ACL OMB No. 0985-00xx
Exp. Date. xx/xx/xx

Appendix H

NFCSP Caregiver Participant Group Survey: 6-month follow-up

National Family Caregiver Support Program (NFCSP) Evaluation
Six-Month Participant Follow-up Survey

[CAREGIVER]. My name is {INTERVIEWER'S NAME} and I am calling on behalf of the U.S. Department of Health and Human Services' Administration for Community Living. We are conducting a survey to find out how we can help meet the needs of caregivers being served by {PROVIDER NAME/AGENCY NAME}. We show you have received caregiver support services from {PROVIDER NAME/AGENCY NAME} to help you take care of {CARE RECIPIENT}. We would like to know if these caregiver support services have been helpful.

This survey will take about 40 minutes to complete. Your participation is voluntary and very important to the success of this study. Responses to this data collection will be used only for purposes of this research. The reports prepared for this study will summarize findings across the sample and will not associate responses with a specific individual. We will not provide information that identifies individuals to anyone outside the study team, except as required by law. Your and {CARE RECIPIENT}'s eligibility for services will not be affected by your decision to participate or by any answers you give.

[INTERPRETER]. My name is {INTERVIEWER'S NAME} and I am calling on behalf of the U.S. Department of Health and Human Services' Administration for Community Living, We are conducting a survey to find out how we can help meet the needs of caregivers being served by {PROVIDER NAME/AGENCY NAME}. We show {NAME OF CAREGIVER} has received caregiver support services from {PROVIDER NAME/AGENCY NAME} to help {him/her} take care of {CARE RECIPIENT}. We would like to know if these caregiver support services have been helpful.

We would like {NAME OF CAREGIVER} to answer the questions as independently as possible. We want to be sure that, wherever possible, we are getting {NAME OF CAREGIVER}'s actual opinions and responses.

This survey will take about 40 minutes to complete. {NAME OF CAREGIVER's} participation is voluntary and very important to the success of this study. Responses to this data collection will be used only for purposes of this research. The reports prepared for this study will summarize findings across the sample and will not associate responses with a specific individual. We will not provide information that identifies individuals to anyone outside the study team, except as required by law. {His/Her} and {CARE RECIPIENT}'s eligibility for services will not be affected by {NAME OF CAREGIVER's} decision to participate or by any answers {s/he} gives

IF NEEDED: We were given your name as the interpreter for {NAME OF CAREGIVER}.

[PROXY]. My name is {INTERVIEWER'S NAME} and I am calling on behalf of the U.S. Department of Health and Human Services' Administration for Community Living, We are conducting a survey to find out how we can help meet the needs of caregivers being served by {PROVIDER NAME/AGENCY NAME}. We got {NAME OF CAREGIVER} information from {PROVIDER NAME/AGENCY NAME}.

We want to be sure that, wherever possible, we are getting {NAME OF CAREGIVER}'s actual opinions and responses. For the remainder of the survey, I would like you to answer as though you were {NAME OF CAREGIVER}. All of the following questions pertain to {him/her} Please provide your best estimate as to {his/her} own response or opinion.

This survey will take about 40 minutes to complete. {His/Her} participation is voluntary and very important to the success of this study. Responses to this data collection will be used only for purposes of this research. The reports prepared for this study will summarize findings across the sample and will not associate responses with a specific individual. We will not provide information that identifies individuals to anyone outside the study team, except as required by law. {His/Her} and {CARE RECIPIENT}'s eligibility for services will not be affected by {NAME OF CAREGIVER}'s decision to participate or by any answers {s/he} gives.

Introduction

Now, let's begin the caregiver survey. {Your/NAME OF CAREGIVER's} participation is voluntary and very important to the success of this study.

A1 {You are/NAME OF CAREGIVER is} listed as someone who currently provides care for {CARE RECIPIENT}. {Are you/Is s/he} still the caregiver for {CARE RECIPIENT}?

YES..... 1
NO..... 2
REFUSED..... -7
DON'T KNOW..... -8

A2 if no, record any comments respondent made about former care recipient (e.g., respondent in nursing home, deceased, etc):

_____

BOX 1

THROUGHOUT THE SURVEY,
CATI WILL REPLACE "CR" WITH THE CR'S NAME.

A3. What is your relationship to {CR} (guided answer: spouse, mother, father, uncle, etc.)

HUSBAND,..... 1
WIFE,..... 2
SON,..... 3
SON-IN-LAW,..... 4
DAUGHTER,..... 5
DAUGHTER-IN-LAW,..... 6
FATHER,..... 7
MOTHER,..... 8
BROTHER,..... 9
SISTER,..... 10
GRANDDAUGHTER,..... 11
GRANDSON, ... 12
NIECE,..... 13
NEPHEW, ... 14
A FRIEND OR NEIGHBOR OR ANOTHER PERSON, OR 15
OTHER RELATIVE..... 91
(SPECIFY: _____)
REFUSED..... -7
DON'T KNOW..... -8

A4. What is {CR's} gender:

MALE..... 1
FEMALE..... 2

A5. What is {CR's} age:

|__|__|__|
AGE

A6. How long have you been the caregiver for {CR}?

|__|__|__|

DAYS..... 1
MONTHS..... 2
YEARS..... 3

BOX 2

ITEMS A7 – A9 ARE FOR NFCSP PARTICIPANTS ONLY.

