

POMP Final: Caregiver Services Survey Instrument

(Telephone Version)

Hello. My name is _____. I am calling from the (name of AAA). I understand that you receive caregiver services. We would like to ask you a few questions about the services that you receive. The interview will take about 30 minutes. We are interested in the length of time you have received caregiver services and whether the caregiver services have been helpful. Your answers will help us make sure that the services meet your needs. Participation in the interview is voluntary and you may skip any question. Your answers will be kept confidential and will not influence the services that you receive.

CR1. Are you still caring for (care recipient's name) or (someone 60 years of age or older)?

- Yes..... 1 → GO TO CR2
- No..... 2
- Refused -7
- Don't Know -8

CR1a. Could you tell me what happened to change your caregiving situation?
DO NOT READ LIST. CHECK ALL THAT APPLY.

- a. Care recipient died 1
- b. Care recipient was placed in a nursing home..... 2
- c. Care recipient was placed in an assisted living facility..... 3
- d. Care recipient was placed in a family type group home (family care home) 4
- e. Care recipient is getting help temporarily from a different caregiver 5
- f. Care recipient has a different permanent caregiving arrangement 6
- g. Care recipient got better and no longer needs help..... 7
- h. Care recipient's needs exceed caregiver's capacity to help..... 8
- i. Caregiver's health status has declined..... 9
- j. Caregiver's employment status has changed..... 10
- k. Caregiver's family situation has changed 11
- l. Other reason 91
Please specify: _____

- Refused..... -7
- Don't Know..... -8

END INTERVIEW

Office Use Only:

Client ID: _____

Service Enrollment Date: _____

Date of Survey Administration: _____

CR2. When was the last time you received caregiver support services?

- Today or yesterday 1
 - More than 1 day, but not more than a week ago 2
 - More than 1 week, but not more than a month ago 3
 - More than 1 month ago 4
 - Over 1 year ago..... 5
 - Refused -7
 - Don't Know -8
- Thank you, but the focus of this survey is on people who have used the service within the past year. END INTERVIEW
- ↑
- END INTERVIEW

CR3. How long have you been receiving caregiver services? Would you say...

- 6 months or less 1
- More than 6 months, but less than 1 year 2
- At least 1 year, but less than 2 years..... 3
- 2 to 5 years..... 4
- More than 5 years 5
- Refused -7
- Don't Know -8

CR4. What is (care recipient's name) relationship to you?

(Care recipient's name) is your...
READ CATEGORIES IF NEEDED

- Husband 1
- Wife 2
- Domestic partner 3
- Father..... 4
- Mother..... 5
- Grandfather..... 6
- Grandmother..... 7
- Brother 8
- Sister 9
- Uncle..... 10
- Aunt 11
- Son 12
- Son-in-Law..... 13
- Daughter..... 14
- Daughter-in-Law 15
- Other relative (not mentioned above) 16
- Friend or neighbor or another person..... 17
- Refused -7
- Don't Know -8

CR5. Has someone at (agency's name) helped you or given you information to connect you to the services and resources that you need as a caregiver?

Yes..... 1
No..... 2
Refused -7
Don't Know -8

CR6. Have you received respite care, which allows you a brief break while temporary care is provided to (care recipient's name), either in your home or someplace else?

Yes..... 1
No..... 2
Refused -7
Don't Know -8

CR7. Have you received caregiver training or education, including participation in support groups, to help you make decisions and solve problems in your role as a caregiver?

Yes..... 1
No..... 2
Refused -7
Don't Know -8

CR8. Has the (agency's name) provided you with any supplemental services to help you provide care, such as INSERT A DESCRIPTION OF LOCAL SERVICES, E.G. HOME MODIFICATIONS, NUTRITIONAL SUPPLEMENTS SUCH AS ENSURE OR BOOST, ASSISTIVE DEVICES SUCH AS CANES OR WALKERS, PERSONAL EMERGENCY RESPONSE SYSTEM, SPECIALIZED EQUIPMENT SUCH AS SLEEP APNEA MACHINES OR HOSPITAL BEDS, STIPENDS, ETC.?

Yes..... 1
No..... 2
Refused -7
Don't Know -8

CR9. Of the caregiver services you received, which one service was the most helpful?
 READ ONLY WHEN THE RESPONDENT NEEDS REMINDER. CHECK ONLY ONE.

