Appendix B: Detailed Methodology

The national study contains the results of 6,806 interviews among adults in the U.S., of whom 1,480 were caregivers who completed interviews. A total of approximately 200 caregiver interviews each of African American, Hispanic, and Asian caregivers were obtained.

In order to strengthen the analysis of caregivers of recipients ages 50 or older, additional interviews were conducted among this subgroup to reach 806 non-minority White caregivers, 200 Hispanics, and 206 African Americans.

The sections below describe the basic research and sample designs for the study, the research procedures used to implement the project, the methodology used for estimating caregivers, weighting specifics, and the response rate is included at the end of this section.

A. Research Design

The research design of this study is based on achieving several goals for NAC and AARP. One driving goal of the project is to estimate the number of caregivers in the U.S. population, as well as the number of caregiving households. For the first time, this number is to include individuals who are caregivers for children under the age of 18. Other aims include exploring caregiver characteristics, roles, and needs, as well as how these have changed since related surveys conducted in 1997 and 2004. New areas of exploration in this year's study are caregiver use of the internet for information, use of technology for the care recipient, and public policies that would help caregivers.

Because of the importance of achieving accurate trend data, the project design closely mirrored that developed for the 2004 Caregiving in the U.S. study.

B. Questionnaire Design

The questionnaire was drafted by Mathew Greenwald & Associates, drawing from the 2004 NAC/AARP study, Family Caregiving in the U.S. The questionnaire, shown in Appendix A, has two components. The first is a screener used to identify a caregiver in the household and to obtain selected demographic information from a randomly-selected respondent in all households contacted—regardless of the presence of caregiving in the household. These data are used to estimate the prevalence of caregiving. The second part of the questionnaire reflects the questions about caregiving administered to all caregivers.

The questionnaire was programmed into a computer aided telephone interviewing system and Greenwald & Associates fully briefed the interviewers on the purpose of the study and how to conduct the interview. Interviews were monitored periodically and interviewers were given refresher briefings.

The questionnaire was professionally translated into Spanish, building from the translation of the 2004 questionnaire.

C. Sample

The research design for the national study called for completing 1,000 interviews with a national random sample of caregivers. Random digit dial (RDD) sample, stratified by geography to generate a set of telephone numbers proportionate to the population, was used for those interviews. In addition, the design called for using oversamples to reach a total of 200 African American caregivers, 200 Hispanic caregivers, and 200 Asian caregivers.

To achieve these targets in the most cost-effective way, targeted samples were used. For African Americans, geographic density samples were used in which RDD samples are drawn from telephone exchanges with a concentration of at least 30% African Americans. For Hispanics, interviews came from a surname sample and a 40% or greater geographic density sample. For Asian Americans, the study relied primarily on an Asian surname sample, as well as a surname sample within a 10% or greater density area, and pre-screened Asian members of Knowledge Networks' RDD-recruited panel. All samples, except the Knowledge Networks Asian sample, came from Survey Sampling, Inc.

The various samples produced the following number of completed interviews and screened respondents:

Sample	Completed Interviews	Additional Screened Respondents
Random digit dial	1,000	3203
African American targeted	127	422
Asian targeted	136	844
Knowledge Networks (Asian)	54	412
Hispanic targeted	163	445
Total	1,480	5,326

From all of these interviews, we obtained interviews with 858 White, non-Hispanic caregivers, 200 African-American caregivers, 201 Hispanic caregivers, 200 Asian American caregivers, and 21 caregivers of another race.

In addition to the 1,480 caregiver interviews in the base study, an additional 288 interviews were conducted among caregivers of individuals age 50 or older, to bring the total among this caregiving subset to 1,397 caregivers, including 803 Whites, 206 African Americans, and 200 Hispanics, as well as 170 Asians and a small number of other minorities from the base study. The Whites and some of the minorities were reached through random digit dialing. The remaining minorities were reached through targeted samples like those described above.