READ: I'd like to ask {you/NAME OF CAREGIVER} some questions about the Family Caregiver services that are provided by {PROVIDER/AGENCY}.

A7. For how long have you been receiving caregiver support services from {PROVIDER/AGENCY}?

|__|__|__|

DAYS..... 1
MONTHS..... 2
YEARS..... 3

READ: We would like to ask you questions about any respite care that you have received from {PROVIDER/AGENCY}. Respite care allows you a brief period of rest or relief while temporary care is provided to {CR} either in your home or someplace else.

A8. In the past 6 months, have you received respite care from {PROVIDER/AGENCY}?

YES..... 1
NO..... 2 GO TO A10
REFUSED..... 7 GO TO A10
DON'T KNOW..... 8

A9. Have you received the following types of respite care?

	YES	NO	REF	DON'T KNOW
a. In-home respite, where someone comes into {your/his/her} home to care for recipient and you feel comfortable enough that you could take a nap or leave the home while that person is there?	1			
	2		7	
			8	
b. Adult daycare, where {CR} goes to a facility for care during the day?	1			
	2		7	
			8	
c. Overnight respite care in a facility?	1			
	2		7	
			8	
d. Overnight respite in the home?	1			
	2		7	
			8	
d. Some other kind?	1			
	2		7	
			8	

(SPECIFY:_____
___)

A9a. How many hours per week of respite care do you usually receive from {PROVIDER/AGENCY}?

|__|__|
HOURS PER WEEK

A10. Other than the respite services you receive from {PROVIDER/AGENCY}…

	YES	NO	REF	DON'T KNOW
a. Do you receive respite from another agency where the services are from a paid source, meaning not from a volunteer?	1			
	2		7	
			8	
b. Do you receive respite from a family member, friend, neighbor, or another volunteer?	1			
	2		7	
			8	
c. Some other kind of respite?	1			
	2		7	
			8	

(SPECIFY)_____

A10a. How many hours per week of respite care do you usually receive - NOT including respite from {PROVIDER/AGENCY}?

|__|__|
HOURS PER WEEK

BOX 3

CATI PROGRAMMING WILL DISPLAY ITEMS A11 – A13 FOR NFCSP PARTICIPANTS ONLY.

READ: "Next I am going to ask you questions about services related to **caregiver education, training, counseling, and support groups.** These services are **intended** to **strengthen your ability and skill at** making decisions and solving problems in your role as a caregiver."

A11. Have you received caregiver education, training, counseling, or support group services from {PROVIDER/AGENCY}?

YES	1	
NO	2	GO TO A13
REFUSED	7	GO TO A13
DON'T KNOW	8	

A12. What type of caregiver education, training, counseling, or support group services have you received from {PROVIDER/AGENCY}?

A12a. Caregiver education or training, such as classroom or on-line courses?

YES	1	
NO	2	GO TO A12b
REFUSED	7	GO TO A12b
DON'T KNOW	8	GO TO A12b

If yes, how often?

One time only	1
Once every 3 months	2
Once a month	3
2-3 times a month	4
Once a week	5
More than once a week	6
REFUSED	7
DON'T KNOW	8

A12b. Counseling to assist with your specific caregiving situation?

YES	1	
NO	2	GO TO A12c
REFUSED	7	GO TO A12c
DON'T KNOW	8	GO TO A12c

If yes, how often?

One time only	1
Once every 3 months	2
Once a month	3
2-3 times a month	4
Once a week	5
More than once a week	6
REFUSED	7
DON'T KNOW	8

A12c. Caregiver support groups?

YES	1	
NO	2	GO TO A12d
REFUSED	7	GO TO A12d
DON'T KNOW	8	GO TO A12d

If yes, how often?

One time only	1
Once every 3 months	2
Once a month	3
2-3 times a month	4
Once a week	5
More than once a week	6
REFUSED	7
DON'T KNOW	8

A12d. Something else that is like counseling?

YES	1	
NO	2	GO TO A13
REFUSED	7	GO TO A13
DON'T KNOW	8	GO TO A13

If yes, how often?

One time only	1
Once every 3 months	2
Once a month	3
2-3 times a month	4
Once a week	5
More than once a week	6
REFUSED	7
DON'T KNOW	8

A13. Haved you received any caregiver education, training, counseling, or support group services, other than those provided by {PROVIDER/AGENCY}…?

YES	1	
NO	2	GO TO A14
REFUSED	7	GO TO A14
DON'T KNOW	8	GO TO A14

A13a. Do you receive caregiver education, training, counseling, or support group services from **another** PAID agency, healthcare provider, organization, or social worker other than those provided by {PROVIDER/AGENCY})?

YES	1	
NO	2	GO TO A13b
REFUSED	7	GO TO A13b
DON'T KNOW	8	GO TO A13b

If yes, how often?

One time only	1
Once every 3 months	2
Once a month	3
2-3 times a month	4
Once a week	5
More than once a week	6
REFUSED	7
DON'T KNOW	8

A13b. Do you receive free caregiver education, support groups, or training informally from a church or community organization?

YES	1	
NO	2	GO TO A14
REFUSED	7	GO TO A14
DON'T KNOW	8	GO TO A14

If yes, how often?

One time only	1
Once every 3 months	2
Once a month	3
2-3 times a month	4
Once a week	5
More than once a week	6
REFUSED	7
DON'T KNOW	8

BOX 4

CATI PROGRAMMING WILL DISPLAY ITEMS A14 –

A16 FOR NFCSP PARTICIPANTS ONLY.

