

POMP 5 CAREGIVER PROGRAM SUPPORT AND ASSESSMENT SURVEY TELEPHONE SURVEY

June 3, 2004

RECORD TIME INTERVIEW BEGAN: _____ AM / PM

Hello. May I speak to [CAREGIVER'S NAME]? My name is [INTERVIEWER'S NAME] from [AGENCY'S NAME]. We are conducting a survey to find out how we can help meet the needs of caregivers and seniors being served by [AGENCY'S NAME]. Our records show that you have received caregiver support services from [AGENCY'S NAME] to help you take care of an elderly person. We would like to know if these caregiver support services have been helpful.

Are you still the caregiver for [CARE RECIPIENT'S NAME] or
[someone 60 years of age or older]?

Yes 1
No 2

IF NO, RECORD ANY COMMENTS RESPONDENT MADE ABOUT FORMER CARE RECIPIENT (E.G., RESPONDENT IN NURSING HOME, DECEASED, ETC):

THANK THE RESPONDENT AND TERMINATE THE INTERVIEW

[IF YES, INTERVIEWEE IS STILL THE PRIMARY CAREGIVER:] This survey typically takes about 25 minutes or so. Some people want to talk more, others talk less. You may be more comfortable answering these questions if you are NOT in the presence of the person you are caring for. Is this a good time for you?

[IF YES, THIS IS A GOOD TIME: GO TO NEXT PAGE]

[IF NO] What is another time that is better for you?
(Get time and phone number where they can be reached.)

Day: _____ Time: _____ Date: _____

Telephone number? _____

**[CONFIRM TIME AND PHONE NUMBER WHERE THEY CAN BE REACHED.
TERMINATE INTERVIEW.]**

Office Use Only: _____ 1 of 24
Type of Administration [check]: Telephone Mail Interview Date: _____
Result Code: _____ Caregiver Enrollment Date: _____ Caregiver ID: _____

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Let's begin the caregiver survey. Your participation is voluntary and very important to the success of this study. Your answers to the questions will be kept confidential to the extent the law allows and will be used only for the purpose of this study. Your eligibility for services will not be affected by your decision to participate nor by any answers you give.

1. What is your relationship to [CARE RECIPIENT'S NAME]? Are you his or her ...

- 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
- Other relative [*Not a relative mentioned above*] 15
- (**SPECIFY:** _____)
- Friend or Neighbor or Another Person 16

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

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2. I'm going to read you several activities that some people need help with. When [CARE RECIPIENT'S NAME] performs or is involved in these activities, how often do you help with ...

	All the time or Most of the time	Some- times	Rarely or Never	REFUSED	DON'T KNOW
A.) Activities like dressing, eating, bathing, or getting to the bathroom? Would you say ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8
B.) Medical needs such as taking medicine or changing bandages? Would you say ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8
C.) Keeping track of bills, checks, or other financial matters?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8
D.) Preparing meals, doing laundry, or cleaning the house?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8
E.) Going shopping or to the doctor's office?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8
F.) Arranging for care or services provided by others?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8

[IF ALL RESPONSES ARE "NEVER," "REFUSED," OR "DON'T KNOW," ASK:]

What kind of care do you provide for [CARE RECIPIENT'S NAME]?

[WRITE RESPONSE VERBATIM. IF "NO CARE PROVIDED," WRITE "NONE."]

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

INTERVIEWER NOTE: IF THIS PERSON DOES NOT PROVIDE CARE OF ANY KIND FOR THE CLIENT, TERMINATE THE INTERVIEW AT THIS POINT AND FOR THE RESULT CODE ON THE FIRST PAGE WRITE T1. RECORD TIME INTERVIEW ENDED _____ AM/PM

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INTERVIEW INTRO: I'd like to ask you some questions about the services that you are receiving from [AGENCY'S NAME] and/or other agencies. We are interested in your experiences with services during the last year.

