A PROFILE OF FAMILY CAREGIVERS: RESULTS OF THE CALIFORNIA STATEWIDE SURVEY OF CAREGIVERS

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EXECUTIVE SUMMARY

This report provides information on California caregivers based on the California Statewide Survey of Caregivers. This statewide telephone survey has been used to determine (1) the prevalence and characteristics of family caregiving (e.g. types of services/tasks undertaken, characteristics of recipients, type of disability, etc.); (2) current use of support services, and satisfaction with those services used; (3) reasons for non-use of support services and potential use of those services; and (4) factors which contribute to caregiver stress. It is hoped that this report will further provide the California Department of Aging and local Area Agencies on Aging with a strong foundation for developing service programs to assist family members in maintaining their caregiver roles for their older family members who are ill or who have disabilities.

Characteristics of California Caregivers

Based on the California Statewide Survey of Caregivers, a telephone-administered interview with a randomly-selected sample of 1,643 state residents who provide care to someone age 50 or over, it is estimated that 16% of all California households (with a telephone) contains at least one caregiver for someone age 50 or over. This translates to a minimum of 1,803,995 caregiver households out of the 11,502,870 households in California.

California caregivers have an average age of 50.87 years, slightly older than caregivers nationally. Three-fourths are women, 60% are married, and 31% have children under the age of 18 living at home (as compared with 41% nationally). Sixty-one percent are White/Caucasian, 25% are Hispanic/Latino, 6% Black/African American, and 5% Asian. Most caregivers were born in the US (86%), but a notable number (6%) report Mexico as their country of origin. About half of California's caregivers are employed – 35% full-time and 14% part-time. Three-fourths of caregivers (74%) evaluate their health as good, very good, or excellent, with 26% indicating that their health is fair or poor; 28% report health or emotional problems.

Care recipients range in age from 50 to over 100, with a mean of 77 years. Seventy percent are women; half are widowed, one-third are married, and 10% are divorced. Thirty-five percent live with the respondent, while another third live alone, 6% live in an assisted living facility, and 3% live in a nursing home. Thirty-six percent suffer from severe memory problems or dementia, 36% have mental health problems, and 82% have multiple physical conditions.

Impact of Caregiving

While caregiving can prove to be a positive experience for many individuals, it also can have negative impacts on caregivers' health and well-being. One third of caregivers report high levels of emotional stress (a rating of "4" or "5" on a 5-point scale) associated with providing care, while 18% report high levels of physical strain, and 15% report high levels of financial hardship. More than one-fifth report suffering either physical or emotional problems as a result of their care giving responsibilities, and one-fourth report sleep disruptions. More than one-fifth have no one they can go to for support and understanding regarding their caregiving situation.

Vulnerable Caregivers

California caregivers who experience the highest levels of financial hardship, physical strain, and emotional stress, are more likely to be female, Latino, low income, and in poor health. They are more likely to care for someone with mental illness/emotional problems, dementia/memory problems, behavioral problems, or stroke or paralysis. Furthermore, they are more likely to report that the caregiving situation has created family conflict and has been a significant hardship for their families.

Care Recipients with Mental Health, Emotional, or Behavioral Problems

A total of 44% of caregiver respondents assist someone who has mental health, emotional, or behavior problems. Compared with other care recipients, more of those with these problems reside in a board and care home, group home, or assisted living facility, and fewer with their spouse. Further, this group of care recipients apparently requires more time of their caregivers. Caregivers of recipients with these problems also are more likely to feel that they are not receiving enough assistance from paid service providers.

Caregivers of individuals with mental, emotional, or behavioral problems access direct types of help (e.g. counseling and day or overnight respite) significantly more often than do caregivers of recipients without those problems. Further, caregivers providing care to those with mental/emotional/behavioral problems were significantly more likely to indicate that caring for the recipient is a financial hardship, a physical strain, and emotionally stressful. They were also less likely to report being in excellent or very good health.

Care Recipients with More Than Two Physical Health Problems

Out of the 1,643 respondents to the survey, 56% indicated that they care for a person with more than two of the physical health problems listed on the survey. Caregivers for those with multiple physical problems spend significantly more time in an average week providing help than do those caregivers assisting those with fewer physical problems. Caregivers in this category also are more likely to seek help in order to access community services. In addition, more "multiple problem" caregivers reported missing work in the past two weeks than do other caregivers. Further, caregivers providing care to those with multiple physical problems were significantly more likely to indicate that caring for the recipient is a financial hardship, a physical strain, and emotionally stressful. They were also less likely to report being in excellent or very good health.

Care Recipients with Severe Memory Problems or Dementia

A total of 36% of caregiver respondents assist someone with severe memory problems or dementia. As might be expected, fewer care recipients with memory problems or dementia live alone in their own home or apartment than do care recipients without these problems. Caregivers of recipients with severe memory problems or dementia spend an average of 53.7 hours per week providing help, as opposed to 34.1 hours spent by caregivers of recipients without these disorders.

Significantly more caregivers of people with memory problems or dementia changed their work schedules (reduced the number of work hours) than did those not dealing with this condition. Further, caregivers providing care to those with memory problems or dementia were significantly more likely to indicate that caring for the recipient is a financial hardship, a physical strain, and emotionally stressful. They were also less likely to report being in excellent or very good health.

INTRODUCTION

This report provides a profile of California's caregivers and care receivers, based on a statewide survey of 1,643 California caregivers providing assistance to individuals aged 50 or older. The statewide sample for the telephone survey was generated using a list of telephone numbers reflective of the state. Respondents were screened to determine whether they "provided assistance or support to someone who was ill, disabled or elderly" and if the person was over age 50. The survey research methodology was designed and implemented by the Inland Empire Research Consortium, which is made up of faculty from the University of California at Riverside and California State University, San Bernardino (CSUSB). The telephone interviews were conducted at CSUSB's Institute of Applied Research, using computer-assisted telephone interviewing (CATI) equipment and software between March 28, and August 22, 2002. This survey represents one component of a three-year, inter-agency collaboration to assist in the implementation and evaluation of the National Family Caregiver Support Program (NFCSP) in California.

The results from this survey not only characterize caregivers and the impact of caregiving on their lives, but also capture their current use of support services, satisfaction with services, and reasons for non-use of services. Furthermore, care recipients' characteristics are described, including their current health status and care requirements. In an effort to enrich the initial survey's results with an in-depth understanding of the needs, issues, and concerns of caregivers and care recipients, focus groups representing distinct ethnic, cultural, and geographical segments also will be conducted.

Building on previous analyses of the state's caregiver support services and model programs, the survey results will enhance efforts to develop and implement a caregiver support system responsive to the diverse needs of California's caregivers, including those who do not currently utilize Title III-E services. Additionally, a pilot study is being developed to collect client-specific data on caregiver and care receiver service utilization, yielding outcome measures to help assess the impact of the NFCSP in California. The ultimate results of this research will provide a better understanding of the nuances of caregiving in California, and will hopefully contribute to more effective and efficient implementation of intervention programs to support family caregivers through the NFCSP.

SURVEY METHODS

Sampling Methodology

In order to generate the initial statewide sampling frame, IERC purchased from Scientific Telephone Samples a list of telephone numbers reflective of households with phones throughout the state. Specifically, STS compiled all telephone prefixes for the State of California, and related them to working blocks (groupings of 100 contiguous numbers which contain at least one listed phone number). Next, a random sampling procedure was used within working blocks to select the telephone numbers to appear in the sample. The numbers were then screened to eliminate business phones, cell phones, fax machines, non-working numbers, and phone numbers of people asking to be excluded from telemarketing calls. Finally, in order to ensure that some unlisted phone numbers were included in the sample, IERC supplemented the original list by using the working number as a seed number from which one other number was generated by adding a constant. To the extent possible, therefore, each state resident with a telephone had an equal chance to be included in the survey.

Two screening questions were used to identify caregivers of an adult age 50 or over. The first question read: "Do you or does anyone in your household currently provide assistance or support to an adult relative or friend who is ill, disabled, or elderly." "Assistance" or "support" were defined within the introduction as providing assistance for at least a couple of hours a month with personal needs, household chores, taking care of finances, or arranging for outside services. The second question asked for the ages (and relationships) of the people the respondent provides care for, thus enabling the interviewer to identify the target population: caregivers of adults age 50 or over. In the event that the respondent provided care for more than one care recipient, the respondent was asked to provide information relative to the care recipient for whom he/she provides the *most* care.

Employing the above procedures to ensure random selection, the final sample size of state residents who provide care to someone age 50 or over was 1,643 (of which 98 were conducted in Spanish and the remaining 1,545 were conducted in English), yielding an accuracy rate of plus/minus approximately 2%, and a 95% level of confidence.

The sampling methodology described above, however, has three minor limitations. First, although it is obvious it must be explicitly acknowledged that the survey respondents are care*givers*, yet they are responding to various questions concerning care *recipients*. As a result, all data relative to the care recipients must be viewed as "second-hand" information. This should not be viewed as a serious limitation in that the caregivers, under most circumstances, are likely to be knowledgeable about the types of information requested in the survey. Further, the primary emphasis of the study is on the caregivers rather than the recipient. The second limitation is that certain groups (e.g. low-income people without phones, non-English & non-Spanish speaking respondents) were excluded from participation in this survey. In order to address this limitation, focus groups will be held throughout the state in early 2003 to gather the needed information from such hard to reach populations. Finally, in an effort to obtain a sufficiently large sample of Asians so as to draw inference to that sub-population, IERC attempted to contact/oversample as many Asians as feasible given budgetary constraints. The resulting sample size of Asians, however, is still insufficient to generalize with a desired measure of confidence. Focus groups will be used to enhance the data from that sub-population.

Questionnaire Construction

Researchers at UC Berkeley initially submitted a draft copy of the questionnaire to IERC for review. The questionnaire was constructed to elicit information regarding the following:

- the demographic characteristics of caregivers and care recipients;
- care recipient health and functioning;
- level of care provided by the caregiver;
- assistance required by the care recipient;
- services provided to caregivers, and unmet needs of the caregivers; and
- impact of caregiving on work-related issues, emotional health, and physical health

IERC made modifications and pre-tested the instrument. On the basis of the pretest, further modifications were made. The questionnaire was translated into Spanish for use with respondents who were deemed by interviewers to be more fluent in Spanish than in English. It should also be noted that minor modifications were made to the survey instrument during the course of the study to improve the clarity of the questions.

In particular, partway through the interviewing process, IERC (in consultation with researchers at UC Berkeley) developed a short, ten-minute version of the questionnaire, which was offered to respondents who initially refused to take the longer version. This version, however, was discontinued after a relatively short period of time when it became clear that it did not significantly improve response rate, yet resulted in a loss of data. On the other hand, the use of this short version did not appear to seriously compromise the statistical validity of the sample, since there were few demographic differences between those caregivers who completed the short version vs. those who completed the long version. Table 1 illustrates the demographic characteristics for caregivers who completed the long version vs. those who completed the short version of the survey. The survey instrument is included as Appendix A.

Interviewing Procedures

Telephone interviews were conducted from the facilities of CSUSB's Institute of Applied Research and Policy Analysis in San Bernardino using computer assisted telephone interviewing (CATI) equipment and software. The pre-tests began on March 28, 2002 and data collection was concluded on August 22, 2002. Surveys were conducted during the following shifts: Monday through Friday 9:30 AM – 11:30 AM, 12:00 PM – 2:30 PM, 3:00 PM – 5:30 PM, 6:00 PM – 8:30 PM; Saturday 10:00 AM to 5:00 PM; and Sunday 1:00 PM – 7:00 PM. If the resident at a selected telephone number did not answer or if the interviewer reached an answerphone, two more callbacks were made before the phone number was deleted from the list, thus reducing systematic bias. In an effort to ensure the quality and reliability of the interviews, an Institute Staff Research Assistant was present for the interviews conducted from phones at CSUSB.