D. Field Methodology

In order to get the most nationally representative sample of adults and households, a randomly selected respondent was selected to interview in each household. Specifically, when contact was established, the interviewer asked to speak with the person in the household aged 18 or older with the most recent birthday. This procedure was initiated in the 2004 study. In the case of the racial/ethnic over-samples, to be eligible, the householder had to be of the targeted race/ethnicity. The interviewer continued with the screener among all randomly-selected respondents, and proceeded to the substantive portion of the questionnaire if a caregiver was identified and agreed to participate.

Pertinent demographic data were collected on all of these initial, randomly-selected respondents (age, race, and gender). Furthermore, data on the household were gathered for the national study (family or non-family status of household members, age of householder, and race of householder).

The screening questions used to identify the presence of a caregiver in the household are as follows:

> *In the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.*
>
> *In the last 12 months, has anyone in your household given unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability? This could include care for ongoing medical conditions or serious short-term ones, emotional or behavioral problems, or developmental problems, including mental retardation.*

If the randomly-selected respondent reported no caregiver in the household, the interview ended after obtaining the demographic data for the individual and the household. If the randomly-selected respondent was a caregiver, interviewers proceeded to administer the full questionnaire. If the randomly-selected respondent was not a caregiver, but he/she identified someone in the household as a caregiver, the interviewer asked to speak with the caregiver after obtaining necessary demographic data from the randomly-selected respondent. Only one caregiver per household was interviewed.

For the oversample among caregivers of recipients ages 50 and older, only the first caregiving question above was asked, with the age of the recipient changed from 18 to 50. If the initial respondent reported that there was no caregiver present in the household, the interview was ended and no household screening data was collected.

In order to be validated as a caregiver and complete the full interview, all self-identified caregivers of an adult also had to report providing help with at least one activity of daily living or instrumental activity of daily living.

For the Knowledge Networks panel, the screener portion of the questionnaire was administered to all of the Asian households on their panel. If a caregiver in the household was identified, the name, phone number, and a convenient time to call were obtained. If more than one caregiver was identified, Knowledge Networks randomly selected one to participate in the telephone interview. Those data were then forwarded to the field service to complete the caregiver interviews by telephone. All caregiver interviews were conducted by telephone instead of online to eliminate the chance of error due to mode effects.

All interviewing was conducted by National Research. A five-call design was used for interviewing so that every number was dialed at least five times in an attempt to establish contact. Every soft refusal was followed by another attempt to convert the refusal into a completed interview.

Respondents were given the option of conducting the interview in Spanish or English, and 31% of Hispanic respondents chose to conduct part or all of the interview in Spanish.

Interviews from the main RDD national sample and the African American and Hispanic oversamples were conducted date through May 23, 2009. The Asian oversample continued through June 6, 2009 and the oversample of caregivers ages 50+ continued through June 17, 2009.

The completed interviews averaged 22.3 minutes in length.

See Appendix A for the full CATI-formatted questionnaire with all instructions.

E. Weighting

Data from all samples in the base study—except those used to reach the additional 288 caregivers of adults age 50 or older—were combined and weighted. The oversample interviews of caregivers of older recipients were also combined later for analyses specific to caregivers of recipients ages 50 or older, in a manner described below.

The household weight was used to weight the base study results in order to estimate the prevalence of caregiving household in the U.S. and to analyze the substantive results from the full interviews. Separately, a population weight was derived to estimate the prevalence of caregiving among the U.S. adult population.

Household Weights

Household weights involved a multi-stage weighting procedure. In the first stage, all base study data were weighted by householder race/ethnicity, and in the second stage, by householder age and household type (family or non-family). The weighting was based on all respondents who were fully screened in the base study, and who did not terminate during the screening process. The dataset included screened respondents who reported no caregivers in the household, caregivers who completed the interview, and respondents who reported the presence of caregivers who chose not to participate in the full interview or who only partially completed it. Weighting targets came from the Current Population Survey, 2008 Annual Social and Economic Supplement, conducted by the U.S. Census Bureau and released in January 2009.