3. Have you received **Respite Care**, which allows you, the caregiver, a brief period of rest or relief while temporary care is provided to [CARE RECIPIENT'S NAME], either in your home or someplace else? [**PROMPT WITH LOCAL SERVICES AS NEEDED.**]

- Yes, 1 [**GO TO Q.3A.**]
- No 2 [**GO TO Q.4.**]
- REFUSED..... -7 [**GO TO Q.4.**]
- DON'T KNOW..... -8 [**GO TO Q.4.**]

3A. To what extent have the **Respite Care Services** you have received helped you as a caregiver? (**READ LIST. CHECK ONLY ONE.**) Would you say...

- They helped a lot,..... 1
- They helped a little,..... 2
- They didn't help, or 3
- They made things worse?..... 4
- REFUSED..... -7
- DON'T KNOW..... -8

4. Has someone, such as your case worker, case manager, or other AAA staff person, **helped you or given you information** to connect you to the services and resources that you need as a caregiver?

- Yes 1 [**GO TO Q.4A.**]
- No 2 [**GO TO Q.5.**]
- REFUSED..... -7 [**GO TO Q.5.**]
- DON'T KNOW..... -8 [**GO TO Q.5.**]

4A. To what extent has the **help or information** you have received helped you connect to the services and resources that you need as a caregiver? (**READ LIST. CHECK ONLY ONE.**) Would you say...

- They helped a lot,..... 1
- They helped a little,..... 2
- They didn't help, or 3
- They made things worse?..... 4
- REFUSED..... -7
- DON'T KNOW..... -8

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5. Have you received **caregiver training or education**, including counseling or support groups, to help you make decisions and solve problems in your role as a caregiver?

- Yes 1 [GO TO Q.5A.]
- No 2 [GO TO Q.6.]
- REFUSED..... -7 [GO TO Q.6.]
- DON'T KNOW..... -8 [GO TO Q.6.]

5A. To what extent has the **caregiver training or education** you have received helped you as a caregiver? (**READ LIST. CHECK ONLY ONE.**) Would you say...

- It helped a lot, 1
- It helped a little, 2
- It did not help, or..... 3
- It made things worse? 4
- REFUSED..... -7
- DON'T KNOW..... -8

6. Has the National Family Caregiver Support Program provided you with any other **Supplemental Services** to help you with the care you provide, such as [INSERT LOCAL SERVICES OR USE: home modifications, assistive technologies, or incontinence supplies]?

- Yes 1 [GO TO Q.6A.]
- No 2 [GO TO BOX]
- REFUSED..... -7 [GO TO BOX]
- DON'T KNOW..... -8 [GO TO BOX]



6A. To what extent have the **Supplemental Services** you have received helped you as a caregiver? (**READ LIST. CHECK ONLY ONE.**) Would you say...

- They helped a lot,..... 1
- They helped a little,..... 2
- They did not help, or..... 3
- They made things worse?..... 4
- REFUSED..... -7
- DON'T KNOW..... -8

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INTERVIEWER NOTE: IF RESPONDENT RECEIVES ANY OF THE ABOVE SERVICES (I.E. "YES" TO Q. 3, 4, 5, OR 6), CONTINUE INTERVIEW. OTHERWISE, THANK RESPONDENT AND END INTERVIEW AND FOR THE RESULT CODE ON THE FIRST PAGE WRITE T2. RECORD TIME ENDED _____.

**7. Of the caregiver services provided, which one service was the most helpful?
(READ LIST. CHECK ONLY ONE.)**

- Respite Care Services, 1
- Help or Information connecting you
to Caregiver Support Services, 2
- Caregiver Training or Education,
including Counseling or a Support Group, or 3
- Other Supplemental Support Services
or Assistance? 4
- REFUSED -7
- DON'T KNOW -8

8. How have the caregiver services that have been provided affected you and your caregiving tasks? [WRITE RESPONSE VERBATIM]

- REFUSED -7
- DON'T KNOW -8

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9. Overall, to what extent have these caregiver services helped you to be a better caregiver? **(READ LIST. CHECK ONLY ONE.)** Would you say...

- They helped a lot,..... 1
- They helped a little,..... 2
- They didn't help, or 3
- They made things worse?..... 4
- REFUSED..... -7
- DON'T KNOW..... -8

10. Have these caregiver services enabled you to provide care for [CARE RECIPIENT'S NAME] for a longer time than would have been possible without these services? **(READ LIST. CHECK ONLY ONE.)** Would you say...