- Help or information connecting you to services and resources 1
- Respite Care Services..... 2
- Caregiver Training or Education, including Counseling or a Support Group, or 3
- Other Supplemental Support Services or Assistance 4
 (Specify) _____
- Refused -7
- Don't Know -8

CR10. As a result of the caregiver services, do you...

	<u>Yes</u>	<u>No</u>	<u>Refused</u>	<u>Don't Know</u>
a. Have more time for personal activities.....	1	2	-7	-8
b. Feel less stress	1	2	-7	-8
c. Have a clearer understanding of how to get the services you and (care recipient) need	1	2	-7	-8
d. Know more about (care recipient's) condition or illness.....	1	2	-7	-8
e. Feel more confident in providing care to (care recipient's name).....	1	2	-7	-8

CR11. Would (care recipient's name) have been able to continue to live in the same home if caregiver services had not been provided?

- Yes..... 1 → GO TO CR12
 - No..... 2 → GO TO CR11a
 - Refused -7
 - Don't Know -8
- } GO TO CR12

CR11a. Where would (care recipient's name) 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
- Care recipient would have died..... 5
- Other 91
 (Specify) _____
- Refused..... -7
- Don't Know..... -8

CR12. Thinking about the caregiver services that you have received, how would you rate these services? Would you say...

- Excellent 1
- Very good 2
- Good 3
- Fair 4
- Poor 5
- Refused -7
- Don't Know -8

CR13. Would you recommend these services to a friend?

- Yes..... 1
- No..... 2
- Refused -7
- Don't Know -8

CR14. Have the caregiver services enabled you to provide care for a longer period of time than would have been possible without these services?

- Yes..... 1
- No..... 2
- Refused -7
- Don't Know -8

CR15. In general, would you say that the caregiver service has helped you?

- Yes..... 1 → GO TO CR15a
- No..... 2 } GO TO CR16
- Refused -7 }
- Don't Know -8 }

CR15a. How has the caregiver service helped you?

CR16. Do you have any recommendations to improve the caregiver service?

Yes.....	1	→ GO TO CR16a
No.....	2	} GO TO ADDITIONAL MODULES OR CLOSE
Refused	-7	
Don't Know	-8	

CR16a. What recommendations do you have for improving the service?

Note to Interviewer:

Additional modules may be used with this survey:

- 1. Module A: Care Provided Module**
- 2. Module B: Burdens and Rewards Module**
- 3. Module C: Impact on Employment Module**
- 4. Module D: Health of Caregiver Module**
- 5. Module E: Demographics Module**
- 6. Module F: Health and Physical Functioning of Care Recipient Module**
- 7. Module G: Service and Information Needs**

Thank you very much for your time and cooperation. Your answers are very important to us in improving the caregiver services.

Module A: Care Provided

In this section of the survey, we would like to obtain some basic information about how much care you provide to (care recipient's name).

CRA1. How long have you been caring for (care recipient's name)?

- | | | |
|------------------|---------------|----|
| __ __ Years | __ __ Months | |
| Refused | | -7 |
| Don't Know | | -8 |

CRA2. Thinking about all the family members or friends who provide help, care, or supervision for (care recipient's name), what proportion of the care do you provide during a typical week?

READ LIST. CHECK ONLY ONE.

Would you say...

- | | |
|------------------------------------|----|
| Less than one-quarter..... | 1 |
| About one-quarter..... | 2 |
| About one-half..... | 3 |
| About three-quarters | 4 |
| All or almost all of the care..... | 5 |
| Refused | -7 |
| Don't Know | -8 |

CRA3. Does (care recipient's name) live with you?

- | | | |
|------------------|----|--------------|
| Yes..... | 1 | → GO TO CRA5 |
| No..... | 2 | |
| Refused | -7 | |
| Don't Know | -8 | |

CRA4. Does (care recipient's name) live alone?

- | | | |
|------------------|----|------------------------|
| Yes..... | 1 | → GO TO NEXT
MODULE |
| No..... | 2 | |
| Refused | -7 | |
| Don't Know | -8 | |

Module B: Burdens and Rewards of Caregiving

The next group of questions ask about the rewards and burdens you may feel as a caregiver.

CRB1. I would like to ask you about positive aspects of caregiving and give you some choices for answers. Please choose the answer that best tells how you feel.