A14. What other caregiver support services do you receive from {PROVIDER/AGENCY}?

_____

_____

_____

A15. Overall, how would you rate the group of services that you receive from {PROVIDER/AGENCY}?

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
REFUSED	7
DON'T KNOW	8

A16. Which of the services from {PROVIDER/AGENCY} is most helpful for you?

_____

_____

_____

SECTION B. CAREGIVING TASKS, FREQUENCY AND INTENSITY

B1. I'm going to read several activities that some people need help with. Your response options are: I do not provide this help, I provide this help: daily, several times a week, once a week, several times a month, once a month. How often {Do you/Does NAME OF CAREGIVER} help {CARE RECIPIENT} with ….

Activities	o not provide this help	aily	everal times a week	nce a week	everal times a month	nce a month	EF	ON'T KNOW
a. Activities like dressing, eating, bathing, or going to the bathroom?.....	0	1	2	3	4	5	7	8
b. Medical needs, such as taking medicine, giving shots, or changing bandages?.....	0	1	2	3	4	5	7	8
c. Mobility, such as walking, getting out of bed, or standing up from a sitting position?.....	0	1	2	3	4	5	7	8
d. Keeping track of bills, insurance issues, or other financial matters?.....	0	1	2	3	4	5	7	8
e. Setting up health-care appointments and speaking with doctors or other providers?.....	0	1	2	3	4	5	7	8
f. Preparing meals, doing laundry, or cleaning the house?.....	0	1	2	3	4	5	7	8
g. Local trips, such as going shopping or to the doctor's office?.....	0	1	2	3	4	5	7	8
h. Arranging for care or services provided by others?.....	0	1	2	3	4	5	7	8

B2. Which ONE activity do you consider to be the most difficult for you to perform?

a. Activities like dressing, eating, bathing, or going to the bathroom?..... 01
b. Medical needs, such as taking medicine, giving shots, or changing bandages?..... 02
c. Mobility, such as walking, getting out of bed, or standing up from a sitting position?..... 03
d. Keeping track of bills, insurance issues, or other financial matters?..... 04
e. Setting up health-care appointments and speaking with doctors or other providers?..... 05
f. Preparing meals, doing laundry, or cleaning the house?..... 06
g. Local trips, such as going shopping or to the doctor's office?..... 07
h. Arranging for care or services provided by others?..... 08
i. REFUSED..... 97
j. DON'T KNOW..... 98

B3. Are there any other activities that you consider among the most difficult to perform?

YES (SPECIFY)_____ 1
NO..... 2
REFUSED..... 7

DON'T KNOW..... 8

B4. On a **typical weekday**, when you care for {CR}, about how many hours do you spend helping?

|__|__| (range 1-24)
HOURS

B5. On a typical **day on the weekend**, when you care for {CR}, about how many hours do you spend helping?

|__|__| (range 1-24)
HOURS

SECTION C. KNOWLEDGE AND USE OF FORMAL SERVICES AVAILABLE

READ: The next set of questions are about other services that you, the caregiver, or your care recipient are receiving.

C1. In the last 6 months, is there help that you needed with applying for and receiving caregiver services from {PROVIDER/AGENCY} that you are not receiving?

YES..... 1
NO..... 2
REFUSED..... 7 } GO TO C2
DON'T KNOW..... 8

C1a. If yes, what help do you need with applying for and receiving caregiver services?

_____

_____

C2. In the last 6 months, has {CR} received any of the following services offered by **any paid agency or organization?**

		YES	NO	REF	DK
a.	Case management (i.e.,coordination & care management).....	1	2	7	8
b.	Counseling (meeting with therapist, social worker or mental health professional).....	1	2	7	8
c.	Adult daycare.....	1	2	7	8
d.	Incontinence supplies.....	1	2	7	8
e.	Legal assistance.....	1	2	7	8
f.	Home modification (i.e., grab bars, ramps)	1	2	7	8
g.	Nutritional supplements (such as Ensure, Boost, etc.).....	1	2	7	8
h.	Transportation.....	1	2	7	8
i.	Home-delivered meals.....	1	2	7	8
j.	Congregate meals (e.g., meals at a center).....	1	2	7	8
k.	Homemaker services.....	1	2	7	8

l.	Home health aide.....	1	2
	7	8	
m.	Other (SPECIFY) _____	1	2
	_____7	8	

C3. Overall, how would you rate this group of services that {CR} has received?

Excellent.....	1
Very good.....	2
Good.....	3
Fair.....	4
Poor.....	5

C4. In the last 6 months, have **you as the caregiver** received any of the following services offered by **any paid agency or organization**.

		YES	NO	REF	DK
a.	Assistance that connects you to resources and services for caregivers (i.e., help applying for and receiving caregiver services).....	1	2		
	7	8			
b.	Training on attending to recipient's medical needs such as wound care, injections, and medications.....	1	2		
	7	8			
c.	Caregiver education or support group.....	1	2		
	7	8			
d.	Counseling (meeting with therapist, social worker or mental health professional).....	1	2		
	7	8			
e.	Legal assistance.....	1	2		
	7	8			
f.	Respite care: Homemaker services.....	1	2		
	7	8			
g.	Respite care: Home health aide.....	1	2		
	7	8			
h.	Respite care: Adult daycare.....	1	2		
	7	8			
i.	Other (SPECIFY) _____	1	2		
	_____7	8			

C5. Overall, how would you rate this group of services that you received?