TABLE 1: DEMOGRAPHIC CHARACTERISTICS FOR CAREGIVERS WHO COMPLETED THE LONG & SHORT SURVEYS

	Caregivers who completed the Long Version (3/28/02 – 8/22/02)	**Caregivers who completed the Long Version (7/8/02 – 7/31/02)**	**Caregivers who completed the Short Version (7/8/02 – 7/31/02)**
Gender			
Male	350 (25%)	82 (27%)	60 (24%)
Female	1034 (75%)	227 (74%)	191 (76.1%)
Marital Status			
Married	818 (60%)	90 (57%)	87 (69%)
Living with partner	30 (2%)	5 (3%)	0 (0%)
Separated	29 (2%)	1 (1%)	3 (2%)
Divorced	175 (13%)	22 (14%)	9 (7%)
Widowed	93 (7%)	7 (4%)	9 (7 %)
Never Married	227 (17%)	33 (21%)	19 (15%)
Hispanic or Latino			
Yes	330 (24%)	87 (28%)	52 (21%)
No	1024 (76%)	220 (72%)	196 (79%)
Race/Ethnicity			
White/Caucasian	830 (61%)	176 (58%)	159 (65%)
Black/African American	82 (6%)	17 (6%)	15 (6%)
Asian	64 (5%)	12 (4%)	8 (3%)
American Indian/Alaska Native	17 (1%)	3 (1%)	0 (0%)
Native Hawaiian or Pacific Islander	2 (0.1%)	0 (0%)	1 (0.4%)
Hispanic/Other	375 (27%)	97 (32%)	61 (25%)
Education			
Less than high school	67 (5%)	16 (5%)	10 (4%)
Some high school	79 (6%)	19 (6 %)	17 (7%)
High school graduate	279 (20%)	65 (21%)	56 (22%)
Post high school education	450 (33%)	96 (31%)	93 (37%)
College graduate	338 (25%)	72 (23%)	46 (18%)
Post graduate degree	162 (12%)	40 (13%)	28 (11%)
Income			
Under $30,000	481 (40%)	112 (41%)	86 (41%)
Over $30,000	730 (60%)	161 (59%)	122 (59%)

Response Rate

After careful review of various methodologies for calculating response rate, IERC has concluded that the single best approach is to use the following formula:

# of completed interviews/Total number of eligible respondents

In our view, this approach best reflects the sampling problems encountered in a study that seeks to study in-depth a "rare" population (caregivers of people age 50 or over) which can only be identified through screening questions. By definition, the simple random sampling approach of households in the state produces a large number of ineligible respondents. In addition, this approach also produces a large number of respondents for which eligibility is unclear (i.e. answer phones, busy signals, language problems). We have chosen to exclude them from the response rate calculation. In our judgment, therefore, the calculation shown above is the simplest and also the most valid approach for reflecting the non-response rate in this study.

Using this formula and as documented by the raw data in Table 2, the response rate was 19% (that is, 19% of identified caregivers completed the survey).

TABLE 2: DISPOSITION OF SURVEY CALLS

Disposition	**# of cases**
Completed surveys	1,648
Eligible	
Refusal – Caregiver	7,000
Callback - Caregiver/Incomplete	142
Not Eligible	
Phone Disconnected/Non Working Number/ FAX/Business	87,746
Provides Care to someone under 50	612
Quota Cell Full/Caregiver - Not Asian	218
Not Caregiver	47,818
Eligibility Unclear	
Busy/No Answer/Answering Machine/Voice Mail	118,647
Language Problem	5,365
Refused before indicating caregiver status	21,180

Although this response rate of 19% appears quite low, it is not surprising given the fact that there was a calculated tradeoff between response rate on the one hand, and richness of data and length/complexity on the other (length of long version: mean = 25.4 minutes, minimum = 8 minutes, maximum = 71 minutes; length of short version: mean = 11.51 minutes, minimum = 4 minutes, maximum = 48 minutes).

Validity of the Data

With such a low response rate, of course, the validity of the findings becomes an immediate concern. Specifically, the issue turns on whether the sampling reflects systematic bias or remains essentially random in nature. In order to address this concern head on, IERC has performed two comparisons relative to ethnicity. First, we compare the ethnicity of all households surveyed (whether including a caregiver or not) with general California figures for individuals and households. Second, we compare the ethnicity of our caregivers with projections of the ethnicity of California caregivers based on a national study.[1] The following table presents the comparisons:

TABLE 3: COMPARISON OF RESPONDENTS TO STATE POPULATION AND NATIONAL SURVEY RESULTS

	General Population (Over 18)			**Caregivers Caring For Person Over Age of 50**	
Ethnicity	Contacted by IERC	California (Individuals)	California (Households)	Completed Survey	Estimate based on National Study [2]
White/Caucasian	56%	51%	58%	61%	69%
Black/ African American	6%	6%	7%	6%	7%
Asian	11%	11%	10%	5%	7%
American Indian/ Alaska Native	1%	1%	1%	1%	0%
Native Hawaiian/ Pacific Islander	0.4%	0.3%	0.2%	0.2%	0%
Hispanic/Latino	24%	28%	22%	25%	15%
Other	2%	3%	2%	2%	2%
Total	100%	100.0%	100%	100.0%	100%

The comparative data presented in the above table provides supporting evidence that the sample was, indeed, relatively representative of the California population (with

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[1] "Family Caregiving in the U.S.: Findings from a National Survey." Prepared by the National Alliance for Caregiving and the American Association of Retired Persons, 1997.

telephones) as a whole (both individually and by household) and the population of caregivers in particular.

Analysis of Survey Data

Data gathered from the interviews were edited, coded and entered into the computer for analysis. The computerized data were analyzed using SPSS (Statistical Package for the Social Sciences). The results are available from the Center for the Advanced Study of Aging Services.

In reading this report and reviewing the data display, it should be noted that some respondents failed to answer some questions due to lack of information or lack of interest in providing responses. The table totals, therefore, are different for each table, and reflect the number of persons responding to the question.

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[2] The estimate was calculated by using the ethnic distribution of caregivers from the National Survey and adjusting it to reflect the demographic distribution of California.

FINDINGS

This section presents a summary of the responses from the statewide caregiver survey. The sample size in the tables at times differs from the total sample size of 1,643 since: (1) some respondents chose not to answer some questions; (2) some questions were only relevant for a subset of the caregiver population; and/or (3) some respondents were given the short version of the questionnaire which contained only the most critical survey questions, so many of the items on the long version were not included in these data records. The full array of findings is available from the Center for the Advanced Study of Aging Services.

Prevalence of Caregiving in California

Although this study is primarily concerned with identifying the characteristics of family caregivers – their profile, level of support, level of stress, etc. – the sampling employed also allows for an estimate of the prevalence of caregiving within California households. Based on the random sampling procedure utilized in the study and the associated telephone disposition report presented in the methodology section, it is estimated that 1 in 6 households (with a telephone) contains at least one caregiver. This translates to a total of 16% of all households in California, a minimum of 1,803,995 caregiver households out of the 11,502,870 households in California. This is comparable to the figures in a 1997 national study[3] which indicated that approximately 17% of all U.S. households with a telephone contain at least one caregiver for someone over age 50. Although the survey focused only on caregivers for those over age 50, the initial survey-screening question asked for the ages of all care recipients and the results show that 27% of caregivers care for someone age 19 - 49, 10% for someone ages 50 - 59, and 74% for someone over age 60.

Description of the Caregivers and Care Recipients

Table 4 summarizes key social and demographic traits among the caregivers who responded to the survey. As noted in the table, most of the caregivers are between 35 and 64 years old (67%), married (60%), and do not have children under the age of 18 living at home (69%). An overwhelming number of the caregivers are women (75%). In addition, the vast majority (61%) are White/Caucasian, with 25% reporting Hispanic/

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[3] "Family Caregiving in the U.S.: Findings from a National Survey." Prepared by the National Alliance for Caregiving and the American Association of Retired Persons, 1997.

Latino background, 6% Black/African American, and 5% Asian. Most caregivers were born in the US (86%) but a notable number (6%) report Mexico being their country of origin. Most have graduated from high school (69%), with 35% reporting either a college degree or post-graduate education. Further, most have incomes over $30,000 (60% of those willing to reveal their income), and a significant number (36% of those willing to reveal their income) report incomes over $50,000. This demographic profile of caregivers is generally consistent with findings from the 1997 national study[4] if viewed in light of the notable differences that exist between the California population and residents in the rest of the nation.

Table 5 summarizes the key social and demographic traits among the care recipients (as reported by the caregivers). Half of the care-recipients are widowed. The largest groups of care-recipients are living either with the caregiver (35%) or alone in their own home (34%). Most of them are in their 80's (35%) or 70's (29%), and most are female (70%). Approximately 66% of the care-recipients are White/Caucasian with the next highest group of recipients reported as Hispanic/Latino (21%), and Black/African American, Asian, and Native American care-recipients all in the single digit range. Most of the care-recipients were born in the United States (78%), with the highest number of the non-U.S. born group being those born in Mexico (9%). Perhaps the most notable characteristic is that insofar as the caregiver respondents are able to estimate the recipient's income, it is clear that the vast majority (79%) have household incomes under $30,000 (and many – 36% -- have household incomes below $10,000).

There are a number of key observations regarding the caregivers (respondents) and care recipients, as shown in Table 6. First, it is clear that by far most care recipients are parents of the caregivers (49%). Additionally, 86% of the respondents care for only one recipient. The vast majority of caregivers either lives with the care-recipient (35%) or live less than 15 minutes away from their care-recipient (35%).

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[4] "Family Caregiving in the U.S.: Findings from a National Survey." Prepared by the National Alliance for Caregiving and the American Association of Retired Persons, 1997.

TABLE 4. CAREGIVER SOCIAL AND DEMOGRAPHIC CHARACTERISTICS

Age (n = 1,597)	**% in sample**	**% in National survey**
Under 35	14%	22%
35 - 49	32%	39%
50 - 64	34%	26%
65 or older	19%	12%
Mean age	51 yrs	46 yrs
Modal age	50 yrs	

Current Marital Status (n = 1,499)	**% in sample**	**% in National survey**
Married	60%	66%
Living with partner	2%	
Separated	2%	13%
Divorced	12%	
Widowed	7%	8%
Never Married	16%	13%

Gender (n = 1,635)	**% in sample**	**% in National survey**
Female	75%	73%
Male	25%	28%

Children < 18 yrs old in household (n = 1,630)	**% in sample**	**% in National survey**
Yes	31%	41%
No	69%	58%

Highest Level of Schooling (n = 1,625)	**% in sample**	**% in National survey**
< High School grad	11%	9%
High School grad	21%	35%
Post HS training	33%	26%
College graduate	24%	20%
Post-graduate degree	12%	9%

Race/Ethnicity (n = 1,614)	**% in sample**	**% in National survey**
White (non-Hisp)	61%	82%
Black (non-Hisp)	6%	11%
Hispanic/Latino	25%	5%
Asian	5%	2%
American Indian/ Alaska Native	1%	1%
Hawaiian/ Pacific Islander	0.2%	

Household Income for 2001 (n = 1,643)	**% in sample**	**% in National survey**
Under $10,000	9%	N/A
$10,000 - $20,000	16%	“
$20,001 - $30,000	13%	“
< $30,000 (unspecified)	2%	
$30,001 - $39,999	11%	“
$40,000 - $50,000	12%	“
$50,001 - $80,000	17%	“
Over $80,000	17%	“
> $30,000 (unspecified)	3%	“

Country of Origin (n = 1,380)	**% in sample**	**% in National survey**
United States	86%	N/A
Mexico	6%	“
Asia/Pacific Islands	2%	“
Central America	2%	“
Europe	2%	“
Canada	1%	“
Other	2%	“

TABLE 5: SOCIAL AND DEMOGRAPHIC CHARACTERISTICS OF CARE RECIPIENTS (AS REPORTED BY CAREGIVERS)

Age (n = 1,620)	**% in sample**	**Current Marital Status (n = 1,384)**	**% in sample**
50 – 59 yrs old	12%	Married	32%
60 – 69 yrs old	13%	Living with partner	0.2%
70 – 79 yrs old	29%	Separated	3%
80 – 89 yrs old	35%	Divorced	11%
90 yrs old or older	12%	Widowed	50%
Mean age	77 yrs	Never Married	5%
Median age	78 yrs		
Modal age	80 yrs		
Gender (n = 1,386)	**% in sample**	**Current living arrangement (n = 1,641)**	**% in sample**
Female	70%	Alone in home or apt.	34%
Male	30%	With caregiver	35%
		With spouse or partner	9%
		With family or friend	10%
		Retirement community	4%
		Board and care home/ Assisted living	6%
		Nursing home/elsewhere	3%
Highest Level of Schooling (n = 1,275)	**% in sample**	**Race/Ethnicity (n = 1,404)**	**% in sample**
< High School grad	32%	White (non-Hisp)	66%
High School grad	33%	Black (non-Hisp)	6%
Post HS training	15%	Hispanic/Latino	21%
College graduate	14%	Asian	5%
Post-graduate degree	6%	American Indian/ Alaska Native	2%
		Hawaiian/Pacific Islander	0.4%
Household Income for 2001 (n = 1,087)	**% in sample**	**Country of Origin (n = 1,372)**	**% in sample**
Under $10,000	36%	United States	78%
$10,000 - $20,000	27%	Mexico	9 %
$20,001 - $30,000	11%	Asia/Pacific Islands	4%
< $30,000 (unspecified)	5%	Central America	2%
$30,001 - $39,999	5%	Europe	4%
$40,000 - $50,000	6%	Canada	1%
$50,001 - $80,000	4%	Other	2%
Over $80,000	4%		
> $30,000 (unspecified)	2%		

TABLE 6: OTHER INFORMATION ABOUT CARE-RECIPIENT AND CAREGIVER

Who Is Caregiver Assisting? (n = 1,635)	**% in sample**
Parent	49%
Spouse/Significant Other	12%
Friend	12%
In-Law Parent	8%
Grandparent	8%
Other Extended Family Member	5%
Sibling	3%
Neighbor	3%

Travel Time (One Way) Between Caregiver and Care Recipient (n = 1,359)	**% in sample**
0 (live together)	35%
Less than 15 minutes	35%
15 to 30 minutes	15%
30 minutes to an hour	7%
More than an hour	7%

Number of People For Whom Caregiver Provides Care (n = 1,641)	**% in sample**
1	86%
2	12%
3	2%
4	0.2%

Care Recipient Health and Functioning

The care recipients suffer from a variety of illnesses and the following table (Table 7) reports the distribution of ailments as reported by the caregivers (Question 11). Caregivers were first offered a “check list” of illnesses and health conditions, and then the respondent was asked if there were any other conditions to report.