	<u>Always</u>	<u>Usually</u>	<u>Some- times</u>	<u>Rarely</u>	<u>Never</u>	<u>Refused</u>	<u>Don't Know</u>	<u>Does Not Apply</u>
a. As a caregiver, how often do you feel that you are helping (care recipient's name) continue to live at home.....	1	2	3	4	5	-7	-8	-9
b. How often does being a caregiver for (care recipient's name) give you the joy of spending time with someone you care about.....	1	2	3	4	5	-7	-8	-9
c. How often does being a caregiver provide you with a sense of accomplishment	1	2	3	4	5	-7	-8	-9
d. How often does providing care for (care recipient's name) give you the satisfaction of knowing that they are receiving the care and attention they need	1	2	3	4	5	-7	-8	-9
e. How often do you feel that (care recipient's name) appreciates the care that you are providing for them	1	2	3	4	5	-7	-8	-9
f. As a caregiver, how often do you feel you are fulfilling your duty by caring for (care recipient's name)	1	2	3	4	5	-7	-8	-9

CRB2. In your experience as a caregiver, what is the one most positive aspect of caregiving? READ LIST. CHECK ONLY ONE.

- Helping your care recipient live at home 1
- Spending time with someone you care about 2
- Feeling a sense of accomplishment 3
- Satisfaction that care and attention are received 4
- Being appreciated, or 5
- Fulfilling a duty 6
- None 7
- Refused -7
- Don't Know -8

CRB3. Now I would like to ask you about potential difficulties you may face in caring for (care recipient's name). Please respond to each of the following questions with one of the options provided. In your experience as a caregiver, how often do you feel that...

	<u>Always</u>	<u>Usually</u>	<u>Some- times</u>	<u>Rarely</u>	<u>Never</u>	<u>Refused</u>	<u>Don't Know</u>	<u>Does Not Apply</u>
a. Caregiving creates a financial burden for you.....	1	2	3	4	5	-7	-8	-9
b. Caregiving does not leave you enough time for yourself.....	1	2	3	4	5	-7	-8	-9
c. Caregiving does not leave enough time for your family	1	2	3	4	5	-7	-8	-9
d. Caregiving interferes with your work.....	1	2	3	4	5	-7	-8	-9
e. Caregiving negatively affects your health.....	1	2	3	4	5	-7	-8	-9
f. Caregiving conflicts with your social life.....	1	2	3	4	5	-7	-8	-9
g. Caregiving causes you stress	1	2	3	4	5	-7	-8	-9

CRB4. What is the greatest difficulty you have faced in your caregiving?
READ LIST. CHECK ONLY ONE.

Would you say caregiving:

- 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
- Conflicts with your social life..... 6
- Creates stress..... 7
- Refused -7
- Don't Know -8

Module C: Impact on Employment

CRC1. Have you ever been employed?

- Yes..... 1
 - No..... 2
 - Refused -7
 - Don't Know -8
- } GO TO NEXT MODULE

CRC2. What is your current employment status? Are you ...

- Working full time..... 1
 - Working part time 2
 - Retired..... 3
 - Not working..... 4
 - Refused -7
 - Don't Know -8
- } GO TO CRC3
- } GO TO NEXT MODULE

CRC2a. Did your caregiving responsibilities cause you to quit work or retire early?

- Yes..... 1
 - No..... 2
 - Refused -7
 - Don't Know -8
- } GO TO NEXT MODULE

CRC3. Has providing care for (care recipient's name) ever interfered with your employment?

- Yes..... 1
 - No..... 2
 - Refused -7
 - Don't Know -8
- } GO TO NEXT MODULE

CRC4. Because of providing care for (care recipient's name), have you ...
 READ LIST AND CHECK ALL THAT APPLY.

	<u>Yes</u>	<u>No</u>	<u>Refused</u>	<u>Don't Know</u>
a. Taken a less demanding job	1	2	-7	-8
b. Changed from full-time to part-time work	1	2	-7	-8
c. Reduced your official working hours	1	2	-7	-8
d. Lost some of your employment fringe benefits.....	1	2	-7	-8
e. Had time conflicts between working and caregiving ...	1	2	-7	-8
f. Used your vacation time to provide care	1	2	-7	-8
g. Taken a leave of absence to provide care.....	1	2	-7	-8
h. Lost a promotion.....	1	2	-7	-8
i. Worked less than your normal number of hours last month	1	2	-7	-8
j. Other	1	2	-7	-8

(Specify) _____

Module D: Health of Caregiver

CRD1. 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 NEXT
MODULE |
| No..... | 2 | |
| Refused | -7 | |
| Don't Know | -8 | |

CRD1a. What is that problem, condition, or disability? DO NOT READ RESPONSES. CHECK ALL THAT APPLY AND PROBE: "Is there anything else?"