Excellent.....	1
Very good.....	2
Good.....	3
Fair.....	4
Poor.....	5

C6. Have you tried to obtain any caregiving support services from an organization but were not able to receive them?

YES	1	GO TO C6a
NO	2	GO TO C7
REFUSED	7	GO TO C7
DON'T KNOW	8	GO TO C7

C6a. If YES, what were the reasons?

a.	You are on a waiting list	1
b.	Services cost too much	2
c.	Your local agency doesn't have the service you need.	3
d.	Other (SPECIFY)_____	4

C7. As {CR's} caregiver, are you receiving all the help that you need?

Yes, definitely	1
Yes, probably	2
Not sure	3
No, probably not	4
No, definitely not	5
REFUSED	7
DON'T KNOW	8

SECTION D. CAREGIVING SATISFACTION AND OTHER ASPECTS

READ: Thank you so much for your help thus far. Next, I would like to ask you about different aspects of caregiving and your experiences as a caregiver.

READ: For this first question, please tell me whether you strongly agree, agree, are not sure, disagree, or strongly disagree with the following statement.

D1. I get a great deal of satisfaction from being a caregiver.

Strongly agree	1
Agree	2
Not sure	3
Disagree	4
Strongly disagree	5

D2. Overall, how would you rate your confidence as a caregiver? Would you say…

Very confident	1
Somewhat confident	2
A little confident	3
Not very confident	4
Not at all confident	5

REFUSED..... 7
DON'T KNOW..... 8

		A lot	Some	A little	Not at all	DK	EF
D3.	How much do you enjoy being with {CR}?….	1	2	3	4	7	
D4.	How much does {CR} argue with you?.....	1	2	3	4	7	
D5.	How much does {CR} appreciate what you do for {him/her}?.....	1	2	3	4	7	

D6. Does helping {CR} gives you satisfaction that {he/she} is well cared for? Would you say…

Very much..... 1
Somewhat..... 2
Not so much..... 3
REFUSED..... 7
DON'T KNOW..... 8

D7. Please think about yourself, and after each statement, tell me whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree?

	trongly agree	omewhat agree	omewhat disagree	trongly disagree	EF	K
a. My life has meaning and purpose.....	1	2	3	4	7	
b. I have an easy time adjusting to changes..…	1	2	3	4	7	
c. I get over (recover from) illness and hardship quickly.....	1	2	3	4	7	

D8. In general, how much has your family disagreed about the details of {CR's} care? Would you say…

Very much, ... 1
Somewhat, or 2
Not so much?..... 3
REFUSED..... 7
DON'T KNOW..... 8

D9. Do you have friends or family whom you talk to about important things in your life?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

D10. Do you have friends or family who help you with your own daily activities, such as running errands or helping you with things around the house?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

D11. Do you have anyone who helps you with your caregiving activities for {CR}? This help could be paid assistance or help from a family member or friend.

YES	1	
NO	2	GO TO D12
REFUSED	7	
DON'T KNOW	8	

D11a. If yes, who provides the assistance? Is it …

Family members, friends, or neighbors	1
Agency, private provider, or housekeeper	2
Volunteers from place of worship	3
Other (SPECIFY)_____	4
REFUSED	7
DON'T KNOW	8

\

BOX 5

ONLY ASK QUESTION D12 IF THE CAREGIVER IS **RELATED TO** CR.

OTHERWISE, SKIP TO D13 ON THE NEXT PAGE.

D12. Please let me know how well each item fits with your belief about your caregiving situation with CR, on a scale from 1-4, with 1 being "definitely false"; 2=somewhat false; 3= somewhat true; 4= "definitely true."

	Definitely false	omewhat	omewhat	Definitely true	REF	DK

		false		true		
a.	I was chosen by my family as a child to provide care for all my family members.....	1		4	7	8
b.	All my choices about life revolve around my responsibilities to provide care.....	1		4	7	8
c.	My family expected me to provide care for them.....	1		4	7	8
d.	I honestly never thought about doing anything else with my life other than working and providing care for others in my family.....	1		4	7	8

D13. Next, I would like to ask {you/NAME OF CAREGIVER} about different aspects of caregiving. Please answer each question as Never, Rarely, Some-times, Quite frequently, or Nearly always.

	Never	Rarely	Some-times	Quite frequently	Nearly always	REF	DK
a. Do you feel that, because of the time you spend with {CR}, you don't have enough time for yourself?.....	0	1	2	3	4	7	8
b. Do you feel stressed between caring for {CR} and trying to meet other responsibilities (work/family)?.....	0	1	2	3	4	7	8
c. Do you feel angry when you are around {CR}?.....	0	1	2	3	4	7	8
d. Do you feel that {CR} currently affects your relationship with family members or friends in a negative way?.....	0	1	2	3	4	7	8
e. Do you feel strained when you are around {CR}?.....	0	1	2	3	4	7	8
f. Do you feel that your health has suffered because of your involvement with {CR}?.....	0	1	2	3	4	7	8
g. Do you feel that you don't have as much privacy as you would like because of {CR}?.....	0	1	2	3	4	7	8
h. Do you feel that your social life has suffered because you are caring for {CR}?.....	0	1	2	3	4	7	8
i. Do you feel that you have lost control of your life since your {CR's} illness?.....	0	1	2	3	4	7	8
j. Do you feel uncertain about what to do about {CR}?.....	0	1	2	3	4	7	8
k. Do you feel you should be doing more for {CR}?.....	0	1	2	3	4	7	8
l. Do you feel you could do a better job in caring for {CR}?.....	0	1	2	3	4	7	8

SECTION E. CAREGIVER AND HOUSEHOLD DEMOGRAPHICS

READ: Now I will ask you a few general questions about yourself. As I said earlier, your responses will be treated as confidential.