- Yes, definitely, 1
- Yes, I think so, 2
- No, I don't think so, or..... 3
- No, definitely not? 4
- REFUSED..... -7
- DON'T KNOW..... -8

11. Overall, how would you rate the caregiver support services that have been provided? **(READ LIST. CHECK ONLY ONE.)** Would you say...

- Excellent, 1
- Very good,..... 2
- Good,..... 3
- Fair, or..... 4
- Poor? 5
- REFUSED..... -7
- DON'T KNOW..... -8

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Now I would like to ask you some questions about your employment.

12. What is your current employment status?

- Working full time,..... 1 [GO TO Q.13.]
- Working part time, 2 [GO TO Q.13.]
- Retired, or 3 [GO TO Q.12A.]
- Not working? 4 [GO TO Q.12A.]
- REFUSED..... -7 [GO TO Q.16.]
- DON'T KNOW..... -8 [GO TO Q.16.]

12A. Did your caregiving responsibilities cause you to quit work or retire early?

- Yes 1 [GO TO Q.16.]
- No 2 [GO TO Q.16.]
- REFUSED..... -7 [GO TO Q.16.]
- DON'T KNOW..... -8 [GO TO Q.16.]

13. Has providing care for [CARE RECIPIENT'S NAME] interfered with your job?

- Yes 1 [GO TO Q.13A.]
- No 2 [GO TO Q.16.]
- REFUSED..... -7 [GO TO Q.16.]
- DON'T KNOW..... -8 [GO TO Q.16.]

13A. How frequently has providing care for [CARE RECIPIENT'S NAME] interfered with your job? Would you say

- Always or usually, 1 [GO TO Q.14.]
- Sometimes, 2 [GO TO Q.14.]
- Rarely or never? 3 [GO TO Q.16.]
- REFUSED..... -7 [GO TO Q.16.]
- DON'T KNOW -8 [GO TO Q.16.]

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14. Because of providing care for [CARE RECIPIENT'S NAME], have you . . .
[READ LIST AND CHECK ALL THAT APPLY.] YES NO

- | | | | | |
|---|--------------------------|---|--------------------------|---|
| A. Taken a less demanding job. | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| B. Changed from full time to part-time work. | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| C. Reduced your official working hours. | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| D. Lost some of your employment fringe benefits. | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| E. Had time conflicts between working and caregiving. | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| F. Used your vacation time to provide care. | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| G. Taken a leave of absence to provide care. | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| H. Lost a promotion | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| I. Worked less than your normal number of hours last
month because of providing care for [CARE
RECIPIENT'S NAME] | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| J. Other [<i>SPECIFY:</i> _____]..... | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |

15. To what extent have caregiver support services helped alleviate these work difficulties?
Would you say...

- | | | |
|------------------------------|--------------------------|----|
| They helped a lot,..... | <input type="checkbox"/> | 1 |
| They helped a little,..... | <input type="checkbox"/> | 2 |
| They didn't help, or | <input type="checkbox"/> | 3 |
| They made things worse?..... | <input type="checkbox"/> | 4 |
| REFUSED..... | <input type="checkbox"/> | -7 |
| DON'T KNOW..... | <input type="checkbox"/> | -8 |

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16. Please tell me how frequently each of the following happens: Always or usually, Sometimes, or Rarely or never.

	Always or Usually	Some- times	Rarely or Never	REFUSED	DON'T KNOW	DOES NOT APPLY
A.) As a caregiver, how often do you feel that you are helping [CARE RECIPIENT'S NAME]? Would you say ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
B.) As a caregiver, how often do you feel that you are helping your family by caring for [CARE RECIPIENT'S NAME]? Would you say ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
C.) How often does being a caregiver provide you with a sense of accomplishment?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
D.) How often does providing care for [CARE RECIPIENT'S NAME] give you the satisfaction of caring for someone who cared for you?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
E.) How often do you feel that [CARE RECIPIENT'S NAME] appreciates the care that you are providing for them?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
F.) How often does being a caregiver for [CARE RECIPIENT'S NAME] provide companionship for you? Would you say...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
G.) OTHER (<i>SPECIFY:</i> _____)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1

INTERVIEWER NOTE: IF ALL OF Q.16 IS "RARELY OR NEVER," "REFUSED," "DON'T KNOW," OR "DOES NOT APPLY," GO TO Q.18.