By far, cardiovascular issues and arthritis are the most prevalent health problems suffered by the care recipients. This is followed by severe memory problems/dementia, and mental health or emotional problems. Less than 1% of the respondents indicated that the care recipients were suffering from HIV/AIDS.

TABLE 7: CARE RECIPIENT ILLNESSES AND HEALTH CONDITIONS REPORTED BY CAREGIVER RESPONDENT

ILLNESS/HEALTH PROBLEM	PERCENT YES
Heart Disease or High Blood Pressure	997 (62%)
Arthritis	966 (60%)
Severe Memory Problems or Dementia	591 (36%)
Mental Health Problems/Emotional Problems	578 (36%)
Blindness or Severe Visual Impairment	470 (29%)
Severe Hearing Impairment	465 (29%)
Diabetes	423 (26%)
Stroke or Paralysis	407 (25%)
Behavior Problems	392 (24%)
Lung Disease or Emphysema	249 (16%)
Cancer	217 (13%)
HIV/AIDS	5 (0.3%)

As one might expect, most respondents (92%) reported more than one condition experienced by the care recipient. In fact, the median number of conditions reported was four. Further, it is not surprising that many respondents (465) mentioned at least one condition other than those on the list provided. The most frequently mentioned "other" health problems were bone problems and nervous system disorders (Table 8).

TABLE 8: OTHER CARE RECIPIENT ILLNESSES AND HEALTH CONDITIONS REPORTED BY CAREGIVER RESPONDENT

ILLNESS/HEALTH PROBLEM	# OF MENTIONS
Bone Problems (Broken Bones, Osteoporosis)	129
Nervous System Disorders	97
GI, Liver, Reproductive Disorders	62
Renal Disease	44
Muscle Pain or Disorder	42
Acute Disorders	28
Blood/Circulation Disorders	25
Skin Problems	10
Other	53

In an effort to provide a more analytical typology of conditions, the illnesses above were collapsed into three categories: (1) mental health problems (including behavior or emotional problems); (2) severe memory problems; and (3) physically based problems. Most of the care recipients (93%) have some physical illness, nearly half (44%) have a mental health condition and 36% are reported to have severe memory problems or dementia. These percentages do not sum to 100% since nearly all of those with mental health problems (94%) and memory problems (92%) also have physical conditions. Further, 18% of the care recipients with physical problems report only a single problem; the remaining 82% have *multiple* physical problems.

Care Provided to the Care Recipient

Respondents also were asked what sorts of services were provided to the care receivers (Question 12). Caregivers reported that "going shopping or getting to the doctor's office" were the most frequently cited services needed by the care recipient. Indeed, nearly 86% of the care recipients require this category of assistance. The next most frequently needed assistance is preparing meals, doing laundry, or cleaning house. The activity for which fewest care recipients required assistance was dressing, eating, bathing, or getting to the bathroom (Table 9).

TABLE 9: ACTIVITIES FOR WHICH CARE RECIPIENT NEEDS ASSISTANCE, AND WHO PROVIDES THE HELP

ACTIVITY FOR WHICH CARE RECIPIENT REQUIRES ASSISTANCE		WHO PROVIDES THE HELP FOR ACTIVITY		
	Needs Help	Caregiver	Family/ Friends	Paid Provider
Going shopping or getting to the doctor's office	86%	73%	31%	10%
Preparing meals, doing laundry, or cleaning house	75%	55%	24%	19%
Keeping track of bills, writing checks, or other financial matters	64%	49%	23%	3%
Arranging for care or services	54%	44%	19%	5%
Medical needs, e.g., taking medicine or changing bandages	50%	37%	15%	13%
Dressing, eating, bathing or getting to the bathroom	42%	29%	14%	14%

As seen in Table 9, 42% of the care recipients need help with the basic activities of daily living (dressing, eating, bathing, or getting to the bathroom). But many of the care-recipients need help with *several* of the other five instrumental activities of living cited in Table 6. Indeed, 49% of care recipients need assistance with four or five of those instrumental activities. Only 5% of the care recipients apparently don't receive assistance in any of these instrumental activities, and only 11% receive assistance in exactly one of them.

Who provides assistance to care recipients? The survey results show clearly that the major burden of responsibility falls upon the caregivers. The activity for which the caregivers were *least* likely to help was dressing, eating, bathing, or getting to the bathroom. Family members and friends/neighbors were the most frequently mentioned as others providing assistance for each of the activities listed, and their rates of help do not vary across categories. The respondents also acknowledged the role of paid providers, particularly in the areas of dressing, eating, bathing, and getting to the bathroom; preparing meals/laundry/cleaning house; and with providing for medical needs. But as the table also demonstrates, care recipients receive assistance from multiple sources (some formal/paid, others informal/unpaid). The majority of caregivers surveyed consider themselves the primary person providing care for the care recipient, and 15% share primary responsibility. The survey results also show that 27% of care recipients get some help from paid providers, while 73% do not.

Among the respondents sampled, 21% have been providing care to the recipient for less than one year (Question 14), with 11% indicating that they have been providing care for less than six months. Other respondents report having considerably more experience with caregiving, with most of the caregivers (54%) having provided care to the recipient for 1 to 5 years. Approximately 25% of the respondents have been "long term" caregivers, in that they began caring for the recipient 6 or more years ago.

Since the level of caregiving is known to be an important contributing factor to the stress of the caregiver, respondents were asked how many hours they spend providing help for their care recipients in an average week (Question 15). The interview also asked about the hours of help provided by family and friends (Question 16). The results indicate that the median number of hours spent by caregivers was 14 and the median time spent by other family and friends was 10. The means are not reported since they are so strongly affected by the large percentages of respondents who indicate they provide "constant" care throughout the week (16% of caregivers provide constant care, and 13% indicate that other family and friends provide constant care).

Respondents were also asked "If you were unable to help your care recipient, is there someone else who would do the things you do?" (Question 17). Most of the respondents (56%) indicated that there was someone else; 25% said there wasn't, and nearly 20% responded that they either did not know or could not answer the question.

Respondents were offered a list of three community services (Question 18), and asked whether the care receiver had used any of them in the past month (at the time of the interview). Twenty-five percent (25%) of caregivers indicated that the recipient had used *at least* one of the listed community services. More specifically, 9% had received mental health counseling, 8% received home-delivered meals (such as Meals on Wheels), 7% had received adult day services, and 14% had received some other community service. Among "other" community services mentioned most frequently were transportation services (49 people) and medical/nutritional rehabilitation (30 people).

Caregiver respondents were asked two questions regarding paid service providers (Questions 19 and 20). 416 out of the 1,643 caregivers indicated that paid service providers provided some care (e.g. dressing, preparing meals, going shopping) to the care recipient during a typical week. Of these 416, 298 chose to answer the question regarding the amount of time each week these paid service providers spent assisting the care recipient. About 25% of these 298 stated that these paid service providers give virtually constant care to their recipient. The median time spent by paid service providers was 24 hours/week. If the 75 people who reported constant care by paid service providers are removed from the analysis, the median number of hours per week of service provided is reduced to 10 hours.

The 416 respondents whose care recipient used paid care were then asked (Question 20): "Do you feel that the care recipient receives enough assistance from paid service providers?" Most of the respondents (70% of the 318 who chose to respond to the question) felt that their care recipient was getting "about the right amount" of assistance. About one-third indicated that they felt their care recipient was not getting enough assistance from paid service providers.

Question 21 focuses on whether any other type of assistance that would be helpful to the care recipient. Forty-four percent of the respondents said “yes.” When asked to specify the type of assistance needed, the most frequently mentioned were in-home care (22%), transportation/delivery services (18%), financial assistance (15%), and medical/rehabilitation services (14%). A variety of other services were mentioned (although less frequently), including physical activity/recreational services, adult day services, food services and home-delivered meals, and mental health/counseling/support services.

Finally, respondents were asked whether they had encountered any problems with the services used, or difficulty in getting services the recipient needs (Question 22). Approximately 21% of the respondents (out of 1,339 answering) answered in the affirmative. Physician/service/medication problems and insurance problems were equally mentioned (12% of the 266 people responding, respectively). Poor service quality was a close second (mentioned by 22%). Another 13% mentioned lack of availability, and 10% mentioned the high cost of services. Other items mentioned included lack of information (7%), and transportation (6%).

Caregiver Services and Support

Caregiver respondents were asked a series of questions (Question 23) regarding their participation in various services or sources of assistance that would either help them in dealing with the demands of providing care or improving the information, skills, and resources to provide care. The services and support that were surveyed are summarized in the following list:

- Have you received information about community services for yourself or your relationship (the care recipient)?
- Have you received help getting or using community services?
- Have you received education or training on how to assist your relationship?
- Have you received professional counseling?
- Have you received advice or counseling from a clergy person?
- Have you talked with a group of other people who are in a similar situation, such as a support group?

- Have you had someone help to take care of your relationship during the day in his/her home so you can have time to do other things or relax (i.e. in-home respite)?
- Have you used a center where your relationship can go during the day, so you can have time to do other things or relax (i.e. day respite)?
- Have you used a place where your relationship can stay overnight, so you can have time to do other things or relax (i.e. overnight respite)?
- Have you received information about your legal rights and obligations as a care provider, such as information on durable power of attorney, living wills, and trusts?
- Have you received financial information or advice to help you plan for the care of your relationship, such as financial benefits, long term care?
- Have you received any other services from an agency or organization that help your provide care or handle the challenges of providing care?

The rates of participation in these various sources of service and support are summarized in Table 10.

TABLE 10: ASSISTANCE RECEIVED BY CAREGIVERS (TYPES AND SOURCES) DURING THE PREVIOUS YEAR (N = 1643)

SERVICES OR SOURCES OF HELP	% from family and/or friends*	% from agency or other provider*	% from unspecified source*	% receiving the service overall
In home respite	26%	9%	3%	38%
Education or training	4 %	24%	3%	31%
Information about community services	4%	22%	4%	30%
Information about legal rights/obligations	6%	17%	3%	26%
Someone to talk to (e.g. support group)	14%	10%	1%	25%
Financial information and advice	4%	13%	3%	20%
Advice/counseling from clergy	2%	7%	10%	19%
Professional counseling	1%	6%	8%	15%
Overnight respite	6%	5%	2%	13%
Day respite	1%	4%	7%	12%
Help getting or using community services	3%	7%	2%	12%
Any other service from another agency or organization	0.4%	4%	7%	11%

* Some care recipients received services from multiple sources

The most frequently accessed services are help in providing care for the care recipient in the home so that the caregiver has time to do other things or relax (that is, in-home respite), education and training on how to assist the care recipient, and information about community services available either to the caregivers or the care recipients.

In all, 70% of caregivers report receiving one or more support services from a community agency or other formal service provider. Analysis reveals that White non-Hispanic caregivers are 1.9 times more likely to use formal services than Asian Americans and Pacific Islanders, and 1.5 times more likely than Latinos. African American caregivers are 2.6 times more likely to use formal services than Asian Americans and Pacific Islanders, and 1.9 times more likely than Latinos.

As Table 10 illustrates, when the specific sources of assistance are examined, it is clear that community organizations and other formal service providers are the primary sources of most types of support. Family members and friends were the primary sources of support with regard to in-home respite, overnight out-of-home respite, and emotional support from peers.

The services most often received from formal service providers include education, general information about services, and legal services. As summarized in Table 11, the most frequently utilized formal sources of support are health care providers (especially for education, information, and counseling), followed by AAAs and other public entities (for financial advice and information about services), residential care providers (for in-home and overnight respite), professionals (for legal and financial advice), other agencies and community-based organizations (for information about services), and religious organizations (for pastoral counseling and peer group support).