E1. NOTE TO INTERVIEWER: ONLY ASK IF NOT OBVIOUS.

What is your gender?

MALE	1
FEMALE	2

E2. What is your marital status?

MARRIED	1	
WIDOWED	2	
DIVORCED	3	
SEPARATED	4	
UNMARRIED PARTNER/CIVIL UNION	5	
NEVER MARRIED	6	
REFUSED	7	
DON'T KNOW	8	

E3. Do you live with {CR}?

YES	1	GO TO E4
NO	2	
REFUSED	7	GO TO E4
DON'T KNOW	8	GO TO E4

E3a. If no, how long does it usually take you to get to {CR}?

_____

MINUTES	1
HOURS	2

E4. Are you taking care of any children under the age of 18?

YES	1	
NO	2	GO TO E5
REFUSED	7	GO TO E5
DON'T KNOW	8	GO TO E5

E4a. If yes, how many?

_____
CHILDREN

E5. How old are you?

|__|__|__|
AGE

E6. Are you of Hispanic or Latino origin?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

READ: I am going to read a list of five race categories.

E7. Please **choose one or more** races that you consider yourself to be:

White	1
Black or African-American	2
Asian	3
American Indian or Alaskan Native	4
Native Hawaiian or other Pacific Islander	5
Other (SPECIFY)_____	6
REFUSED	7
DON'T KNOW	8

E8. What is your highest level of schooling?

Some high school	1
High school diploma or GED	2
Post high school other than college	3
Some college or two-year degree	4
Four-year college degree	5
More than four-year college degree	6
REFUSED	7
DON'T KNOW	8

E9. Not counting you, how many other people live where you live?

NOTE: This means people who usually stay there. Please **DO** include people who are away, such as students, people on vacation or traveling for business, or people who are in the hospital for a brief stay. Do **not include** people in institutions, in the military, or people who are temporary visitors.

|__|__|
LIVE WITH YOU

E10. I am going to read you a list of categories. We assure you that your response will remain confidential.

a. Please stop me when I reach your **total household income** before taxes last year from all sources, including Veterans benefits, Social Security, and other government programs. Your best estimate is fine.

$11,500 or less..... 01
$11,501 - $20,000 02
$20,001 - $30,000 03
$30,001 - $40,000 04
$40,001 - $50,000 05
$50,001 - $60,000..... 06
$60,001 -$70,000..... 07
More than $70,000 08
REFUSED 97
DON'T KNOW..... 98

IF RESPONDENT CHOSE "DON'T KNOW" TO THE ABOVE QUESTION, SAY:

"Perhaps it would be easier to think about your monthly income. I am going to read you a list of categories. Please stop me when I reach your **household's total income for last month**. Was it…"

$958 or less..... 11
$959 - 1,666 12
$1,667 - $2,500 13
$2,501 - $3,333 14
$3,334 - $4,167 15
$4,168 - $5,000..... 16
$5,001 -$5,833..... 17
More than $5,833 18
REFUSED..... 97
DON'T KNOW..... 98

SECTION F. IMPACT OF CAREGIVING (HEALTH, SOCIAL AND FINANCIAL)

READ: Next, I have some questions about how caregiving affects different parts of your life such as physically, emotionally, and financially. Please be assured that your responses will be kept strictly confidential.

F1. The following questions are about YOUR health and well-being:

	Excellent	Very good	Good	Fair	Poor	REF	DK
a. In general, would you say your **quality of life** is:.....	5	4	3	2	1	7	8
b. In general, how would you rate your physical health?.....	5	4	3	2	1	7	8
c. In general, how would you rate your mental health, including your mood and your ability to think?.....	5	4	3	2	1	7	8
d. In general, how would you rate your satisfaction with your social activities and relationships?.....	5	4	3	2	1	7	8
e. In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.).	5	4	3	2	1	7	8

F2. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

Completely.....	5
Mostly.....	4
Moderately.....	3
A little.....	2
Not at all.....	1
REFUSED.....	7
DON'T KNOW.....	8

F3. In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?

Never.....	1
Rarely.....	2
Sometimes.....	3
Often.....	4
Always.....	5
REFUSED.....	7
DON'T KNOW.....	8

F4. In the past 7 days, how would you rate your fatigue on average?

None	1
Mild	2
Moderate	3
Severe	4
Very Severe	5
REFUSED	7
DON'T KNOW	8

F5. In the past 7 days, how would you rate your pain on average? **From 0 – 10** with 0 being no pain and 10 being the worst imaginable pain.

0 – No pain	0
1	1
2	2
3	3
4	4
5	5
6	6
7	7
8	8
9	9
10 – Worst pain imaginable	10
REFUSED	97
DON'T KNOW	98

F6. How physically difficult would you say that caring for {CR} recipient is for you?