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17. In your experience as a caregiver, what would you say is the **one most positive aspect** of caregiving? **[READ LIST. CHECK ONLY ONE.]** Would you say that the one most positive aspect is ...

- Helping your care recipient,..... 1
- Helping your other family members,..... 2
- Feeling a sense of accomplishment,..... 3
- Caring for someone who cared for you,..... 4
- Being appreciated, or 5
- Providing companionship for you?..... 6
- OTHER (*SPECIFY:* _____)..... 7
- NONE 8
- REFUSED..... -7
- DON'T KNOW..... -8

18. In your experience as a caregiver, how often do you feel that...	Always or Usually	Some- times	Rarely or Never	REFUSED	DON'T KNOW	DOES NOT APPLY
A.) Caregiving creates a financial burden for you? Would you say ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
B.) You do not have enough time for yourself? Would you say ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
C.) You do not have enough time for your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
D.) Caregiving negatively affects your health?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
E.) Caregiving conflicts with your social life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
F.) You are stressed?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1
G.) OTHER (<i>SPECIFY:</i> _____)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> -7	<input type="checkbox"/> -8	<input type="checkbox"/> -1

INTERVIEWER NOTE: IF ALL OF Q.18 IS "RARELY OR NEVER," "REFUSED," "DON'T KNOW," OR "DOES NOT APPLY," GO TO Q.21.

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19. Which of these difficulties is **the greatest difficulty** you have faced in your caregiving? [READ LIST. CHECK ONLY ONE.] Would you say caregiving's greatest difficulty is that it ...

Creates a financial burden,..... 1
Doesn't leave enough time for yourself,..... 2
Doesn't leave enough time for your family, 3
Interferes with your work,..... 4
Creates or aggravates health problems, 5
Affects your family relationships, or 6
Creates stress?..... 7
OTHER (*SPECIFY:* _____)..... 8
REFUSED..... -7
DON'T KNOW..... -8

20. To what extent have the **Caregiver Support Services** you have received helped alleviate these difficulties? [READ LIST. CHECK ONLY ONE.] Would you say...

They helped a lot,..... 1
They helped a little,..... 2
They didn't help, or 3
They made things worse?..... 4
REFUSED..... -7
DON'T KNOW..... -8

21. Do you have any kind of health problem, physical condition, or disability that affects the kind or amount of care that you can provide to [CARE RECIPIENT'S NAME]?

Yes 1 [GO TO Q.21A.]
No 2 [GO TO Q.23.]
REFUSED..... -7 [GO TO Q.23.]
DON'T KNOW..... -8 [GO TO Q.23.]

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21A. [IF YES] What is that problem, condition, or disability? [DON'T READ LIST. WRITE RESPONSE VERBATIM OR CHECK ALL THAT APPLY.]

Physical

1. Back problems and other joint problems/ Arthritis..... 1

Illness

2. Heart problems / High Blood Pressure / Hypertension / Stroke. 1

3. Diabetes..... 1

4. Allergies/Asthma/Other breathing and lung problems. ... 1

5. **Mental health (all).** 1

6. **Eye problems.** 1

7. **Other (SPECIFY: _____)**..... 1

REFUSED..... -7

DON'T KNOW..... -8

22. Have your caregiving activities created or worsened any of these problems, conditions, or disabilities?

Yes 1

No 2

REFUSED..... -7

DON'T KNOW..... -8

Next, I would like to ask you some questions about [CARE RECIPIENT'S NAME].

23. How long have you been caring for [CARE RECIPIENT'S NAME]?

 |_|_| Months |_|_| Years

REFUSED..... -7

DON'T KNOW..... -8

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24. How far away do you live from [CARE RECIPIENT'S NAME]? [READ LIST. CHECK ONLY ONE.] Do you live...