TABLE 11: FORMAL SERVICE PROVIDERS UTILIZED BY CAREGIVERS DURING THE PREVIOUS YEAR (N = 1643)

Formal Provider Type	Info.	Access	Educ.	Counsel	Clergy	Support	Home Respite	Day Respite	Night Respite	Legal	Finance	Other	Total	%
Health care provider	63	26	172	40	6	22	12	4	8	36	32	25	446	27%
Public agency	43	25	9	5		6	6	3	1	27	51	11	187	11%
Residential care	9	4	16			2	85		40	19	5	3	183	11%
Other professional	1	1		2		2	1			96	56	2	161	10%
Agency (non specified)	21	5	19	17	3	14	20	13	11	14	12	12	161	10%
Community Based Org	57	15	12	3		20	7	18	2	7	9	2	152	9%
Religious Organization	4	4	1	1	95	28	5	4	1	1	1	4	149	9%
Media	79	6	13	1		5		1		15	13		133	8%
Educational Program	8		78	4	3	6	2	1		9	4		115	7%
Through work/job	7		42	2	1	10	1		1	11	1		76	5%
Counselor/Social Work	12	14	1	11		3		1		7	8	4	61	4%
Disease-specific org	16	6	10	1		20		2		3	2		60	4%
CG-specific program	6	1	4	1		8				4	1	1	26	2%
Social/Cultural Org	2	1				3		15					21	1%
Other	22	8	12	6	2	7	5	4	5	19	9	1	100	6%
Total Specified	350	116	389	94	110	156	144	66	69	268	204	65	2031	

Following is a summary of the main sources of assistance to caregivers for each service:

In home respite:

Caregivers reported that in home respite was the service they most frequently utilized (38%). Most often, in home respite was provided by friends or family (26%), making it the service most often provided by family and/or friends. Less common was in home respite provided by an agency or other service provider (9%). Of those reporting using formal in-home respite, the most frequently reported source was a residential care provider (59%).

Education or training:

Education or training on how to assist the care recipient was the service caregivers reported they were most likely to receive from agencies or other providers (24%). Of those caregivers using formal sources of education or training, most reported receiving it from health care providers (44%), educational programs (20%) or through work (11%).

Information about community services:

Caregivers reported that they were most likely to receive information about community services from agencies or other service providers (22%). Of those reporting using a formal source of information, most reported receiving it from published or electronic media (22%), health care providers (18%), community based organizations (16%), and public agencies (13%).

Information about legal rights/obligations:

Information about legal rights and obligations is another service that caregivers most often received from agencies and other providers (17%). Of those caregivers using formal services for this information, most received it from "other professionals," possibly attorneys (36%), health care providers (13%), and public agencies (13%).

Talking with a group of other people (e.g. support group):

Caregivers were most likely to turn to friends and family to provide peer group support (14%). Of those using formal sources of support, most received it through religious organizations (18%), health care providers (14%), community based organizations (13%), and disease-specific organizations (13%). Disease-specific organizations were utilized far more often for this type of assistance than any other service in the survey.

Financial information and advice:

Caregivers receiving financial information and advice were most likely to receive it from agencies or other providers (13%). Of those caregivers, most utilized the services of "other professionals" (28%), public agencies (25%), and health care providers (16%).

Advice/counseling from clergy:

Unsurprisingly, most of those caregivers receiving advice or counseling from clergy through an agency or provider (7%) received it directly from a religious organization (86%).

Professional Counseling:

Of those caregivers who reported receiving counseling from an agency or other provider (6%), most frequently received it through health care providers (43%), non-specified agencies (18%), and counselors/social workers (12%).

Overnight respite care:

Those caregivers who used overnight respite care most frequently turned to friends and family to provide it (6%). Of those who received overnight respite care from an agency or other provider (5%), residential care providers were the most common source (58%).

Daytime respite care:

Daytime respite care was most frequently provided by unspecified sources (7%). Of those caregivers specifying a formal source of care, community-based organizations (27%) and social/cultural organizations (23%) were most frequently cited. Social/cultural organizations were utilized far more often for this type of assistance than any other service in the survey.

Help getting or using community services:

Caregivers who received help accessing community services most frequently received it from an agency or other provider (7%), particularly health care providers (22%), public agencies (22%), community based organizations (13%), and social workers/counselors (12%).

Satisfaction with Services

As shown in Table 12, caregivers generally feel that their needs were met regardless of the service that they used, with satisfaction levels exceeding 90% for most types of services.

TABLE 12. SATISFACTION WITH CAREGIVER SERVICES RECEIVED

SERVICES OR SOURCES OF HELP	Percent reporting needs were met
Advice/counseling from clergy	94%
In home respite	93%
Information about legal rights/obligations	93%
Overnight respite	93%
Education or training	92%
Day respite	92%
Help getting or using community services	92%
Support group	91%
Financial information and advice	89%
Professional counseling	88%
Any other service from another agency or organization	86%
Information about community services	83%

Barriers to Service Use Experienced by Caregivers

The California Statewide Survey of Caregivers included questions designed to assess caregivers' reasons for not using services they would otherwise find useful. As shown in Table 13, 19% to 67% of caregivers who did not use particular types of support would have considered those supports helpful if they could have used them. The services that would be most helpful would be information about community services, legal assistance, financial advice, help accessing services, and education or training.

TABLE 13. SERVICES CONSIDERED POTENTIALLY HELPFUL TO CAREGIVERS (of those who did not receive service)

SERVICES OR SOURCES OF HELP	Service would have been helpful	Do not know where to get service
Information about community services	67%	64%
Information about legal rights/obligations	64%	74%
Financial information and advice	57%	74%
Help getting or using community services	53%	54%
Education or training	49%	66%
Support group	42%	58%
Help with care receiver in home	33%	56%
Professional counseling	32%	58%
Day respite	30%	48%
Advice/counseling from clergy	27%	26%
Overnight respite	19%	62%

Lack of knowledge was the major reason for not using services. Three-fourths of caregivers needing financial or legal assistance and two-thirds of those desiring education, training or information about services did not know where to get these services.

A significant number of those who received services indicated that they had some problems obtaining the service (Table 14).

TABLE 14. SERVICES WHICH CAREGIVERS HAD PROBLEMS OBTAINING

SERVICES OR SOURCES OF HELP	Problems obtaining service
1. In home respite	19% (151 of 792)
2. Education or training	11% (96 of 856)
3. Information about community services	14% (138 of 967)
4. Information about legal rights/obligations	11% (104 of 914)
5. Support group	11% (87 of 774)
6. Financial information and advice	16% (131 of 825)
7. Advice/counseling from clergy	4% (22 of 621)
8. Professional counseling	11% (66 of 590)
9. Overnight respite	18% (79 of 430)
10. Day respite	13% (67 of 533)
11. Help getting or using community services	15% (110 of 748)
12. Any other service from another agency or organization	19% (114 of 615)

Open-ended probes corroborated the information above, revealing that for the most part, caregivers simply didn't know where to get a service. Other problems included cost, quality of service or lack of availability. Following, for each service, are the primary problems (mentioned by at least 8 people) either experienced or anticipated by the caregiver while attempting to get the service.

In home respite:

- Cost (29)
- Desired services not received or available (22)
- Don't know where to get it (21)
- Quality of service (19)

- Eligibility requirements (10)
- Care recipient special needs (8)

Education or training:

- Don’t know where to get it (32)
- Lack of information available (12)
- Not available in area (11)

Information about community services:

- Don’t know where to get it (53)
- Not available in area (16)
- Eligibility requirements (14)
- Lack of information available (10)
- Paperwork/red tape (8)

Information about legal rights/obligations:

- Don’t know where to get it (62)

Talking with a group of other people, such as a support group:

- Don’t know where to get it (43)
- Not available in area (14)

Financial information and advice:

- Don’t know where to get it (64)
- Lack of information (8)

Advice/counseling from clergy:

No single problem was listed by more than 8 people.

Professional Counseling:

- Cost (20)
- Don’t know where to get it (18)
- Eligibility requirements (8)

Overnight respite care

- Don’t know where to get it (33)
- Not available in area (13)

Daytime respite care at a center

- Don’t know where to get it (31)

Help getting or using community services:

- Don’t know where to get it (33)
- Lack of information available (13)
- Services not available (13)
- Eligibility requirements (12)

Other service from another agency or organization:

- Don’t know where to get it (48)
- Cost (11)

Reasons for Not Receiving More Outside Help

The final question in the series of items regarding caregiver support attempted to determine why a caregiver had not received more outside help. The material above already notes that many people simply didn’t know where to access services. The following table summarizes the results of the question posing a list of items that might account for the lack of more outside help for the caregiver.

TABLE 15. REASONS GIVEN FOR NOT RECEIVING MORE OUTSIDE HELP

(excludes those who say they already have all the help they need)

	% listing this reason
Services cost too much	17%
Care receiver doesn't want the help	13%
Services are not available	12%
Service quality is poor	11%
Not available at times needed	10%
There is no one to stay with care receiver while help is sought	8%
No time to get help for yourself (the caregiver)	8%
Services not offered by people who are like you (caregiver)	8%
Transportation is not available	7%
Service providers don't speak language	5%

The reasons most often given for not using desired services were the cost of services, the reluctance of the care recipient to want help, the lack of availability, poor quality of service, and lack of availability at the times it is needed, as shown in Table 15. 70% of caregivers said that they already have all the help they need.

IMPACT OF CAREGIVING

Work and Employment Effects

About 49% of the respondents reported being employed, while 51% indicated that they were not (Question 26). When non-employed respondents were asked the reason for their lack of employment, 49% indicated that they were retired, 8% reported taking a leave of absence, and another 43% simply responded that they were "not employed."

Of those caregivers who are employed, over 71% of them are employed full-time, while 29% are employed part-time. Approximately 77% of the respondents indicate that there have been no changes in their job status (Question 27) because of their caregiving activities. About 13% of the respondents indicated reducing the number of their work hours. A small percentage, about 4%, reported changing jobs.

Among the 679 employed respondents, 21% report having missed work in the two weeks prior to the interview. 15% were absent for at least one entire day (with nearly a quarter of them indicating 3 or more days) and 18% reported taking at least some time off during the workday, including arriving late or leaving early. Considering together people who missed either entire days or just a few hours, on average, a total of 20.71 hours of work were missed during the two-week period (with a median of 16 hours).

Other Impacts

The interview asked respondents to detail a number of other impacts (in addition to possible effects on their employment) that might be caused by their participation as caregivers. Respondents were asked specifically, "On a scale of 1 to 5, where 1 is no hardship at all and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for your relationship is for you?" (Question 29). The following table reports the results, indicating that a significant majority of the 1,359 respondents to this item *do not* find caring for their relationship to be a financial hardship. Only 15% responded their level of hardship as "4" or "5" (a great deal of hardship).

TABLE 16. FINANCIAL HARDSHIP OF CARING FOR CARE RECIPIENT

Level of Hardship	%
1. No Hardship ↓	56
2.	15
3	14
4.	6
5. Great deal of hardship	9

While respondents do not report much financial hardship, somewhat more of them indicate that they do experience physical strain (Question 30), as reported in the following table. In fact, nearly 18% of the respondents report a large amount of physical strain in caring for the care recipient.

TABLE 17. PHYSICAL STRAIN OF CARING FOR CARE RECIPIENT

Level of Strain	%
1. Not a strain ↓	45
2.	21
3.	17
4.	8
5. Very much of a strain	10

It is emotional stress that is most often reported, with nearly 33% reporting the experience to be quite stressful (rating of "4" or "5"). The data indicate that respondents do experience relatively higher levels of emotional stress than either physical strain or financial hardship. The following table reports the results of asking respondents about how stressful caring for their care recipient is for them.

TABLE 18. EMOTIONAL STRESS OF CARING FOR CARE RECIPIENT

Level of Emotional Stress	%
1. Not at all stressful	28
2.	19
3.	20
4.	16
5. Very stressful	17

Despite the stresses reported above, the vast majority of respondents (about 78% of the 1,377 answering Question 32), indicate that they did not suffer any physical or emotional problems as a result of providing care. However, it is notable that about 22% (over 300 respondents) suffer either physical, emotional, or *both* physical and emotional problems as a result of their care giving responsibilities (7% physical, 9% mental health, 6% both). Further, approximately 26% (355 respondents) of the caregivers indicate that they have had their sleep interrupted during the week prior to their interview. Again, depending on whether this sleep disruption rotates throughout the sample or whether it is concentrated in the same people, this sleep deprivation issue could be a more or less serious care giving consequence.