The 288 oversample interviews among caregivers of recipients ages 50 or older were weighted to the weighted distribution of caregivers of 50+ recipients in the base sample by race/ethnicity, age of householder, and type of household (family or non-family).

Population Weights

Population weights were based on the subset of fully screened respondents in the base study who were the initial randomly selected individuals. They were weighted using a single-stage weighting procedure by age, sex, and race/ethnicity to the 2008 population estimates released by the Population Division of the U.S. Census Bureau on May 14, 2009.

F. Estimating Prevalence of Caregiving

Household Prevalence

There were 6,806 total screened households. Using household weighted figures, 1,711 of these households had caregivers, as validated through a complete survey (n=1,618) or through a partial survey (n=93). In addition, there were 446 households who reported presence of a caregiver, but who did not continue the interview through to validate the caregiver.

However, among the respondents who initially reported a caregiver in the household and continued far enough in the survey to validate their presence, a very large proportion (92.8%) were ultimately validated. Accordingly, we also count as caregivers 92.8% of the 446 households (resulting n=414) who reported a caregiver but did not continue with the full survey. Thus 1,711 validated caregivers plus an estimated 414 additional caregivers, on a base of 6,806 total screened caregivers, leads to a household prevalence rate of 31.2%.

	Prevalence	Number of Households in the U.S.	Estimated Number of Caregiving Households
Overall	31.2%	116,783,000	36.5 million
White (Non-Hispanic)	30.5%	82,765,000	25.2 million
Black	33.6%	14,111,000	4.7 million
Asian	20.0%	4,409,000	0.9 million
Hispanic	36.1%	13,339,000	4.8 million

The study also examined prevalence of households in which the caregiver's principal recipient is a person who is at least 50 years of age. This prevalence was found to be 21.1% based on the following figures. Of the 6,806 screened households, there were 1,204 interviews among validated caregivers of recipients age 50+. An additional 57 were among non-validated caregivers of 50+ recipients; these were multiplied by 92.8%—the proportion of the *households* with reported caregivers who went far enough in the survey to verify their status and who were validated—resulting in 53 additional caregivers. There were 246 non-validated caregivers whose recipient age was unknown; they were multiplied by 92.8% and then by 71.8%, the proportion of caregivers who care for someone age 50 or older (resulting in n=171 additional caregivers). Finally, there were 10 validated caregivers whose recipient age was unknown, and they were multiplied by 71.8% (resulting in n=7 additional caregivers). A total of 1,435 caregivers divided by 6,806 screened caregivers leads to the 21.1% prevalence estimate.

	Prevalence	Number of Households in the U.S.	Estimated Number of Caregiving Households
Caregivers of Recipients Age 50+	21.1%	116,783,000	24.6 million

Population Prevalence

Using the 6,806 randomly selected initial respondents weighted with population weights, we find that 1,633 are caregivers, as validated through a complete or partial survey. In addition, 350 reported they were caregivers but did not continue the interview to validate that. However, among the *initial* respondents who initially reported being a caregiver and continued far enough in the survey to validate their status, 88.5% were ultimately validated. Applying this percentage to the 350 non-validated caregivers results in n=310 additional caregivers. The 1,633 plus 310 caregivers, on a base of 6,806 total screened caregivers, leads to a population prevalence rate of 28.5% and an estimate of 65.7 million individual caregivers in the U.S. The prevalence for each race/ethnicity is shown in the following table.