In the same house,..... 1 [GO TO Q.26.]
Less than 20 minutes away, 2
Between 20 and 60 minutes away,..... 3
Between 1 and 2 hours away, or 4
More than two hours away? 5
REFUSED..... -7 [GO TO Q.26.]
DON'T KNOW..... -8 [GO TO Q.26.]

25. Does [CARE RECIPIENT'S NAME] live alone?

Yes 1
No 2
REFUSED..... -7
DON'T KNOW..... -8

26. Can [CARE RECIPIENT'S NAME] be left alone? Would you say . . .

He/she can be left alone, 1
He/she needs someone there at least part of the day, or 2
He/she needs someone there all or nearly all the time? 3
REFUSED..... -7
DON'T KNOW..... -8

27. In your judgment, how many hours per day of help, care, or supervision does [CARE RECIPIENT'S NAME] need?

NUMBER OF HOURS PER DAY..... |__|__|
REFUSED..... -7
DON'T KNOW..... -8

28. In a **typical 24-hour week day**, how many hours do **you** provide help, care or supervision for [CARE RECIPIENT'S NAME] in person?

NUMBER OF HOURS PER DAY..... |__|__|
REFUSED..... -7
DON'T KNOW..... -8

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29. In a **typical 24-hour weekend day**, how many hours do **you** provide help, care or supervision for [CARE RECIPIENT'S NAME] in person?

- NUMBER OF HOURS PER DAY..... |__|__|
 REFUSED..... -7
 DON'T KNOW..... -8

30. Do any agencies, family members or friends help you get **time off** or relief from the responsibility of caring for [CARE RECIPIENT'S NAME]?

- Yes 1
 No 2
 REFUSED..... -7
 DON'T KNOW..... -8

31. **[IF Q.30 IS "YES," ASK:]** Do you need more time off?
[IF Q.30 IS "NO," "REFUSED," OR "DON'T KNOW," ASK:] Do you need time off?

- Yes 1
 No 2
 REFUSED..... -7
 DON'T KNOW..... -8

32. Thinking about all the family members or friends who provide unpaid help, care, or supervision for [CARE RECIPIENT'S NAME], what proportion of the care do **you** provide? **[READ LIST. CHECK ONLY ONE.]** Would you say...

- All, 1
 Nearly all,..... 2
 More than one-half, but not nearly all, 3
 About half, 4
 More than a little, but less than one-half, or 5
 A little? 6
 REFUSED..... -7
 DON'T KNOW..... -8

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Next I'd like to ask you some questions about the services that [CARE RECIPIENT'S NAME] is receiving from [AGENCY'S NAME] and/or other agencies. We are interested in your experiences with services during the last year.

INTERVIEWER NOTE: PLACE A CHECKMARK IN THE APPROPRIATE BOX. ASK IF THE CARE RECIPIENT RECEIVED THE INDICATED SERVICE.

- 33.** Does [CARE RECIPIENT'S NAME] receive the following service? **[READ LIST.]**
- | | Yes | No | REFUSED | DON'T KNOW |
|--|----------------------------|----------------------------|-----------------------------|-----------------------------|
| A.) Adult Daycare (Center-provided daycare)? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |
| B.) Case Management? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |
| C.) Homemaker Service? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |
| D.) Home Health Aide? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |
| E.) Home Delivered Meals? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |
| F.) Chore Service? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |
| G.) Transportation Service (includes Assisted Transportation)? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |
| H.) Information about services? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |
| I.) Other services or assistance (not listed above)? | | | | |
| <i>1. SPECIFY:</i> _____ | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |
| <i>2. SPECIFY:</i> _____ | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> -7 | <input type="checkbox"/> -8 |

INTERVIEWER NOTE: IF ALL OF Q.33 IS "NO," REFUSED, OR "DON'T KNOW," GO TO Q.37.

- 34.** Overall, how would you rate the services that [CARE RECIPIENT'S NAME] receives? **[READ LIST. CHECK ONLY ONE.]** Would you say...