The interview also posed a series of items dealing with the quality of family life. There are substantial pockets of difficulty for caregivers' families. Still the data indicates that many of the respondents find that care giving can have positive effects on family life:

- 69% of the respondents feel that they are contributing to their families "very much" (Question 34a).
- 78% of the respondents feel that they are "very much" setting an example for the children in their family (Question 34b).
- 36% of the respondents feel that caregiving has brought their families closer together (Question 35a), while 28% feel the situation has "somewhat" brought their families together. 25% of the respondents indicated that care giving has not brought their families together at all.
- 53% of the respondents report that care giving has not created conflict or disagreements "at all" in their families (Question 35b), although about 30% do indicate that such conflict is "very much" or "somewhat" created by care giving in their family.

- When asked whether care giving has created "a hardship" for their family (Question 35c), about 45% of the respondents indicate "not at all," while 15% say "very much" and 21% say that care giving is "somewhat" of a hardship.

- When asked if there are any other ways that serving as a caregiver has affected the person or their families, about a third of the 609 people who responded indicated that it "feels good to help." Further, when positive comments of any type are combined and compared with negative comments of any type, the results are overwhelming: ***positive comments far outweigh the negative by 2 to 1.***

Caregiver Health and Functioning

Respondents were asked to indicate whether "In general, compared to other people your age, would you say your health is excellent, very good, good, fair, or poor?" Of the 1,377 respondents answering this question, the distribution of answers is as follows:

TABLE 19. REPORTED COMPARISON OF HEALTH COMPARED TO OTHERS OF RESPONDENT'S AGE

Health is:	
Poor	5%
Fair	21%
Good	34%
Very good	24%
Excellent	16%

The preceding data indicate that the vast majority of caregivers (74%) evaluate their own health as good to excellent (Question 37). But the flip side of this is that about a quarter of the respondents indicate that their health is fair to poor, indicating that many of the respondents are struggling with their own health problems even as they act as caregivers. In fact, when asked directly whether respondents have any illnesses or health or emotional challenges that make it difficult to provide care, over 28% indicated that they did. Most frequently mentioned conditions include: heart disease/high blood pressure (86 respondents), arthritis and other joint pains (67), mental health/mood disorders (65), muscle pain and disorders (48), diabetes/hypoglycemia (47), bone problems (e.g. osteoporosis) (42), and a host of other conditions.

Many caregivers, however, report being connected to various support systems to help them deal with the stresses of caregiving. Approximately 78% of the respondents indicate that they have someone to whom they can go for "support and understanding regarding what you are going through in caring for your relationship" (Question 39). Approximately four in ten caregivers (43%) mention attending religious services, meetings, and/or activities *at least* once a week (Question 40). Nearly 68% of the respondents report praying or meditating on their own nearly every day (Question 41).

Vulnerable Caregivers

As continually noted throughout this report, the vast majority of caregivers apparently do not find caregiving as burdensome as some might believe. Indeed, many report that the caregiving experience has enriched their lives in various ways. But for some, the stresses and strains of caregiving are taking a toll financially, physically, and emotionally.

For the purposes of this analysis, we selected the respondents who indicated that they were experiencing the most hardship financially, and the most stress physically and emotionally (a code of "5" on questions 29, 30, and 31). A total of 329 respondents fell into this category. We conducted an analysis of these "most stressed" caregivers vs. other caregivers to determine the possible reasons for their perceived increased level of stress.

First, an analysis was conducted comparing care recipient conditions for the "most stressed" caregivers vs. all other caregivers. The hypothesis behind this comparison was straightforward: the "most stressed" subset of caregivers was apt to be dealing with more difficult caregiving circumstances. Interestingly, there were virtually no significant differences between "most stressed" caregivers and all others in terms of the incidence of physical conditions of the care recipients. The only exception to that finding was the most stressed caregivers were more likely to be caring for an individual with stroke or paralysis. Additionally, there were also striking and statistically significant differences in the incidence of mental health/emotional problems, memory problems/dementia, and behavioral problems, with the "most stressed" group significantly more likely to be dealing with these problems than those in the "other" group.

TABLE 20. COMPARISON OF HEALTH CONDITIONS BETWEEN CAREGIVERS EXPERIENCING THE MOST STRESS AND OTHER CAREGIVERS

	Incidence of care recipient condition among….	
TYPE OF CONDITION	**Most Stressed**	**All Others**
Heart Disease or High Blood Pressure	64%	62%
Arthritis	60%	61%
Severe Memory Problems or Dementia	52%	33%
Mental Health Problems/Emotional Problems	52%	31%
Blindness or Severe Visual Impairment	33%	28%
Severe Hearing Impairment	32%	28%
Diabetes	30%	25%
Stroke or Paralysis	33%	22%
Behavior Problems	39%	20%
Lung Disease or Emphysema	16%	16%
Cancer	14%	13%
HIV/AIDS	1%	0.2%

Next, crosstabs reveal some significant differences between the most stressed group and the other caregivers in terms of their demographic profiles. Specifically, the most stressed group has a higher percentage of females (84% to 72%), a higher percentage of low-income (below $30,000) caregivers (49% vs. 37%), and a higher percentage of Hispanics (30% vs. 24%). There were no significant differences in education or age.

There also was a difference between the number of hours of care provided by the “most stressed” group (average = 62 hours) compared to that of other caregivers (average = 35 hours). Comparing the two groups on the types of care provided, the only difference found was that the “most stressed” were more likely to provide help with medical needs (80%) when compared to all others (72%).

A further analysis was conducted to determine whether there were significant differences in types and evaluations of services accessed by caregivers in the “most stressed” group vs. others. Differences found included:

- **Information about community services**: approximately the same percentages of caregivers in each subgroup accessed the service, but 28% of the most stressed group indicated that their needs were *not met*, as opposed to 14% of the other group.
- **Professional counseling**: people in the most stressed group seek out professional counseling more often than those in the “other” group (19% vs. 13%), and their needs were slightly more likely to be unmet (14% vs. 11%).

- **Advice/counseling from clergy:** 24% of the most stressed group sought advice/counseling from clergy, as opposed to 19% in the other group. But again, they show a greater incidence of unmet needs (9% to 4%).
- **Talking with people (e.g. support group)**: People in the "most stressed" group participated in groups such as support groups in slightly greater numbers than those in the "other group" (27% vs. 25%), however they reported a much larger incidence of unmet needs (18% vs. 6%).
- **In home respite:** People in the most stressed group are more likely to take advantage of in home respite services (43% vs. 37%), but they are more likely to have their needs remain unmet (13% vs. 5%).
- **Day respite:** People in the most stressed group are slightly more likely to take advantage of day respite services (15% vs. 10%), but they are more likely to have their needs remain unmet (13% vs. 6%).
- **Overnight respite:** About the same percentage of people in the two groups received overnight respite (14% in the "most stressed" group vs. 12% in the "other" group), but the level of unmet needs was higher among the stressed group (11% vs. 6%).
- **Information about legal rights and obligations:** There was approximately equal access to this service (25% vs. 27%), however again, dissatisfaction (i.e. level of unmet needs) was higher among the most stressed group (12% vs. 5%).
- **Financial information:** Access was about the same for the two groups (19% vs. 21%), however the level of unmet needs was significantly higher among the "most stressed" group (16% vs. 9%).

In summary, the above findings show that stressed people might feel that they need more help than family, friends, or agencies can provide. On the other hand, unmet needs for services might be creating more stress. Although this may be seen as a "chicken and egg" situation, it is our feeling that it is a classical reciprocal relationship in which case the causality goes in both directions.

Finally, earlier in this report we noted that generally caregivers report being in good to excellent health, and that many view caregiving as an enriching experience. When the two groups of caregivers are compared, however, a different picture emerges. Highly stressed caregivers report significantly worse evaluations of their own health, with only 58% of highly stressed caregivers reporting good to excellent health, versus the vast majority of caregivers in the other group (80%). Further, this group feels that caregiving has created more conflict in their families (28% vs. 7%), and has been “very much” a hardship for their family (39% vs. 7%). However, caregivers in the “very stressed” category are somewhat more likely to report feeling “very much” that they are contributing to their family (76% vs. 67%) and feeling that they are “very much” setting an example for the children in their family (82% vs. 77%). Whether or not these positive feelings are simply rationalization, they appear to be coping mechanisms in the face of a difficult situation.

COMPARISONS OF CAREGIVERS BASED ON CARE RECIPIENT CONDITION

In this section of the report, we compare caregivers in terms of various demographic variables (i.e. gender, income), feelings about hardships of caregiving (e.g. financial and physical hardships), positive feelings about caregiving (e.g. brings their family closer together), and types and evaluations of services accessed. Three separate comparisons are made: (1) a comparison of caregivers who deal with people with mental health, emotional, or behavioral problems vs. caregivers who deal with people who do not experience those problems; (2) a comparison of caregivers who provide care for those with memory problems or dementia vs. those who are not caring for someone with that condition; and (3) a comparison of caregivers who deal with people with more than two physical problems vs. those who deal with people with one or two physical problems.

In this section of the report we treat these three condition categories as analytically distinct, although we recognize that in the "real world" they are not. For example, two thirds of those with memory problems and dementia also have mental health/emotional problems or behavioral problems, thus demonstrating that there is tremendous overlap in caregivers dealing with those issues. Also, 60% of those with mental health, memory, or behavioral problems have more than two of the physical problems listed on the survey. It is clear that these groups of caregivers are not mutually exclusive, and that the caregivers in our study are in the position of dealing with multiple problems/issues.

With this caveat in place, the findings related to the three analyses are presented.

Care Recipients with Mental Health, Emotional, or Behavioral Problems

A total of 44% of caregiver respondents deal with someone with mental health problems or emotional problems (such as appearing anxious or worried, sad or depressed, or having crying spells), or behavior problems (such as arguing, being irritable, verbally aggressive or waking the respondent or other family members up at night). There are striking differences between these caregivers and those who do not deal with these conditions.

First, there are differences in current living arrangements between those care recipients who have mental health/emotional/behavioral problems and those who don't. The percentages residing with the caregiver are approximately the same for both groups (about a third), however more of the respondents with these problems reside in a board and care home, group home, or assisted living facility (8.2% vs. 4.1%), and fewer with their spouse (6.7% vs. 11.6%). Further, this group of care recipients apparently requires more time of their caregivers, since caregivers of these recipients spend an average of 50.5 hours per week providing help, as opposed to 34.4 hours spent by caregivers of recipients without these disorders.

As shown in Table 21, care recipients with mental/emotional/behavioral problems are much more likely to need assistance with all of the instrumental activities of daily living than are other care recipients. These differences are statistically significant at the .05 level. There are *no differences* in the proportions of caregivers meeting those needs between the two groups. But it is also true that 39% of caregivers of recipients with these problems feel that they are not receiving enough assistance from paid service providers, as opposed to 27% of caregivers in the other group.

TABLE 21. DIFFERENCES IN CARE RECIPIENT NEEDS

NEEDS (met by the recipient, family, friends, or paid providers)	**Care recipients who have:**	
	Mental/Emotional/ Behavioral Problems	Problems Other Than Mental/ Emotional/ Behavioral
Dressing, eating, bathing, or getting to the bathroom	52%	34%
Preparing meals, doing laundry, or cleaning house	80%	70%
Medical needs	61%	42%
Going shopping	89%	83%
Financial matters	72%	58%
Arranging for care or services	63%	48%

An analysis of types and evaluation of services accessed by the caregiver (Table 22) shows that caregivers in the two groups are approximately equal in their tendency to seek out information regarding legal or financial issues, or community services. On the other hand, caregivers of individuals with mental, emotional, or behavioral problems appear to access more direct types of help (counseling and day or overnight respite) significantly more often than caregivers of recipients without those problems. The percentages of caregivers reporting that their needs were not met are approximately the same for these two groups.

TABLE 22. COMPARISON OF CAREGIVER SERVICES AND SUPPORT (ACCESS AND UNMET NEEDS) BETWEEN THOSE CARING FOR RECIPIENTS WITH MENTAL/EMOTIONAL/BEHAVIORAL PROBLEMS VS. NOT*

	% accessing the service		**% with needs not met**	
SERVICE	**Ment./Emot./ Behavior Problems**	**Other Problems**	**Ment./Emot./ Behavior Problems**	**Other Problems**
1. In home respite	41%	36%	9%	6%
2. Education or training	34%	30%	10%	6%
3. Information about community services	30%	30%	21%	15%
4. Information about legal rights/obligations	26%	26%	7%	7%
5. Someone to talk to (e.g. support group)	25%	25%	10%	8%
6. Financial information and advice	20%	21%	17%	5%
7. Advice/counseling from clergy	22%	18%	8%	4%
8. Professional counseling	17%	13%	14%	10%
9. Overnight respite	17%	10%	9%	5%
10. Day respite	16%	10%	11%	4%
11. Help getting or using community services	14%	12%	7%	9%

* Categories in bold print are those for which there are statistically significant differences between groups at the .05 level

There were no significant differences between caregivers in the two groups in terms of impact on work status (job position or number of work hours). Further, caregivers providing care to those with mental/emotional/behavioral problems were significantly more likely to indicate that caring for the recipient is a financial hardship, a physical strain, and emotionally stressful. They were also less likely to report being in excellent or very good health. Yet these caregivers are equally likely to experience some of the “cognitive balancing” that we have noted in this report that provides them with positive feelings of accomplishment, contributing to the family, setting an example for their children, and/or creating a situation which will draw the family closer together.

