUUM OF CARE** - encompasses a continuous, inseparable court of care over various care services and their locations of services considered necessary over the full course of an illness.

**DEMENTIA** - a significant loss of cognitive functions such as thinking and memory, which interferes with an individual's daily function and everyday life; it may be caused by many different disorders.

**DEPRESSION** - a prolonged mood disturbance that affects self-worth, outlook, and living; it is capable of cure or improvement and should be diagnosed by a capable professional.

**ESTATE PLANNING** - thoughtful consideration and planning, usually legal, for an individual's future in the area of finances and property; in some cases planning for health care decisions may begin at this time.

**FUNCTIONAL STATUS/CAPABILITIES** - the measurement (usually through a scale or instrument of assessment) of a person's abilities in activities of daily living and/or instrumental activities of daily living.

**GUARDIAN** - a legal term for a person who is lawfully vested with the care of the property and/or person who is legally incompetent.

**HOSPICE** - a philosophy and approach to care for individuals who are terminally ill. This care is palliative or comfort oriented and assists the family and individuals with their emotional, physical, social, and spiritual needs.

**INFORMED CONSENT** - a legal term referring to the disclosure and consideration of all relevant facts available on which to base an intelligent decision and consent to a particular medical treatment.

**INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs)** - secondary level of activities of daily living such as cooking, cleaning, shopping, driving, transportation, etc.

**LIFE EXPECTANCY** - the age to which a given person or population is anticipated to live based on survival statistics.

**LIFE SPAN** - the maximum projected age to which a given person or population is anticipated to live.

**LONG-TERM CARE** - the extended care (usually outside the home) of an individual who is dependent on others for his/her needs. This term usually implies nursing home care administered over a prolonged period of time.

**MEDICAID** - a federal-state program administered by states to provide health care and services for low-income individuals.

**MEDICARE** - a federal health insurance program (whose aim is to protect against health care costs, but does not cover all medical expenses nor long term care) for persons over 65 years, particular disabled persons under 65 years and those of any age who have permanent kidney failure.

**MEMORY IMPAIRMENT** - damage in the brain that interferes with memory processes. This damage may be attributable to numerous conditions, disease or accidents.

**NURSING HOME** - an institutional setting that offers 24-hour supervision and care to individuals, usually older persons, who are no longer able to be responsible for themselves in an independent living setting.

**OMBUDSMAN** - an advocate, designated by a government agency to promote the quality of the delivery of governmental services; the Executive Office on Aging has an Ombudsman to promote quality of care in nursing facilities.

**PACING/WANDERING** - walking about, either purposefully in a pattern, and/or randomly in motion.

**PERSONAL CARE** - assistance with intimate activities (such as grooming, bathing, eating, dressing, etc.) of daily living.

**PREVALENCE** - proportion of people in the population who have a certain disease or characteristic at a certain point in time. For example, prevalence of caregiving of 12% among adults aged 18 years old and older means that 12% of adults aged 18 and over are caregivers.

**PROFESSIONAL EDUCATION** - education on a focused subject for professionals, perhaps with some accreditation process for different disciplines.

**PUBLIC AWARENESS** - information in a focused area broadly disseminated throughout the community.

**REIMBURSEMENT** - financial reimbursement for costs incurred by individuals in the care of their loved one.

**RESEARCH** - study, collection of data, and analysis based on hypotheses regarding a focused topic. It may involve laboratory or clinical study, social and behavioral scrutiny or programmatic evaluation.

**RETIREMENT/ LEISURE PLANNING** - consideration of and preparation for an individual's use of time and resources after retiring from work.

**RETIREMENT COMMUNITY** - a group of single or multiple unit residences that are marketed to and utilized by predominately older adults who are retired. Some may be age-restricted. There are often business and retailing amenities and diverse organized interest groups to make the community self sufficient.

**RIGHT-TO-DIE** - a person's individual medical care choices that impact the end of life. These rights relate to competency, and considerations should

include appropriate assessment, advanced directives, quality of life and a supportive environment.

**RIGHTS** - good and natural expectations that may or may not be assured by law.

**SENILE** - refers to old age and since originally used to describe older persons who were Dementing, it is often used in place of dementia. Senility encompasses a collection of symptoms that may be caused by a host of different disease processes or conditions.

**SHARED RISK** - a negotiated agreement between a care provider, a cognitively impaired person and the family in an attempt to balance autonomy and safety without overprotecting the individual.

**SKILLED NURSING FACILITY** - provides skilled nursing care and related services for residents who require medical or nursing care, rehabilitation services for injured, disabled, or sick persons, and health-related care and services above the level of board and room and not primarily for the care and treatment of mental diseases.

**SUPPORT GROUP** - a formal gathering of persons sharing common interests and issues. The participants and facilitators share information, mutual support and often exchange coping skills with one another.

**SUPPORTIVE HOUSING** - alternative residential care setting (other than skilled nursing facilities) that link housing and services. These may be licensed or unlicensed by the State.

**SURROGATE** - a substitute who makes decisions for someone who is no longer capable of making decisions for him/herself. The surrogate may be appointed as guardian or conservator by a court or identified when the person is competent through a power of attorney process.

**THERAPY** - a treatment or intervention intended to change an outcome or course of disease.

**TRANSPORTATION** - provision of transportation to and/or from a service often arranged through an agency or organization.

## STAGES IN CAREGIVING FROM CAREGIVER PERSPECTIVE<sup>71,72</sup>

STAGE	DESCRIPTION
I. Performing caregiving tasks	When a dependency situation emerges in which a family member or close acquaintance performs tasks designed to assist an older individual with routine activities previously performed without assistance.
II. Self-definition as a caregiver	When individuals come to view themselves as caregivers and incorporate this activity onto their social or personal identity.
III. Performing personal care	When the caregiver begins providing personal care such as assistance with bathing, dressing, bladder and bowel evacuation, or other aspects of personal hygiene. Whereas the need for personal care marks the end of informal caregiving for many children, it often signals an unambiguous start of caregiving for spouses.
IV. Seeking assistance and formal service use	When the caregiver actively seeks out formal support services designed to assist informal caregivers. The frequent observation that many support services go unused likely reflects the fact that the services have been targeted to caregivers who have not yet reached this stage, which can be considered the "servable" moment.
V. Consideration of nursing home placement	When the caregiver seriously considers placing the elder into a nursing home as an alternative to informal caregiving. When caregivers fail to seek services prior to seriously considering nursing home placement, there is little opportunity for services to play a preventive role.
VI. Institutionalization	When nursing home placement occurs. As many dependent elders die without ever residing in a nursing home, not all caregivers reach this stage.
VII. Termination of the caregiving role	When caregiving has an explicit end. There are three possible reasons: 1) death of the elder (or caregiver); 2) recovery of the elder; or 3) termination of the caregiving role (i.e.—caregiver quits). The significance of this stage is that it acknowledges that care by informal caregivers continues to be provided after the elder has been institutionalized.

<sup>71</sup> Montgomery, R.J.V., & Hatch L. *The Feasibility of Volunteers and Families Forming a Partnership for Caregiving*. In Brubaker T (Ed.), *Family and Long-term Care* (pp. 143-161). 1997. Beverly Hills, CA: Sage Publications.

<sup>72</sup> Pearlin, L.I. The Careers of Caregivers. *The Gerontologist*, 32:647. 1992.



*"E Loa Ke Ola"  
May Life Be Long*

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