- Excellent, 1
- Very good,..... 2
- Good,..... 3
- Fair, or..... 4
- Poor? 5
- REFUSED..... -7
- DON'T KNOW..... -8

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35. Have the services received by [CARE RECIPIENT'S NAME] enabled you to provide care for a longer time than would have been possible without these services? [READ LIST. CHECK ONLY ONE.] Would you say ...

- Yes, definitely, 1
- Yes, I think so, 2
- No, I don't think so, or 3
- No, definitely not? 4
- REFUSED -7
- DON'T KNOW -8

36. Thinking **only** about the services that [CARE RECIPIENT'S NAME] received, how have the services that [CARE RECIPIENT'S NAME] received affected you and your caregiving tasks? [WRITE RESPONSE VERBATIM.]

- REFUSED -7
- DON'T KNOW -8

37. In your judgment, if the services that you and [CARE RECIPIENT'S NAME] have received had **not** been available, would [CARE RECIPIENT'S NAME] be living in a different place now?

- Yes 1 [GO TO Q.37A.]
- No 2 [GO TO Q.38.]
- REFUSED -7 [GO TO Q.38.]
- DON'T KNOW -8 [GO TO Q.38.]

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37A. Where would [CARE RECIPIENT'S NAME] be living?
[DON'T 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, or 3
- In a nursing home? 4
- OTHER (*SPECIFY:* _____) ... 5
- CARE RECIPIENT WOULD HAVE DIED 6
- REFUSED -7
- DON'T KNOW -8

38. In addition to the kinds or amounts of services [CARE RECIPIENT'S NAME] is now receiving, what additional or new kinds of **help** would be valuable to you as a caregiver?
[READ LIST. CHECK YES OR NO FOR EACH.] How about...

- | | <u>YES</u> | <u>NO</u> |
|---|-----------------------------|----------------------------|
| A. Help with housekeeping, | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| B. Help with shopping, | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| C. Help with transportation, getting places, | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| D. Help with making meals, | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| E. Help with bathing, dressing, grooming, toileting,
feeding, other personal care, | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| F. Help with medicines (administering medicine,
monitoring side effects, etc.),..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| G. Help with getting other family members involved in
caring for [CARE RECIPIENT'S NAME],..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| H. Financial support, tax break, stipend, government
subsidy, | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| I. In-home respite care for [CARE RECIPIENT'S
NAME], | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| J. Adult daycare for [CARE RECIPIENT'S NAME], or.... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| K. Money management assistance or financial advice, | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| L. OTHER (<i>SPECIFY:</i> _____) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| - OR - | | |
| M. No additional help needed? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| REFUSED..... | <input type="checkbox"/> -7 | |
| DON'T KNOW..... | <input type="checkbox"/> -8 | |

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39. In addition to the kinds or amounts of information that you already have, what additional or new kinds of **information** would be valuable to you as a caregiver? **[READ LIST. CHECK YES OR NO FOR EACH ONE.]** How about...

- | | <u>YES</u> | | <u>NO</u> | |
|---|--------------------------|---|--------------------------|----|
| A. A help line (or central place to call to find out what kind of help is available and where to get it), | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| B. Someone to talk to or counseling services or support group, | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| C. Information about [CARE RECIPIENT'S NAME]'s condition or disability, | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| D. Information about changes in laws that might affect your situation, | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| E. Help in understanding how to select a nursing home or group home or other care facility, | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| F. Help in understanding how to pay for nursing homes, adult day care, or other services, | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| G. Help in dealing with agencies (bureaucracies) to get services, or | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| H. OTHER
(SPECIFY: _____) | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| - OR - | | | | |
| I. No additional information needed? | <input type="checkbox"/> | 1 | <input type="checkbox"/> | 2 |
| REFUSED..... | <input type="checkbox"/> | | <input type="checkbox"/> | -7 |
| DON'T KNOW..... | <input type="checkbox"/> | | <input type="checkbox"/> | -8 |

We are interested in knowing more about the demographic characteristics of people receiving these services. We would appreciate it if you would answer the following questions. All this information will be kept confidential to the extent allowed by law.