TABLE 23. OTHER IMPACTS OF CAREGIVING*

	Care recipients who have:	
	Mental/Emotional/ Behavior Problems	**Other Problems**
NEGATIVE IMPACTS		
Financial hardship	**18%**	**12%**
Physical Strain	**25%**	**12%**
Emotionally Stressful	**46%**	**22%**
Sleep Interrupted	**37%**	**17%**
POSITIVES		
Excellent or very good health	**36%**	**45%**
"Very much" contributing to the family	72%	67%
"Very much" setting an example for kids	77%	78%
"Very much" brought family together	32%	39%

* Categories in bold print are those for which there are statistically significant differences between groups at the .05 level.

Considering the stresses and strains of assisting care recipients who have mental, emotional, or behavioral problems, it would be desirable for the caregiver to have a support system of people to whom they can go for support and understanding regarding their caregiving role. Yet only 75% of these caregivers have such a support system, as opposed to 80% of those caregivers not dealing with those problems (a statistically significant difference). There were no significant differences between groups in terms of attendance at religious services or frequency of prayer.

There are few demographic differences between caregivers assisting recipients in the two groups. Caregivers of people with mental, emotional, or behavioral problems are equally likely to be female (75% in each group), but more likely to have an income below $30,000 (45% vs. 36%). There are no significant differences in terms of caregiver's marital status, race, or age.

Care Recipients with More Than Two Physical Health Problems

Out of the 1,643 respondents to the survey, 56% (924 respondents) indicated that they care for a person with more than two of the physical health problems listed on the survey: arthritis, heart disease or high blood pressure, diabetes, severe hearing impairment, blindness or severe visual impairment, lung disease or emphysema, cancer, stroke or paralysis, or HIV/AIDS. For the purposes of this analysis, these care recipients will be termed as people with "multiple physical problems."

There are no significant differences in current living arrangements between those care recipients who have multiple physical problems and those who don't, with about a third of recipients in each group living with the caregiver. On the other hand, there are significant differences in the needs of recipients in those two groups. As shown in Table 24, care recipients with multiple physical problems are much more likely to need assistance with all of the instrumental activities of daily living than are care recipients with two or less physical problems.

TABLE 24. DIFFERENCES IN CARE RECIPIENT NEEDS

NEEDS (met by the recipient, family, friends, or paid providers)	**Care recipients who have:**	
	Multiple Physical Problems	Two or Less Physical Problems
Dressing, eating, bathing, or getting to the bathroom	46%	35%
Preparing meals, doing laundry, or cleaning house	80%	68%
Medical needs	54%	45%
Going shopping	89%	81%
Financial matters	68%	60%
Arranging for care or services	59%	48%

It is not surprising that caregivers for those with multiple physical problems spent significantly more time in an average week providing help than do those caregivers working with recipients with two, one, or no physical problems (47.5 hours vs. 33.75 hours).

There were virtually no differences between groups in terms of types and evaluation of services accessed by the caregiver (Table 25). The only difference was in the category of getting or using community services, which was accessed more often by caregivers dealing with recipients with multiple physical problems.

TABLE 25. COMPARISON OF CAREGIVER SERVICES AND SUPPORT (ACCESS AND UNMET NEEDS) BETWEEN THOSE CARING FOR RECIPIENTS WITH MULTIPLE PHYSICAL PROBLEMS VS. NOT

	% accessing the service		**% with needs unmet**	
SERVICE	**Multiple Physical Problems**	**Two or Less Problems**	**Multiple Physical Problems**	**Two or Less Problems**
1. In home respite	39%	37%	9%	5%
2. Education or training	32%	31%	9%	6%
3. Information about community services	31%	29%	20%	13%
4. Information about legal rights/obligations	27%	25%	8%	5%
5. Someone to talk to (e.g. support group)	24%	25%	10%	8%
6. Financial information and advice	20%	22%	11%	11%
7. Advice/counseling from clergy	21%	18%	6%	5%
8. Professional counseling	15%	14%	10%	15%
9. Overnight respite	12%	14%	3%	11%
10. Day respite	12%	14%	9%	7%
11. Help getting or using community services	**14%**	**10%**	9%	7%

* Categories in bold print are those for which there are statistically significant differences between groups at the .05 level.

Further, there were no differences between caregivers in the two groups in terms of impact on work status (job position or number of work hours). However, more "multiple problem" caregivers reported missing work in the past two weeks than did other caregivers (26% vs. 16%). Further, caregivers providing care to those with multiple physical problems were significantly more likely to indicate that caring for the recipient is a financial hardship, a physical strain, and emotionally stressful (Table 26). They were also less likely to report being in excellent or very good health. Interestingly, these caregivers reported in virtually *equal* numbers some of the "cognitive balancing" that provides them with positive feelings of accomplishment: contributing to the family, setting an example for their children, and/or creating a situation which will draw the family closer together.

TABLE 26. OTHER IMPACTS OF CAREGIVING*

	Care recipients who have:	
	Multiple Physical Problems	Two or Less Physical Problems
NEGATIVE IMPACTS		
Financial hardship	**17%**	**11%**
Physical Strain	**21%**	**14%**
Emotionally Stressful	**36%**	**29%**
Sleep Interrupted	**30%**	**20%**
POSITIVES		
Excellent or very good health	**36%**	**47%**
"Very much" contributing to the family	71%	66%
"Very much" setting an example for kids	78%	77%
"Very much" brought family together	35%	36%

* Categories in bold print are those for which there are statistically significant differences between groups at the .05 level.

There were no significant differences between groups in the presence of people to whom the caregivers can go for support and understanding, in attendance at religious services, or in frequency of prayer and/or meditation.

There are a few demographic differences between caregivers in these two groups. Caregivers of people with multiple physical problems are more likely to be female (78% vs. 71%) and have an income below $30,000 (43% vs. 36%). There are no significant differences in terms of caregiver's marital status, race, or age.

Care Recipients with Severe Memory Problems or Dementia

A total of 36% of caregiver respondents assist someone with severe memory problems or dementia (such as asking the same question over and over, forgetting what day it is, or losing or misplacing things). As noted above, there is a great deal of overlap between people with severe memory problems/dementia and those with behavioral problems or mental health/emotional problems; thus, some of the previous conclusions are relevant for both groups. In this analysis, we focus only on the differences between caregivers who deal with memory problems/dementia and those who do not.

As might be expected, fewer care recipients with memory problems/dementia live alone in their own home or apartment than do care recipients without these problems (27% vs. 37%). The percentages residing with the caregiver are approximately the same for both groups (about a third). However, caregivers of recipients with severe memory problems/dementia spend an average of 53.7 hours per week providing help, as opposed to 34.1 hours spent by caregivers of recipients without these disorders.

As shown in Table 27, care recipients with severe memory problems/dementia are much more likely to need assistance with all of the instrumental activities of daily living than are other care recipients. These differences are all statistically significant at the .05 level. In contrast to the two previous groups, in which it was stated that caregivers of recipients with those problems feel more strongly than others that they are not receiving enough assistance from paid service providers, caregivers in the two groups are equally likely to say that their care recipient receives enough assistance from paid providers.

TABLE 27. DIFFERENCES IN CARE RECIPIENT NEEDS

NEEDS (met by the recipient, family, friends, or paid providers)	**Care recipients who have:**	
	Severe Memory Problems/Dementia	Problems Other Than Memory/ Dementia
Dressing, eating, bathing, or getting to the bathroom	**58%**	**32%**
Preparing meals, doing laundry, or cleaning house	**82%**	**70%**
Medical needs	**69%**	**39%**
Going shopping	**91%**	**82%**
Financial matters	**79%**	**56%**
Arranging for care or services	**68%**	**47%**

* Categories in bold print are those for which there are statistically significant differences between groups at the .05 level.

An analysis of types and evaluation of services accessed by the caregiver (Table 28) shows that caregivers dealing with care recipients having severe memory problems/dementia are more likely to access services "giving them a break" from the burdens of daily caregiving (e.g. in home respite, day respite, and overnight respite). They also seek support groups, education and training, and information about community services more often than caregivers not dealing with these problems. The percentage of caregivers reporting that their needs were not met is approximately the same for these two groups.

TABLE 28. COMPARISON OF CAREGIVER SERVICES AND SUPPORT (ACCESS AND UNMET NEEDS) BETWEEN THOSE CARING FOR RECIPIENTS WITH SEVERE MEMORY PROBLEMS/DEMENTIA VS. NOT

	% accessing the service		**% with needs not met**	
SERVICE	Severe Memory Problems/ Dementia	Problems Other Than Memory/ Dementia	Severe Memory Problems/ Dementia	Problems Other Than Memory/ Dementia
1. In home respite	**42%**	**36%**	6%	8%
2. Education or training	**35%**	**30%**	8%	8%
3. Information about community services	**34%**	**28%**	22%	15%
4. Information about legal rights/obligations	29%	24%	6%	8%
5. Someone to talk to (e.g. support group)	**29%**	**22%**	9%	9%
6. Financial information and advice	23%	19%	12%	10%
7. Advice/counseling from clergy	20%	19%	8%	4%
8. Professional counseling	17%	13%	14%	11%
9. Overnight respite	**16%**	**11%**	4%	10%
10. Day respite	**18%**	**10%**	7%	9%
11. Help getting or using community services	14%	12%	8%	8%

* Categories in bold print are those for which there are statistically significant differences between groups at the .05 level

Significantly more caregivers of people with memory problems/dementia changed their work schedules (reduced the number of work hours) than those not dealing with this condition. Further, caregivers providing care to those with memory problems/dementia were significantly more likely to indicate that caring for the recipient is a financial hardship, a physical strain, and emotionally stressful. They were also less likely to report being in excellent or very good health. Yet as noted in previous analyses, these caregivers are equally likely to experience some of the "cognitive balancing" that we have noted throughout this report which provides them with positive feelings of accomplishment, contributing to the family, setting an example for their children, and/or creating a situation which will draw the family closer together.

TABLE 29. OTHER IMPACTS OF CAREGIVING*

	Care recipients who have:	
	Severe Memory Problems/ Dementia	Problems Other Than Memory/ Dementia
NEGATIVE IMPACTS		
Financial hardship	**19%**	**11%**
Physical Strain	**24%**	**13%**
Emotionally Stressful	**44%**	**26%**
Sleep Interrupted	**32%**	**22%**
POSITIVES		
Excellent or very good health	**36%**	**44%**
"Very much" contributing to the family	70%	69%
"Very much" setting an example for kids	77%	79%
"Very much" brought family together	35%	37%

* Categories in bold print are those for which there are statistically significant differences between groups at the .05 level.

About three-quarters of the caregivers in each group have a support system of people to whom they can go for support and understanding regarding their caregiving role. There were no significant differences between groups in terms of attendance at religious services or frequency of prayer.

There are few demographic differences between caregivers in the two groups. Caregivers of people with dementia are equally likely to be female (about three-quarters of each group), but more likely to have an income below $30,000 (44% vs. 38%). There are no significant differences in terms of caregivers' marital status or race.

CONCLUSION

The California Statewide Survey of Caregivers, drawing upon a random sample of California households, is the most comprehensive statewide survey of caregivers to date. The survey highlights the diversity of the caregiver experience among California caregivers who provide assistance or support to an adult relative or friend over the age of 50 who is ill, disabled or elderly. While many are coping well with the challenges of caregiving, this study has identified some caregivers who are especially vulnerable. California caregivers who experience the highest levels of financial hardship, physical strain, and emotional stress, are more likely to be female, Latino, low income, and in poor health. They also are more likely to care for someone with mental illness/emotional problems, dementia/memory problems, behavioral problems, or stroke or paralysis. It is hoped that this report will further provide the California Department of Aging and local Area Agencies on Aging with a strong foundation for developing service programs to assist family members in maintaining their caregiver roles for ill or disabled elderly Californians.

APPENDIX A: SURVEY INSTRUMENT

CALIFORNIA STATEWIDE SURVEY OF CAREGIVERS

Hi. This is (full name of interviewer) from the Institute of Applied Research, calling on behalf of the University of California at Berkeley and California Department of Aging. We are conducting a scientific study of people who provide assistance for at least a couple of hours a month to a family member, friend, or neighbor. This might include help with personal needs, household chores, taking care of their finances or arranging for outside services.