Not at all	1
A little	2
Somewhat	3
Very physically difficult	4

F7. How emotionally difficult would you say that caring for {CR} recipient is for you?

Not at all	1
A little	2
Somewhat	3
Very emotionally difficult	4
REFUSED	7
DON'T KNOW	8

F8. In the last month, how often did helping {CR} cause your sleep to be interrupted?

Every day	1
Most days	2
Some days	3
Rarely	4
Never	5
REFUSED	7
DON'T KNOW	8

READ: Thank you. The next group of questions is to understand your current employment situation.

F9. Are you currently working for pay – either full or part time?

Yes, currently working	1	
No, not working	2	GO TO F11
REFUSED	7	
DON'T KNOW	8	

F9a. In a typical week, how many hours do you usually work on all of your jobs together?

_____
HOURS

F9b. What kind of work do you do, that is, what is your occupation? (For example, plumber, typist, farmer, engineer, health care worker, etc.)

_____
OCCUPATION DESCRIPTION

F10. During the last 6 months and when you were working (for pay), did any of these things happen as a result of your caregiving responsibilities for CR?

	YES	NO	DK	REF
Had to go in late, leave early, or take time off during the day to provide care?	1	2	7	8
Had to take a leave of absence?	1	2	7	8
Had to reduce your regular work hours, or take a less demanding job?	1	2	7	8
Had to give up working entirely?	1	2	7	8
Caregiving had no impact on employment	1	2	7	8

Other (SPECIFY)_____	1	2
_____7	8	
REFUSED.....	1	2
.....7	8	
DON'T KNOW.....	1	2
.....7	8	

BOX 2

DO NOT ASK QUESTION F11 IF THE CAREGIVER IS MARRIED TO CR.

READ: Caregivers often have to spend their own money to help pay for the expenses of the person they are caring for. So, I will ask some questions about that.

F11. In the last year have you used **your own money** to pay for:

	YES	NO	REF	DON'T KNOW
{CR's} medications or medical care?.....	1	2		
.....7	8			
{CR's} Medicare premiums or copayments, or other insurance premiums and copayments?.....	1	2		
.....7	8			
Mobility devices for {CR} such as a walker, cane, or wheelchair?	1	2		
.....7	8			
Things that made {CR's} home safer, such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system?	1	2		
.....7	8			
Any other assistive devices for {CR} that make it easier or safer for {him/her} to do activities on {his/her} own? (This includes devices to help {him/her} see, hear, reach, hold things, or pick things up).....	1	2		
.....7	8			
A paid in-home helper for {CR}?	1	2		
.....7	8			

F12. How financially difficult would you say that caring for {CR} is for you?

Not at all difficult.....	1
A little difficult.....	2
Somewhat difficult.....	3
Very difficult.....	4
REFUSED.....	7
DON'T KNOW.....	8

SECTION G. DELAYED INSTITUTIONALIZATION AND CONTINUED CAREGIVING

READ: Now, I would like you ask you about how {PROVIDER/AGENCY's} programs may have affected your caregiving capacity.

G1. Have the services you received from {PROVIDER/AGENCY's} enabled you to provide care longer than would have been possible without these services?

Definitely yes	1
Probably yes	2
Not sure	3
No, probably not	4
No, definitely not	5
REFUSED	7
DON'T KNOW	8

G2. In your opinion, if the services that you received from {PROVIDER/AGENCY} had not been available would {CR} be living in a nursing home now?

Not at all likely	1
Somewhat likely	2
Very likely	3
Almost certain	4
REFUSED	7
DON'T KNOW	8

G3. Would {CR} have been able to continue to live at home if caregiver services from {PROVIDER/AGENCY} had not been provided?

Definitely yes	1	GO TO H1
Probably yes	2	
Not sure	3	
No, Probably not	4	
No, Definitely not	5	
REFUSED	7	
DON'T KNOW	8	

G4. Where do you think {CR} would be living?

DO NOT READ LIST. CHECK ONLY ONE ANSWER.

IN YOUR (CAREGIVER'S) HOME	1
IN THE HOME OF ANOTHER FAMILY MEMBER OR FRIEND	2
IN AN ASSISTED LIVING FACILITY	3
IN A NURSING HOME	4
CR WOULD HAVE DIED	5
OTHER (SPECIFY)_____	6
REFUSED	7
DON'T KNOW	8

SECTION H. CAREGIVER HEALTH STATUS AND HEALTHCARE UTILIZATION

READ: Now I would like to ask you questions about your own health.

H1. Please tell me YES or NO if a doctor ever told you that you had:

	YES	NO	REF	DK
A heart attack or myocardial infarction	1	2		
	7	8		
Any other heart disease, including angina or congestive heart failure	1	2		
	7	8		
Arthritis	1	2		
	7	8		
Osteoporosis or thinning of the bones	1	2		
	7	8		
Diabetes	1	2		
	7	8		
Lung disease, such as emphysema, asthma, or chronic bronchitis	1	2		
	7	8		
Cancer	1	2		
	7	8		
Serious difficulty seeing	1	2		
	7	8		
Serious difficulty hearing	1	2		
	7	8		
Any other disease or condition? (SPECIFY)___	1	2		
_____	7	8		

READ:: Examples include liver disease, kidney disease, a mini-stroke or TIA, peripheral neuropathy that causes numbness and pain in your feet

H2. Do you have health insurance? This can be from either a private insurer, Medicare, Medicaid, Tricare, or some other insurer?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

H3. Do you have prescription drug coverage?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

H4. During the past six months…..