	Prevalence	Number of Adults Age 18+ in the U.S.	Estimated Number of Adult Caregivers in the U.S.
Overall	28.5%	230,087,100	65.7 million
White (Non-Hispanic)	27.6%	157,927,600	43.6 million
Black	32.4%	26,377,500	8.5 million
Asian	17.6%	10,287,000	1.8 million
Hispanic	32.3%	30,851,100	10.0 million

The population prevalence of caregivers whose principal recipient is at least 50 years of age is 18.9%, based on a total of 1,286 caregivers out of 6,806 screened individuals. The 1,286 caregivers were identified as follows. First, 1,133 of the initial respondents were validated caregivers of an older recipient. An additional 58 were non-validated caregivers of age 50+ recipients; these were multiplied by 88.5%—the proportion of initially-reported caregivers who were asked validating questions and ultimately were confirmed to be caregivers. This results in 51 additional caregivers. There were 152 non-validated caregivers whose recipient age was unknown; they were multiplied by 88.5% and then by 71.4%, the proportion of initial caregivers who care for someone age 50 or older (resulting in n=96 additional caregivers). Finally, there were 8 validated caregivers whose recipient age was unknown, and they were multiplied by 71.4% (resulting in n=6 additional caregivers).

	Prevalence	Number of Adults Age 18+ in the U.S.	Estimated Number of Adult Caregivers in the U.S.
Caregivers of Recipients Age 50+	18.9%	230,087,100	43.5 million

G. Weighting Substantive Results

As described above, a population weight and a household weight were created to estimate the incidence of caregiving among the population and in households in the U.S. For reporting the results of the national survey in this report among the 1,480 caregivers interviewed, the data weighted by households was used, as it was in 2004. The main reason is that the final caregiver sample was derived from identifying caregivers in the household even if they were not the initial, randomly-selected respondent. Hence, the sample is representative of caregivers in U.S. households. In addition, it gave the most valid comparisons to the 1997 NAC/AARP caregiving study which reported household-level data.

H. Calculation of the Level of Care Index

The calculation of the level of burden index begins by assigning points for the number of hours of care, as follows:

Hours of Care	
0 to 8 hours	1 point
9 to 20 hours	2 points
21 to 40 hours	3 points
41 or more hours	4 points

In addition, points are assigned for the number of ADLs and IADLs performed, as follows. Note that for caregivers of children, "Caregiving Support Activities" (CSAs) are substituted for IADLs in the calculations.

Types of Care Provided	
0 ADLs, 1 IADL/CSAs	1 point
0 ADLs, 2+ IADLS/CSAs	2 points
1 ADL, any number of IADLs/CSAs	3 points
2+ ADLs, any number of IADLs/CSAs	4 points

Then, the total number of points is consolidated into five levels of care. In this report, analysis often further collapses the five levels into three categories of burden, with “high burden” equating to Levels 4 to 5, “medium burden” corresponding to Level 3, and “low burden” equating to Levels 1 and 2.

Consolidating Points into Five Levels of Care and Three Burden Categories		
2 to 3 points	Level 1	Low burden
4 points	Level 2	
5 points	Level 3	Medium burden
6 to 7 points	Level 4	High burden
8 points	Level 5	

I. Margin of Error and Response Rate

The margin of sampling error, at the 95% confidence level, for the overall sample and for the three age-specific subsets, which are the focus of separate companion reports, are shown in the following table. The margin of error will be larger for subgroups within each sample.

Sample (with unweighted n's)	Margin or error
Overall prevalence estimates Based on 6,806 screened interviews	1.5 percentage points
Results of entire substantive base study Based on 1,480 completed interviews	3.1 percentage points
Results for caregivers of children ages 0 to 17 Based on 173 completed interviews	8.5 percentage points
Results for caregivers of 18- to 49-year olds Based on 187 completed interviews	8.9 percentage points
Results for caregivers of recipients ages 50 or older Based on 1,397 completed interviews	3.2 percentage points

The response rate of each sample is shown in the following table. The response rates are based upon a standard method provided by the American Association for Public Opinion Research (AAPOR).[1]

Sample	Response Rate
Random digit dial	9.9%
African American targeted	9.3%
Asian targeted	3.5%
Hispanic targeted	4.6%

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[1] The American Association for Public Opinion Research. 2000. *Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys*. Ann Arbor, Michigan: AAPOR. Response rate formula #2. Knowledge Networks' pre-screening interviews are not included in the response rate calculation because dispositions from online screening are not comparable.