- | | |
|--|----|
| 1. Back problems and other joint problems/Arthritis | 1 |
| 2. Heart problems/High Blood Pressure/Hypertension/Stroke ... | 2 |
| 3. Diabetes | 3 |
| 4. Allergies/Asthma/Other breathing/Lung problems | 4 |
| 5. Mental health (anxiety, fear, depression,
emotional problems)..... | 5 |
| 6. Eye problems..... | 6 |
| 7. Other..... | 91 |
| (Specify) _____ | |
| Refused | -7 |
| Don't Know | -8 |

CRD2. Have your caregiving activities created or worsened any of these conditions, problems, or disabilities?

- | | |
|------------------|----|
| Yes..... | 1 |
| No..... | 2 |
| Refused | -7 |
| Don't Know | -8 |

Module E: Demographics

We are interested in knowing more about the demographic characteristics of our clients. We would appreciate if you would answer a few questions about yourself. All this information will be kept confidential.

CRE1. **ASK IF NOT OBVIOUS.** What is your gender?

- Male 1
- Female 2
- Refused -7
- Don't Know -8

CRE2. In what year were you born?

- |__|__|__|__| Year
- Refused -7
- Don't Know -8

CRE3. What is your highest education level?

- Less than high school diploma 1
- High school diploma 2
- Some college, including associate degree 3
- Bachelor's degree 4
- Some post-graduate work or advanced degree 5
- Refused -7
- Don't Know -8

CRE4. Are you Spanish, Hispanic, or Latino?

- Yes 1
- No 2
- Refused -7
- Don't Know -8

CRE5. What is your race? (CHECK ALL THAT APPLY.)

- a. American Indian or Alaskan Native 1
- b. Asian..... 2
- c. Black or African-American 3
- d. White/Caucasian 4
- e. Native Hawaiian/Other Pacific Islander..... 5
- f. Other race 6
(Specify) _____
- g. Refused -7
- h. Don't Know -8

CRE6. What is your marital status?

- Now married..... 1
- Widowed 2
- Divorced 3
- Separated 4
- Never married 5
- Refused -7
- Don't Know -8

CRE7. Where is your home located? Would you say...

- In a city 1
- In a suburban area 2
- In a rural area 3
- Refused -7
- Don't Know -8

CRE8. How many people live in your household, including yourself?

- |__| |__| Number of Household Members
- Refused -7
- Don't Know -8

CRE9. How many persons total are you caring for, not counting (care recipient's name)?

- |__| |__| Number of Persons
- Refused -7
- Don't Know -8

CRE10. Thinking about the total combined income from all sources for all persons in this household, was your total household annual income during the past year above or below \$20,000? (IF NEEDED: including income from jobs, Social Security, retirement income, public assistance, and all other sources)

- Below \$20,000..... 1 → GO TO CRE11
- Above \$20,000 2 → GO TO CRE12
- Refused -7
- Don't Know -8

CRE11. Which category best describes your total household annual income during the past year?

- \$10,000 or less..... 1
- \$10,001 to \$15,000..... 2
- \$15,001 to \$20,000..... 3 } GO TO CRE13
- Refused -7
- Don't Know -8

CRE12. Which category best describes your total household annual income during the past year?

- \$20,001 to \$30,000..... 1
- \$30,001 to \$40,000..... 2
- \$40,001 to \$50,000..... 3
- Over \$50,000 4
- Refused -7
- Don't Know -8

CRE13. **ASK IF NOT OBVIOUS.** What is the gender of (care recipient's name)?

- Male 1
- Female 2
- Refused -7
- Don't Know -8

CRE14. What is the age of (care recipient's name)?

- |__|__|__| Years
- Refused -7
- Don't Know -8

Module F: Health and Physical Functioning of Care Recipient

CRF1. Does (care recipient) have difficulty getting around inside the home?

- Yes..... 1
 - No..... 2
 - Refused-7
 - Don't Know-8
- } GO TO CRF2

CRF1a. Does (he or she) need the help of another person to perform this activity?

- Yes 1
- No 2
- Refused.....-7
- Don't Know.....-8

CRF2. Does (he or she) have difficulty going outside the home, for example to shop or visit a doctor's office?

- Yes..... 1
 - No..... 2
 - Refused-7
 - Don't Know-8
- } GO TO CRF3

CRF2a. Does (he or she) need the help of another person to perform this activity?