	YES	NO	DK	REF
Were you hospitalized?.....	1	2		
.....3	4			
Were you a patient at a skilled nursing facility or nursing home?.....	1	2		
.....3	4			
Did you have to go to the emergency department?.....	1	2		
.....3	4			
Did you go to a hospital outpatient department or ambulatory surgical center?.....	1	2		
.....3	4			

H5. During the past six months, how often did you go to the doctor?

At least once a week.....	1
2-3 times a month.....	2
Once a month.....	3
Once every 3 months.....	4
Once every 6 months.....	5
Once a year.....	6
REFUSED.....	7
DON'T KNOW.....	8

I

SECTION I. . CAREGIVER REPORT OF RECIPIENT'S DEMOGRAPHICS, HEALTH, AND FUNCTION

READ: We are interested in knowing more about the demographic and health characteristics of care recipients. We would appreciate it if you would answer the following questions. Your answers will be used only for the purposes of this research. The reports prepared for this study will summarize findings across the sample and will not associate responses with a specific individual. We will not provide information that identifies any individuals to anyone outside the study team. Remember your answers are confidential and you don't have to answer any question you don't want to.

I1. What is {NAME OF CAREGIVER's} home ZIP code?

|__|__|__|__|__|

I2. What is the marital status of CR?

MARRIED..... 1
WIDOWED..... 2
DIVORCED..... 3
SEPARATED..... 4
UNMARRIED..... 5
PARTNER/CIVIL UNION..... 6
NEVER MARRIED..... 7
REFUSED..... 97
DON'T KNOW..... 98

I3. Is {CR} of Hispanic or Latino origin?

YES..... 1
NO..... 2
REFUSED..... 3
DON'T KNOW..... 4

I4. I am going to read a list of five race categories. Please choose one or more races that [the {CR} considers himself/ herself] to be.

White..... 1
Black or African-American..... 2
Asian..... 3
American Indian or Alaskan Native..... 4
Native Hawaiian or other Pacific Islander..... 5
Other (SPECIFY)_____ 6
REFUSED..... 7
DON'T KNOW..... 8

I5. Is {CR} a veteran of the U.S. Armed Forces?

YES..... 1

NO..... 2
REFUSED..... 3
DON'T KNOW..... 4

I6. Does {CR} have health insurance? {Examples include Medicare, Medicare Advantage, Medicaid, TRICARE, CHAMPUS (the old name for part of military health coverage), private insurance}

YES..... 1
NO..... 2
REFUSED..... 3
DON'T KNOW..... 4

I7. Does {CR} have prescription-drug insurance/benefits? {Example: Medicare Part D}

YES..... 1
NO..... 2
REFUSED..... 3
DON'T KNOW..... 4

BOX 3

ONLY ASK THE NEXT TWO QUESTIONS IF
CAREGIVER DOES NOT LIVE WITH CR.

REMIND THE RESPONDENT THAT THIS
INFORMATION WILL BE KEPT CONFIDENTIAL.

READ: Since you do not live with CR, I am going to read you a short list of categories to understand CR's household income. {If necessary, reiterate that the response is kept confidential.}

I8. Please stop me when I reach **CR's total household income** before taxes last year from all sources, including Veterans benefits, Social Security and other government programs. Your best estimate is fine.

Less than $20,000..... 1
$20,001 - $40,000..... 2
More than $40,000..... 3
REFUSED..... 4
DON'T KNOW..... 5

INTERVIEWER: IF RESPONDENT DOESN'T KNOW CR'S ANNUAL INCOME, SAY:

Perhaps it would be easier to think about CR's monthly income. I am going to read you a list of categories. Please stop me when I reach CR's total income for last month. Was it…

Less than $1,700..... 11
$1,700 - $3,300..... 12
More than $3,300..... 13
REFUSED..... 97
DON'T KNOW..... 98

READ: "OK, we are almost done. Next I will read a list of some diseases that a doctor might have said {CR} has.

I9. Please tell me if a doctor has ever told you or {CR} that **he/she** had:"

	YES	NO	DK	REF
A heart attack or myocardial infarction.....	1	2		
.....3	4			
Any other heart disease, including angina or congestive heart failure.....	1	2		
.....3	4			
Arthritis.....	1	2		
.....3	4			
Osteoporosis or thinning of the bones.....	1	2		
.....3	4			
Diabetes.....	1	2		
.....3	4			
Lung disease, such as emphysema, asthma, or chronic bronchitis.....	1	2		
.....3	4			
Cancer.....	1	2		
.....3	4			
Serious difficulty seeing.....	1	2		
.....3	4			
Serious difficulty hearing.....	1	2		
.....3	4			
Any other disease or condition? (SPECIFY)_____	1	2		
_____3	4			

READ:: Examples include liver disease, kidney disease, a mini-stroke or TIA, peripheral neuropathy that causes numbness and pain in your feet.

I10. Does {CR} have Alzheimer's disease, dementia, or other type of memory problem?

YES.....	1
NO.....	2
MAYBE.....	3
REFUSED.....	7
DON'T KNOW.....	8

I11. Does {CR} display any of these behaviors?