J. Banner Definitions

The banners used in the analysis of the main report are defined as follows:

	BANNER #1		
1	2009 Total	2009 Total	Year=2009 and status=1 and smpl le 4
2	TREND CR 18+	2004	Year=2004, status=1, and selc1=1 (after Q5 and Q6)
3		2009	Year=2009, status=1, and selc1=1
4	Care recipient age	0-17	Selc1=1
5		18-49	Agecr 18-49
6		50+	CG50=1 (Includes base sample and oversample)
7	Caregiver race/ethnicity	White	Racecg=1
8		Black	Racecg=2
9		Hispanic	Racecg=5
10		Asian	Racecg=3
11	Primary Caregiver Status	Primary	Q28=2 or Q29=1
12		Not	Q28=1 and Q29=2-3
13	Did caregiver have choice	Choice	Q39=1
14		No Choice	Q39=2
15	Burden of care	Low	Burden=1-2
16		Medium	Burden=3
17		High	Burden=4-5
18	Hours Spent Caregiving	0-8	Q25=0-8, 169
19		9-20	Q25=9-20
20		21+	Q25=21-168, 170
21	Hours Spent Caregiving	0-20	Q25=0-20, 169
22		21+	Q25=21-168, 170
23	Where recipient lives	In caregiver's household	Q11=1
24		Not in household	Q11=2-7
25	Distance from recipient	< 1 hr, but not in household	Q11=2-3
26		1 hr+	Q11=4-5
27	Where recipient lives by hours of care provided	In household, 0-20 hours	Q11=1, Q25=0-20, 169
28		In household, 21+ hours	Q11=1, Q25=21-168, 170
29		Not in household, 0-20 hours	Q11=2-5, Q25=0-20, 169
30		Not in Household, 21+ hours	Q11=2-5, Q25=21-168, 170

Notes: Columns 3, 4, 5, and 7 thru 30 are all subsets of Column 1. That is, they are based on year=2009, status=1 (completed questionnaires only), and smpl le 4 (base study, no oversample for recipients 50+). Column 6 also includes smpl ge 5 (oversample of recipients ages 50+).

	BANNER #2		
1	2009 Total		Year=2009 and status=1 and smpl le 4
2	Caregiver Gender	Male	Sexcg=1
3		Female	Sexcg=2
4	Caregiver age	18-49	Agecg=18-49
5		50-64	Agecg=50-64
6		65+	Agecg=65-100
7	Education	<=HS	Educ (D7)=1-2
8		Some College or technical school	Educ=3-4
9		College grad or higher	Educ=5-6
10	Household income	<$50K	Income (D8)= 1-3, 9, 11
11		$50K+	Income=4 -6, 10
12	Household income	<$30K	Income=1,2,11
13		$30-$49K	Income=3
14		$50-$99K	Income=4-5
15		$100K+	Income=6
16	Employed while caregiving	Empl	(Q1=1 and (Q32=1-2 or q33=1)) or (Q1>= 2 and Q33=1)
17		Not empl	(Q1=1 and Q32 ge 3 and Q33=2) or (Q1>= 2 and Q33=2)
18	Is caregiver a parent caring for his/her own child	Yes	Q7=5 or 19
19		No	Q7 not = 5 or 19
20	Presence of Physical Conditions	Any long term physical condition	Q17b=1
21		Short-term physical condition but no long-term condition	Q17b=2 and Q17a=1
22		No physical condition	Q17a=2 and Q17b=2
23	Presence of a mental/emotional condition	Mental/emotional condition	Q17c=1
24		No mental/emotional cond.	Q17c=2
26	Duration of caregiving	<1 year	Q21x=95-96
26		1 to 4 years	Q21x=1-4
27		5+ years	Q21x=5-93
28	Presence of Alzheimer's or dementia	Yes	Alzdem=1
29		No	Alzdem=2

Notes: Columns 2 thru 29 are all subsets of Column 1. That is, all columns are for year=2009, status=1 (completed questionnaires only), and smpl le 4 (base study, no oversample for recipients 50+).