1. Do you or does anyone in your household currently provide assistance or support to an adult relative or friend who is ill, disabled, or elderly?

YES, PERSON ON PHONE IS CAREGIVER*	01; GO TO Q. 2
YES, OTHER PERSON IN HOUSEHOLD IS CAREGIVER*	02; ASK TO SPEAK WITH THAT PERSON AND BEGIN WITH INTRODUCTION
*IF BOTH, ASK TO SPEAK WITH WHOEVER IS THE PRIMARY CARE PROVIDER FOR SOMEONE AGE 50 OR OLDER	03
NO CAREGIVER IN HOUSEHOLD	04; THANK YOU, GOODBYE.
REFUSED	RF

2. What are the ages and relationships of the people you provide care for?

1. RELATIONSHIP:	AGE:
2. RELATIONSHIP:	AGE:
3. RELATIONSHIP:	AGE:

IF RESPONDENT **PROVIDES CARE TO SOMEONE AGE 50 OR OVER, PROCEED** TO QUESTION 3.

IF RESPONDENT **DOES NOT PROVIDE CARE TO SOMEONE AGE 50 OR OVER, DO NOT CONTINUE** WITH INTERVIEW.

IF MORE THAN ONE PERSON IS AGE 50+, ASK RESPONDENT TO IDENTIFY THE PERSON AGE 50+ FOR WHOM THEY PROVIDE THE MOST CARE AND INDICATE WHO IT IS.

3. We're conducting this survey to better understand the experiences of people like yourself. The information you provide will be used to help the California Department of Aging develop policies and programs for Californians who help family members and friends. Your responses are confidential and you may refuse to answer any question. Your participation is voluntary and you may stop the interview at any time for any reason. The survey will take about 20 - 30 minutes. May I ask you some questions now?

YES	01; PROCEED WITH SURVEY
NO	02; GOODBYE

Thank you.

CARE RECIPIENT SOCIAL AND DEMOGRAPHIC CHARACTERISTICS

I would like to start by asking you some general questions about your (Relationship).

4. ASK ONLY IF NOT OBVIOUS: What is your (Relationship)'s gender?

MALE	01
FEMALE	02

5. ASK ONLY IF NOT OBVIOUS: Is your (Relationship) currently married?

MARRIED	01
LIVING WITH PARTNER	02
SEPARATED	03
DIVORCED	04
WIDOWED	05
NEVER MARRIED	06
DON'T KNOW	DK
REFUSED	RF

6. a. What is your (Relationship)'s current living arrangement?

ALONE IN THEIR OWN HOME OR APARTMENT	01
WITH CAREGIVER	02; **SKIP TO Q.6e** ☪
WITH SPOUSE OR PARTNER ONLY	03
IN THE HOME OF ANOTHER FAMILY MEMBER OR FRIEND	04
IN A RETIREMENT COMMUNITY	05
IN A BOARD AND CARE HOME, GROUP HOME OR ASSISTED LIVING FACILITY, WHERE SOME CARE MAY BE PROVIDED	06
IN A NURSING HOME	07
SOMEWHERE ELSE (PLEASE SPECIFY:______________________________)	08
DON'T KNOW	DK
REFUSED	RF

b. What town or city does your (Relationship) live in?

DON'T KNOW	DK;
REFUSED	RF

c. And what is the zip code there?

DON'T KNOW	DK
REFUSED	RF

d. Typically, how long does it take you to travel to (his/her) residence, each way?

Less than 15 minutes	01
15-30 minutes	02
30 minutes to an hour	03
More than an hour	04
DON'T KNOW	DK
REFUSED	RF

☪ e. What town or city do you live in?

DON'T KNOW	DK
REFUSED	RF

f. And what is the zip code there?

DON'T KNOW	DK
REFUSED	RF

7. Is your (Relationship) of Hispanic or Latino origin?

YES	01
NO	02
DON'T KNOW	DK
REFUSED	RF

8. What is your (Relationship)'s race or ethnicity? CHECK ALL THAT APPLY.

WHITE OR CAUCASIAN	01
BLACK OR AFRICAN AMERICAN	02
ASIAN	03
Asian Indian	03.1
Cambodian	03.2
Chinese	03.3
Filipino	03.4
Japanese	03.5
Laotian	03.6
Korean	03.7
Vietnamese	03.8
Other Asian:	03.9
AMERICAN INDIAN OR ALASKA NATIVE	04
Alaska Native	04.1
American Indian	04.2
Tribe Name:	04.3
NATIVE HAWAIIAN OR PACIFIC ISLANDER	05
Native Hawaiian	05.1
Guamanian or Chamorro	05.2
Samoan	05.3
Other Pacific Islander:	05.4
OTHER	00
DON'T KNOW	DK

REFUSED	RF

9. What country was your (Relationship) born in?

IF NOT BORN IN THE UNITED STATES:
a. And what year did he/she arrive in the U.S.?

10. How much schooling has your (Relationship) had?

LESS THAN HIGH SCHOOL	01
SOME HIGH SCHOOL	02
HIGH SCHOOL GRADUATE	03
POST HIGH SCHOOL EDUCATION/TRAINING	04
COLLEGE GRADUATE	05
POST-GRADUATE DEGREE	06
DON'T KNOW	DK
REFUSED	RF

CARE RECIPIENT HEALTH AND FUNCTIONING

Next I would like to ask you some questions about your (Relationship)'s health.

11. I am going to read a list of different illnesses and health conditions. Please indicate whether or not your (Relationship) has each illness or condition. Does s/he have:

Arthritis	YES NO DON'T KNOW	01 02 DK
Heart Disease or High Blood Pressure	YES NO DON'T KNOW	01 02 DK
Diabetes	YES NO DON'T KNOW	01 02 DK
Severe Hearing Impairment	YES NO DON'T KNOW	01 02 DK
Blindness or Severe Visual Impairment	YES NO DON'T KNOW	01 02 DK
Lung Disease or Emphysema	YES NO DON'T KNOW	01 02 DK
Cancer	YES NO DON'T KNOW	01 02 DK
Stroke or Paralysis	YES NO DON'T KNOW	01 02 DK
HIV or AIDS	YES NO DON'T KNOW	01 02 DK
Mental Health Problems or Emotional Problems, Such as appearing anxious or worried, sad or depressed, or having crying spells	YES NO DON'T KNOW	01 02 DK
Severe Memory Problems or Dementia, Such as asking the same question over and over, forgetting what day it is, or losing or misplacing things	YES NO DON'T KNOW	01 02 DK
Behavior Problems, Such as arguing, being irritable, verbally aggressive or waking you or other family members up at night	YES NO DON'T KNOW	01 02 DK
Any other illnesses or health conditions? PLEASE SPECIFY:	YES NO DON'T KNOW	01 02 DK

CARE PROVIDED BY CAREGIVER

12. (i) Next, I am interested in the types of assistance you provide to your (Relationship) as a result of their health condition(s), and whether anyone else also helps, such as a relative, friend, or a paid service provider.

Does your (relationship) need help …		**Who helps your (relationship) with this activity? [SELECT ALL THAT APPLY]**
12a. **With dressing, eating, bathing or getting to the bathroom?**	YES ⇒ NO *Go to 12b.* DK *Go to 12b* RF *Go to 12b*	**1. Respondent** **2. Family/friends** **3. Paid service providers** **4. Neighbors** **5. Other (Specify)** **6. Don't know** **7. Refused**
12b. **With preparing meals, doing laundry, or cleaning the house?**	YES ⇒ NO *Go to 12c.* DK *Go to 12c* RF *Go to 12c*	**1. Respondent** **2. Family/friends** **3. Paid service providers** **4. Neighbors** **5. Other (Specify)** **6. Don't know** **7. Refused**
12c. **With medical needs such as taking medicine or changing bandages?**	YES ⇒ NO *Go to 12d.* DK *Go to 12d* RF *Go to 12d*	**1. Respondent** **2. Family/friends** **3. Paid service providers** **4. Neighbors** **5. Other (Specify)** **6. Don't know** **7. Refused**
12d. **Going shopping or getting to the doctor's office?**	YES ⇒ NO *Go to 12e.* DK *Go to 12e* RF *Go to 12e*	**1. Respondent** **2. Family/friends** **3. Paid service providers** **4. Neighbors** **5. Other (Specify)** **6. Don't know** **7. Refused**
12e. **Keeping track of bills, writing checks, or other financial matters?**	YES ⇒ NO *Go to 12f.* DK *Go to 12f* RF *Go to 12f*	**1. Respondent** **2. Family/friends** **3. Paid service providers** **4. Neighbors** **5. Other (Specify)** **6. Don't know** **7. Refused**

12f. **Arranging for care or services?**	YES ⇒ NO *Go to 13* DK *Go to 13* RF *Go to 13*	**1. Respondent** **2. Family/friends** **3. Paid service providers** **4. Neighbors** **5. Other (Specify)** **6. Don't know** **7. Refused**

13. Who would you consider to be the person who provides **most** of the care for your (Relationship)?

SELF	01
SOMEONE ELSE:	02
SPECIFY RELATIONSHIP	
RELATIVE (SPECIFY):	02.1
FRIEND	02.2
SERVICE PROVIDER	02.3
OTHER	02.4
SHARED:	03
SPECIFY RELATIONSHIP	
RELATIVE (SPECIFY):	03.1
FRIEND	03.2
SERVICE PROVIDER	03.3
OTHER	03.4
DON'T KNOW	DK
REFUSED	RF

14. How long ago did you first have to start helping your (Relationship) do things that he/she was no longer able to do?

LESS THAN 6 MONTHS AGO	01
BETWEEN 6 AND 12 MONTHS AGO	02
1-5 YEARS	03
6-10 YEARS	04
OVER 10 YEARS	05
DON'T KNOW	DK
REFUSED	RF

15. Thinking now of all the kinds of help you provide for your (Relationship), about how many hours do you spend, in an average week, doing these things? DO NOT INCLUDE HOURS OF SLEEP.

NUMBER OF HOURS/WEEK _______________
(COMPUTE BY HOURS/DAY, IF NECESSARY)
CC CONSTANT CARE
DK DON'T KNOW
RF REFUSED

16. [IF RESPONDENT SAID THAT NO FAMILY OR FRIENDS ARE PROVIDING HELP WITH ACTIVITIES (12A – 12F), THEN SKIP THIS QUESTION]
On average, about how much time each week do other family members and friends spend assisting your (Relationship), including personal care, helping with household chores, taking him/her places, buying things, managing finances, and arranging care?

_________________HOURS
(COMPUTE HOURS/DAY X DAYS, IF NECESSARY)

17. If you were unable to help your (Relationship), is there someone else who would do the things you do?

YES	01
NO	02
DON'T KNOW	DK
REFUSED	RF

18. In the past month, has your (Relationship) used any of the following community services? Has your (Relationship) used…..

Home-Delivered Meals? (SUCH AS MEALS ON WHEELS)	YES NO DON'T KNOW	01 02 DK
Adult Day Services? (SUCH AS ADULT DAY HEALTH CARE)	YES NO DON'T KNOW	01 02 DK
Mental Health Counseling? (SUCH AS SEEING A THERAPIST OR PROFESSIONAL COUNSELOR)	YES NO DON'T KNOW	01 02 DK
Any Other Community Services? PLEASE SPECIFY:	YES NO DON'T KNOW	01 02 DK

19. [IF RESPONDENT SAID THAT NO PAID SERVICE PROVIDERS ARE PROVIDING HELP WITH ACTIVITIES (12A – 12F), THEN SKIP THIS QUESTION]
On average, about how much time each week do paid service providers spend assisting your (Relationship), including personal care, helping with household chores, taking him/her places, buying things, managing finances, and arranging care?

_________________hours
(COMPUTE HOURS/DAY X DAYS, IF NECESSARY)

20. Do you feel that your (Relationship) receives enough assistance from paid service providers? Would you say that it is…

NOT ENOUGH	01
ABOUT THE RIGHT AMOUNT	02
TOO MUCH	03
N/A	NA
DON'T KNOW	DK
REFUSED	RF

21. Is there any other type of assistance that would be helpful to your (Relationship)?

YES; PLEASE SPECIFY	01
NO	02
DON'T KNOW	DK
REFUSED	RF

22. Have you had any problems with the services used, or difficulty in getting services your (Relationship) needs?

YES; PLEASE SPECIFY	01
NO	02
DON'T KNOW	DK
REFUSED	RF

CAREGIVER SERVICES AND SUPPORT

23. Now I would like to change the focus of the questions, and ask you some questions about yourself. I would like to ask you about types of assistance **you** may have received within the past year, or may find useful to support you in providing care to your (REL).