	YES	NO	DK	REF
Yells.....	1	2	7	8
Moans frequently.....	1	2	7	8
Resists your attempts to provide aid.....	1	2	7	8
Tries to hit or bite you.....	1	2	7	8
Wanders or gets lost.....	1	2	7	8

I12. Has {CR} been hospitalized in the past 6 months for anything?

YES	1	GO TO I12a
NO	2	GO TO I13
REFUSED	7	GO TO I13
DON'T KNOW	8	GO TO I13

I12a. If yes, why?

(INTERVIEWER: TRY TO GET A SHORT ANSWER SUCH AS STROKE, MINI-STROKE, A FALL - HIP OR PELVIS FRACTURE, HEART ATTACK, JOINT REPLACEMENT, PNEUMONIA, INFECTION, ETC.)

_____

READ: We would like to ask about {CR's} abilities to perform some common activities of everyday life and whether {CR} needs assistance performing these activities. We are only interested in long-term conditions, not temporary conditions.

I13. Does {CR} have difficulty getting around inside the home?

YES	1	GO TO I13a
NO	2	GO TO I14
REFUSED	7	GO TO I14
DON'T KNOW	8	GO TO I14

I13a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I14. Does {s/he} have difficulty going outside the home, for example to shop or visit a doctor's office?

YES	1	GO TO I14a
NO	2	GO TO I15
REFUSED	7	GO TO I15
DON'T KNOW	8	GO TO I15

I14a. Does {s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I15. Does {CR} have difficulty getting in or out of bed or a chair?

YES	1	GO TO I15a
NO	2	GO TO I16
REFUSED	7	GO TO I16
DON'T KNOW	8	GO TO I16

I15a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I16. Does {s/he} have difficulty when taking a bath or shower?

YES	1	GO TO I16a
NO	2	GO TO I17
REFUSED	7	GO TO I17
DON'T KNOW	8	GO TO I17

I16a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I17. Does {CR} have difficulty when dressing?

YES	1	GO TO I17a
NO	2	GO TO I18
REFUSED	7	GO TO I18
DON'T KNOW	8	GO TO I18

I17a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I18. Does {s/he} have difficulty when walking?

YES	1	GO TO I18a

NO	2	GO TO I19
REFUSED	7	
DON'T KNOW	8	

I18a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I19. Does {CR} have difficulty eating?

YES	1	GO TO I19a
NO	2	GO TO I20
REFUSED	7	GO TO I20
DON'T KNOW	8	GO TO I20

I19a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I20. Does {s/he} have difficulty using the toilet or getting to the toilet?

YES	1	GO TO I20a
NO	2	GO TO I21
REFUSED	7	GO TO I21
DON'T KNOW	8	GO TO I21

I20a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I21. Does {CR} have difficulty keeping track of money or bills?

YES	1	GO TO I21a
NO	2	GO TO I22
REFUSED	7	GO TO I22
DON'T KNOW	8	GO TO I22

I21a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I22. Does {s/he} have difficulty preparing meals?

YES	1	GO TO I22a
NO	2	GO TO I23
REFUSED	7	GO TO I23
DON'T KNOW	8	GO TO I23

I22a. {Does s/he} need the help of another person to perform this activity?

YES	1	
NO	2	
REFUSED	7	
DON'T KNOW	8	

I23. Does {CR} have difficulty doing light housework, such as washing dishes or sweeping a floor?

YES	1	GO TO I23a
NO	2	GO TO I24
REFUSED	7	GO TO I24
DON'T KNOW	8	GO TO I24

I23a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I24. Does {s/he} have difficulty doing heavy housework, such as scrubbing floors or washing windows?

YES	1	GO TO I24a
NO	2	GO TO I25
REFUSED	7	GO TO I25
DON'T KNOW	8	GO TO I25

I24a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7
DON'T KNOW	8

I25. Does {s/he} have difficulty taking the right amount of prescribed medicine at the right time?

YES	1	GO TO I25a
NO	2	GO TO I26
REFUSED	7	GO TO I26
DON'T KNOW	8	GO TO I26

I25a. {Does s/he} need the help of another person to perform this activity?

YES	1
NO	2
REFUSED	7

DON'T KNOW..... 8

I26. Does {CR} have difficulty using the telephone?

YES.....1 GO TO I26a
NO..... 2
REFUSED..... 7
DON'T KNOW..... 8

I26a. {Does s/he} need the help of another person to perform this activity?

YES..... 1
NO..... 2
REFUSED..... 7
DON'T KNOW..... 8

READ: The evaluation design calls for a brief interview with the {CR} to ask about {His/Her} feelings. May we have your permission to call {CR} for a five-minute interview?

YES..... 1
NO..... 2
REFUSED..... 7
DON'T KNOW..... 8

IF YES: please tell me the name, address, and telephone number of the{CR} to allow us to conduct this brief interview.

[VERIFY SPELLING]

FIRST NAME: _____ LAST NAME: _____

[DO NOT ENTER P.O. BOX]

& STREET:_____

APT. # _____

CITY:_____STATE:_____ ZIP CODE: _____

What is [FIRST NAME/LASTNAME]'s home telephone number?
HOME TELEPHONE NUMBER: (XXX) XXX-XXXX

READ: CLOSING

CLOSE1. Those are all the questions I have for you today. We would like to call you back in six months to ask if there are any changes in your answers to these questions at that time. Thank you very much for your help with this important national survey. We appreciate your time.