40. What is the age of [CARE RECIPIENT'S NAME]?

- | | | | | |
|-----------------------|--------------------------|--|--------------------------|----|
| NUMBER OF YEARS | | | | |
| REFUSED..... | <input type="checkbox"/> | | <input type="checkbox"/> | -7 |
| DON'T KNOW..... | <input type="checkbox"/> | | <input type="checkbox"/> | -8 |

41. **[DON'T ASK IF OBVIOUS, JUST CHECK.]** What is the gender of [CARE RECIPIENT'S NAME]?

- | | | | | |
|-----------------|--------------------------|--|--------------------------|----|
| Male | | | | |
| Female | <input type="checkbox"/> | | <input type="checkbox"/> | 2 |
| REFUSED..... | <input type="checkbox"/> | | <input type="checkbox"/> | -7 |
| DON'T KNOW..... | <input type="checkbox"/> | | <input type="checkbox"/> | -8 |

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42. How many other persons total are you caring for, not counting [CARE RECIPIENT'S NAME]?

NUMBER OF PERSONS..... |__|__|
 REFUSED..... -7
 DON'T KNOW..... -8

42A. [IF NOT ZERO] Who are those people? [DO NOT READ LIST. CHECK ALL THAT APPLY]

- 1. Husband or wife 1
 - 2. Son(s) or daughter(s) 1
 - 3. Father 1
 - 4. Mother 1
 - 5. Brother(s) or sister(s) 1
 - 6. Grandson(s) or granddaughter(s) 1
 - 7. Other relative(s) not mentioned above..... 1
 - 8. Friend(s) or neighbor(s) 1
 - 9. Other persons not mentioned above
(SPECIFY: _____)..... 1
- REFUSED..... -7
 DON'T KNOW..... -8

D1. [RECORD SEX OF RESPONDENT. IF NOT OBVIOUS, ASK:]
 What is your gender?

MALE 1
 FEMALE..... 2
 REFUSED..... -7
 DON'T KNOW..... -8

D2. What is your age?

NUMBER OF YEARS |__|__|__|
 REFUSED..... -7
 DON'T KNOW..... -8

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D3. What is your highest educational level?

- Less than high school diploma,..... 1
- High school diploma or GED, 2
- Some college, including Associate's degree, 3
- Bachelor's degree, or 4
- Some post-graduate work or advanced degree?..... 5
- REFUSED..... -7
- DON'T KNOW..... -8

D4. Are you Spanish, Hispanic or Latino?

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

D5. What is your race? [**DON'T READ LIST. CHECK ALL THAT APPLY.**]

- A. White or Caucasian, 1
- B. Black or African-American,..... 1
- C. Asian, 1
- D. American Indian or Alaska Native, or 1
- E. Native Hawaiian or Other Pacific Islander? 1
- F. OTHER (***SPECIFY:*** _____)..... 1
- REFUSED..... -7
- DON'T KNOW..... -8

D6. Where is your home located? Would you say...

- In a City,..... 1
- In a Suburban Area, or 2
- In a Rural area? 3
- REFUSED..... -7
- DON'T KNOW..... -8

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TELEPHONE SURVEY**

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D12. Thinking about the total combined income from all sources for all persons in this household, was your total household annual income for the past 12 months \$20,000 or less or more than \$20,000?

[IF NEEDED: Including income from jobs, Social Security, retirement income, public assistance, and all other sources.]

- \$20,000 OR LESS, OR 1 **[GO TO Q.D13.]**
- MORE THAN \$20,000 2 **[GO TO Q.D14.]**
- REFUSED -7 **[GO TO CLOSE]**
- DON'T KNOW -8 **[GO TO CLOSE]**

D13. Which category best describes your total household annual income for the last 12 months? Would you say...

- \$10,000 or less, 1
- \$10,001-\$15,000, or 2
- \$15,001 - \$20,000? 3
- REFUSED -7
- DON'T KNOW -8

D14. Which category best describes your total household annual income for the last 12 months? Would you say...

- \$20,001 - \$25,000, 1
- \$25,001 - \$30,000, 2
- \$30,001-\$35,000, 3
- \$35,001 - \$40,000, or 4
- Over \$40,000? 5
- REFUSED -7
- DON'T KNOW -8

RECORD TIME INTERVIEW ENDED: _____ AM / PM