The banners used in the analysis of caregivers of recipients age 50 or older are defined as follows:

RECIPIENT 50+ BANNER #1			
1	1997	1997 50+	Year=1997 and status=1 and CR50=1
2	2004	2004 50+	Year=2004 and status=1 and CR50=1
3	2009	2009 50+	Year=2009 and status=1 and CR50=1
4	Caregiver race/ethnicity	White	Racecg=1
5		Black	Racecg=2
6		Hispanic	Racecg=5
7		Asian	Racecg=3
8	Primary Caregiver Status	Primary	Q28=2 or Q29=1
9		Not	Q28=1 and Q29=2-3
10	Did caregiver have choice	Choice	Q39=1
11		No Choice	Q39=2
12	Burden of care	Level 1	Burden=1
13		Level 2	Burden=2
14		Level 3	Burden=3
15		Level 4	Burden=4
16		Level 5	Burden=5
17	Hours Spent Caregiving	0-8	Q25=0-8, 169
18		9-20	Q25=9-20
19		21+	Q25=21-168, 170
20	Hours Spent Caregiving	0-20	Q25=0-20, 169
21		21+	Q25=21-168, 170
22	Where recipient lives	In caregiver's household	Q11=1
23		Not in household	Q11=2-7
24	Distance from recipient	< 1 hr, but not in household	Q11=2-3
25		1 hr+	Q11=4-5
26	Where recipient lives by hours of care provided	In household, 0-20 hours	Q11=1, Q25=0-20, 169
27		In household, 21+ hours	Q11=1, Q25=21-168, 170
28		Not in household, 0-20 hours	Q11=2-5, Q25=0-20, 169
29		Not in Household, 21+ hours	Q11=2-5, Q25=21-168, 170

Notes: Columns 4 through 29 are all subsets of Column 3. That is, they are based on year=2009, status=1 (completed questionnaires only), and CG50 (recipient age 50 or older, including base sample and oversample).

RECIPIENT 50+ BANNER #2			
1	2009 Total		Year=2009 and status=1 and CR50=1
2	Caregiver Gender	Male	Sexcg=1
3		Female	Sexcg=2
4	Caregiver age	18-49	Agecg=18-49
5		50-64	Agecg=50-64
6		65+	Agecg=65-100
7	Education	<=HS	Educ (D7)=1-2
8		Some College or technical school	Educ=3-4
9		College grad or higher	Educ=5-6
10	Household income	<$50K	Income (D8)= 1-3, 9, 11
11		$50K+	Income=4 -6, 10
12	Household income	<$30K	Income=1,2,11
13		$30-$49K	Income=3
14		$50-$99K	Income=4-5
15		$100K+	Income=6
16	Employed while caregiving	Empl	(Q1=1 and (Q32=1-2 or q33=1)) or (Q1>= 2 and Q33=1)
17		Not empl	(Q1=1 and Q32 ge 3 and Q33=2) or (Q1>= 2 and Q33=2)
18	Is caregiver a parent caring for his/her own child	Yes	Q7=5 or 19
19		No	Q7 not = 5 or 19
20	Caregiver Health	Excellent	D1=5
21		Very good or good	D1=3 or 4
22		Fair/poor	D1=1 or 2
23	Use of technology	Used technology	Q44ct >=1
24		Did not use technology	Q44ct=0
26	Duration of caregiving	<1 year	Q21x=95-96
26		1 to 4 years	Q21x=1-4
27		5+ years	Q21x=5-93
28	Presence of Alzheimer's or dementia	Yes	Alzdem=1
29		No	Alzdem=2

Notes: All columns are for year=2009, status=1 (completed questionnaires only) and CG50 (recipient age 50 or older, including base sample and oversample)