In the past year…..		**Where did you get this service? CHECK ALL THAT APPLY**	**Do you feel that your needs were met?**	**Do you think that would be helpful?**	**Would you know where to get this?**	**Have you had any problems getting this type of service or would you expect any difficulties in getting it? IF SO, Could you please describe them?**
Have you received information about community services for yourself or your (Relationship)?	YES ⇒	Family	YES ⇒			
		Friends				
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		
Have you received help getting or using community services?	YES ⇒	Family	YES ⇒			
		Friends				
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		
Have you received education or training on how to assist your (Relationship)?	YES ⇒	Family	YES ⇒			
		Friends				
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		

Have you received professional counseling?	YES ⇒	Family Friends	YES ⇒			
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		
Have you received advice or counseling from a clergy person?	YES ⇒	Family Friends	YES ⇒			
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		
Have you talked with a group of other people who are in a similar situation; such as a support group?	YES ⇒ NO ⇒	Family Friends	YES ⇒			
		Other individual or community organization (Specify)	NO ⇒			
				YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		
Have you had someone help to take care of your (Relationship) during the day <u>in his/her home</u>, so you can have time to do other things or relax?	YES ⇒	Family Friends	YES ⇒			
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		

Have you used a center where your (Relationship) can go during the day, so you can have time to do other things or relax?	YES ⇒	Family Friends	YES ⇒			
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		
Have you used a place where your (Relationship) can stay overnight, so you can have time to do other things or relax?	YES ⇒	Family Friends	YES ⇒			
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		
Have you received information about your legal rights and obligations as a care provider? (SUCH AS INFORMATION ON DURABLE POWER OF ATTORNEY, LIVING WILLS, TRUSTS)	YES ⇒	Family Friends	YES ⇒			
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		

Have you received financial information or advice to help you plan for the care of your (Relationship)? (SUCH AS FINANCIAL BENEFITS, LONG-TERM CARE PLANNING)	YES ⇒	Family	YES ⇒			
		Friends				
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		
Have you received any other services from an agency or organization that help you provide care or handle the challenges of providing care?	YES ⇒	Family	YES ⇒			
		Friends				
		Other individual or community organization (Specify)	NO ⇒			
	NO ⇒			YES ⇒	YES ⇒	
				NO ⇒		
	DK ⇒			YES ⇒	YES ⇒	
				NO ⇒		

24. Are there any other services that I did not mention that might be helpful to you?

YES (PLEASE SPECIFY)	01
NO	02
DON'T KNOW	DK
REFUSED	RF

25. Now I would like to know if there are reasons you have not received more outside help caring for your (Relationship). I am going to read a list of different reasons and I would like you to let me know whether or not each reason applies to you.

You already have all the help you need.	YES [SKIP TO Q 26]	01
	NO	02
	DON'T KNOW	DK
Your (Relationship) doesn't want it.	YES	01
	NO	02
	DON'T KNOW	DK
Services are not available.	YES	01
	NO	02
	DON'T KNOW	DK
Service quality poor.	YES	01
	NO	02
	DON'T KNOW	DK
Service providers don't speak your language.	YES	01
	NO	02
	DON'T KNOW	DK
There is no one to stay with your (Relationship) while you get help.	YES	01
	NO	02
	DON'T KNOW	DK
No time to get help for yourself.	YES	01
	NO	02
	DON'T KNOW	DK
Not available the times you need.	YES	01
	NO	02
	DON'T KNOW	DK
Transportation is not available.	YES	01
	NO	02
	DON'T KNOW	DK
Services cost too much.	YES	01
	NO	02
	DON'T KNOW	DK
Services are not offered by people who are like you.	YES	01
	NO	02
	DON'T KNOW	DK
Other: (PLEASE SPECIFY)		

IMPACT OF CAREGIVING

26. Are you currently employed?

NO ASK ⇒	Not Employed?	01
	Retired?	02
	Leave of Absence?	03
YES ASK ⇒	[redacted]	[redacted]
	Full-Time?	04
	Part-Time?	05

27. Has your work situation changed because of helping your (Relationship), such as a change in job position, reduced number of work hours, quitting or retiring?

NO CHANGE IN JOB STATUS	01
CHANGED JOB	02
TAKEN A SECOND JOB	03
REDUCED NUMBER OF WORK HOURS	04
TEMPORARY LEAVE OF ABSENCE	05
QUIT JOB	06
RETIRED	07
OTHER (PLEASE SPECIFY)	00

IF NOT CURRENTLY EMPLOYED, SKIP TO Q. 29 ☪.

28. Have you missed work in the past two weeks because of helping your (Relationship)?

YES	01
NO (SKIP TO Q29)	02

a. Were you absent an entire day in the past two weeks because of helping your (Relationship)?

YES; IF YES, ASK: How many times were you absent an entire day?	01
NO	02

a.

b. Did you take time off during the workday, including arriving late or leaving early?

YES; IF YES, ASK: How many hours in the past two weeks have you taken off during the workday because of helping your (Relationship)?	01
NO	02

☪ 29. On a scale from 1 to 5, where 1 is no hardship at all and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for your (Relationship) is for you?

A great deal of hardship	5
	4
	3
	2
No hardship at all	1
DON'T KNOW	DK

REFUSED	RF

30. On a scale from 1 to 5, where 1 is not a strain at all and 5 is very much of a strain, how much of a physical strain would you say that caring for your (Relationship) is for you?

Very much of a strain	5
	4
	3
	2
Not at all of a strain	1
DON'T KNOW	DK
REFUSED	RF

31. Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say that caring for your (Relationship) is for you?

Very stressful	5
	4
	3
	2
Not at all stressful	1
DON'T KNOW	DK
REFUSED	RF

32. Have you suffered any physical or mental health problems yourself as a result of providing care to your (Relationship)?

YES, PHYSICAL HEALTH PROBLEMS	01
YES, MENTAL HEALTH PROBLEMS	02
YES, BOTH PHYSICAL AND MENTAL HEALTH PROBLEMS	03
NO	04
DON'T KNOW	DK
REFUSED	RF

33. Has your sleep been interrupted during the past week as a result of caring for your (Relationship)?

YES	01
NO	02
DON'T KNOW	DK
REFUSED	RF

34. Sometimes people learn things about themselves or their families from taking care of a friend or relative. What about you? How much do you…..

Feel that you are contributing to your family?	Very much Somewhat Just a little Not at all	01 02 03 04
Feel that you are setting an example for the children in your family?	Very much Somewhat Just a little Not at all Not Applicable/No Children in the family	01 02 03 04

35. And how has your family been affected by your (Relationship)'s need for care? How much has this situation…..

Brought your family closer together?	Very Much Somewhat Just a little Not at all	01 02 03 04
Created conflict or disagreements in your family?	Very Much Somewhat Just a little Not at all	01 02 03 04
Been a hardship for your family?	Very Much Somewhat Just a little Not at all	01 02 03 04

36. Are there other ways that helping your (Relationship) has affected you or your family, either positively or negatively?

CAREGIVER HEALTH AND FUNCTIONING

Now I would like to ask you some more specific questions about yourself. As I mentioned earlier, your responses will be completely confidential.

37. In general, compared to other people your age, would you say your health is:

Poor	01
Fair	02
Good	03
Very Good	04
Excellent	05

38. Do you have any illnesses or health conditions or emotional problems which make it difficult for you to provide assistance or support to your (Relationship)?

YES (IF YES, PLEASE SPECIFY)	01
NO	02
DON'T KNOW	DK

39. Is there anyone whom you can go to for support and understanding regarding what you are going through in caring for your (Relationship)?

YES	01
NO	02
DON'T KNOW	DK
REFUSED	RF

40. How often do you usually attend religious services, meetings, and/or activities?

Never	01
Once a year	02
A few times a year	03
At least once a month	04
At least once a week	05
Nearly every day	06
DON'T KNOW	DK
REFUSED	RF

41. How often do you usually pray or meditate on your own?

Never	01
Once a year	02
A few times a year	03
At least once a month	04
At least once a week	05
Nearly every day	06
DON'T KNOW	DK
REFUSED	RF

CAREGIVER SOCIAL AND DEMOGRAPHIC CHARACTERISTICS

We are almost finished with the interview. I would just like to ask you a few more general questions about yourself.

42. ASK ONLY IF NOT SPOUSE OR PARTNER OF CR: Are you married?

MARRIED	01
LIVING WITH PARTNER	02
SEPARATED	03
DIVORCED	04
WIDOWED	05
NEVER MARRIED	06
REFUSED	RF

43. Are there any children under 18 living in your home, for whom you have primary responsibility?

YES	01; **GO TO Q. 43a**
NO	02
REFUSED	RF

a. How many? ____________ And what are their ages: __________

44. ASK ONLY IF NOT OBVIOUS: What is your gender?

MALE	01
FEMALE	02

45. And how old are you?

REFUSED	RF

46. Are you of Hispanic or Latino origin?

YES	01
NO	02
REFUSED	RF

47. What is your race or ethnicity? CHECK ALL THAT APPLY

WHITE OR CAUCASIAN	01
BLACK OR AFRICAN AMERICAN	02
ASIAN	03
Asian Indian	03.1
Cambodian	03.2
Chinese	03.3
Filipino	03.4
Japanese	03.5
Laotian	03.6
Korean	03.7
Vietnamese	03.8
Other Asian:	03.9
AMERICAN INDIAN OR ALASKA NATIVE	04
Alaska Native	04.1
American Indian	04.2
Tribe Name:	04.3
NATIVE HAWAIIAN OR PACIFIC ISLANDER	05
Native Hawaiian	05.1
Guamanian or Chamorro	05.2
Samoan	05.3
Other Pacific Islander:	05.4
OTHER	00
DON'T KNOW	DK

48. What country were you born in?

IF NOT BORN IN THE UNITED STATES:
a. What year did you arrive in the U.S.?

49. What is your highest level of schooling?

LESS THAN HIGH SCHOOL	01
SOME HIGH SCHOOL	02
HIGH SCHOOL GRADUATE	03
POST HIGH SCHOOL EDUCATION/TRAINING	04
COLLEGE GRADUATE	05
POST-GRADUATE DEGREE	06
REFUSED	RF

50. Finally, I would like to ask you about your current household income from all sources. This question is optional, but it would help us with statistics. Was your household income in 2001 under or over $30,000 before taxes?

UNDER $30,000 IF SO, ASK:	
Under $10,000 (Less than $834/month)	01
$10,000 - $20,000 ($834 - $1667/month)	02
Over $20,000 ($1667 - $2500/month	03
DON'T KNOW	DK
REFUSED	RF
OVER $30,000 IF SO, ASK:	
Under $40,000 ($2500 - $3334/month)	04
$40,000 - $50,000 ($3334 - $4167/month)	05
$50,001 - $80,000 ($4167 - $6667/month)	06
Over $80,000 (More than $6667/month)	07
DON'T KNOW	DK
REFUSED	RF

INTERVIEWER: IF THEY HESITATE, GIVE THEM A REMINDER: RESPONSES ARE CONFIDENTIAL.

51. And what was your (Relationship)'s approximate household income, from all sources, for 2001? Was your (Relationship)'s household income in 2001 under or over $30,000 before taxes?

UNDER $30,000 IF SO, ASK:	
Under $10,000	01
$10,000 - $20,000	02
Over $20,000	03
DON'T KNOW	DK
REFUSED	RF
OVER $30,000 IF SO, ASK:	
Under $40,000	04
$40,000 - $50,000	05
$50,001 - $80,000	06
Over $80,000	07
DON'T KNOW	DK
REFUSED	RF

52. Last, is there anything we haven't covered that you would like to share about your experiences helping your (Relationship)?

53. Would it be okay to contact you again in a number of months?

YES Is there someone who would know how to contact you if for any reason your phone number had changed? i. Name: ii. Phone Number:	01
NO	02

Thank you very much for your time. We know that this can be a very emotional topic to discuss, and your responses have been very helpful to us.

If you would like further information about services that assist people who provide care:
(800) 510-2020.

INTERVIEWER QUESTIONS

To be completed by interviewer immediately following interview.

1. How cooperative was the Respondent during most of the interview?

Very cooperative	01
Cooperative	02
Uncooperative	03
Very uncooperative	04

2. Did the Respondent cry during the interview?

Respondent sobbed or cried continuously	01
Respondent cried quietly a few times	02
Respondent cried quietly at one point	03
Respondent did not cry	04

3. Overall, how frank was the Respondent?

Entirely frank	01
Mostly frank	02
Probably not too frank	03

4. Is there anything else you would like to add about the interview that would help us to understand the Respondent? For example, was (he/she) reluctant to answer any questions? What were (his/her) strengths?