- Yes 1
- No 2
- Refused.....-7
- Don't Know.....-8

CRF3. Does (care recipient) have difficulty getting in or out of bed or a chair?

Yes.....	1	} GO TO CRF4
No.....	2	
Refused	-7	
Don't Know	-8	

CRF3a. Does (he or she) need the help of another person to perform this activity?

Yes	1
No	2
Refused.....	-7
Don't Know.....	-8

CRF4. Does (he or she) have difficulty when taking a bath or shower?

Yes.....	1	} GO TO CRF5
No.....	2	
Refused	-7	
Don't Know	-8	

CRF4a. Does (he or she) need the help of another person to perform this activity?

Yes	1
No	2
Refused.....	-7
Don't Know.....	-8

CRF5. Does (care recipient) have difficulty when dressing?

Yes.....	1	} GO TO CRF6
No.....	2	
Refused	-7	
Don't Know	-8	

CRF5a. Does (he or she) need the help of another person to perform this activity?

Yes	1
No	2
Refused.....	-7
Don't Know.....	-8

CRF6. Does (he or she) have difficulty when walking?

Yes.....	1	} GO TO CRF7
No.....	2	
Refused	-7	
Don't Know	-8	

CRF6a. Does (he or she) need the help of another person to perform this activity?

Yes	1
No	2
Refused.....	-7
Don't Know.....	-8

CRF7. Does (care recipient) have difficulty eating?

Yes.....	1	} GO TO CRF8
No.....	2	
Refused	-7	
Don't Know	-8	

CRF7a. Does (he or she) need the help of another person to perform this activity?

Yes	1
No	2
Refused.....	-7
Don't Know.....	-8

CRF8. Does (he or she) have difficulty using the toilet or getting to the toilet?

Yes.....	1	} GO TO CRF9
No.....	2	
Refused	-7	
Don't Know	-8	

CRF8a. Does (he or she) need the help of another person to perform this activity?

Yes	1
No	2
Refused.....	-7
Don't Know.....	-8

CRF9. Does (care recipient) have difficulty keeping track of money or bills?

Yes.....	1	} GO TO CRF10
No.....	2	
Refused	-7	
Don't Know	-8	

CRF9a. Does (he or she) need the help of another person to perform this activity?

Yes	1
No	2
Refused.....	-7
Don't Know.....	-8

CRF10. Does (he or she) have difficulty preparing meals?

Yes.....	1	} GO TO CRF11
No.....	2	
Refused	-7	
Don't Know	-8	

CRF10a. Does (he or she) need the help of another person to perform this activity?

Yes	1
No	2
Refused.....	-7
Don't Know.....	-8

CRF11. Does (care recipient) have difficulty doing light housework, such as washing dishes or sweeping a floor?

Yes.....	1	} GO TO CRF12
No.....	2	
Refused	-7	
Don't Know	-8	

CRF11a. Does (he or she) need the help of another person to perform this activity?

Yes	1
No	2
Refused.....	-7
Don't Know.....	-8

CRF12. Does (he or she) have difficulty doing heavy housework, such as scrubbing floors or washing windows?

- | | | |
|------------------|----|---------------|
| Yes..... | 1 | } GO TO CRF13 |
| No..... | 2 | |
| Refused | -7 | |
| Don't Know | -8 | |

CRF12a. Does (he or she) need the help of another person to perform this activity?

- | | |
|-----------------|----|
| Yes | 1 |
| No | 2 |
| Refused..... | -7 |
| Don't Know..... | -8 |

CRF13. Does (he or she) have difficulty taking the right amount of prescribed medicine at the right time?

- | | | |
|------------------|----|---------------|
| Yes..... | 1 | } GO TO CRF14 |
| No..... | 2 | |
| Refused | -7 | |
| Don't Know | -8 | |

CRF13a. Does (he or she) need the help of another person to perform this activity?

- | | |
|-----------------|----|
| Yes | 1 |
| No | 2 |
| Refused..... | -7 |
| Don't Know..... | -8 |

CRF14. Does (care recipient) have difficulty using the telephone?

- | | | |
|------------------|----|---------------|
| Yes..... | 1 | } GO TO CRF15 |
| No..... | 2 | |
| Refused | -7 | |
| Don't Know | -8 | |

CRF14a. Does (he or she) need the help of another person to perform this activity?

- | | |
|-----------------|----|
| Yes | 1 |
| No | 2 |
| Refused..... | -7 |
| Don't Know..... | -8 |

CRF15. Does (he or she) have difficulty driving an automobile?

- Yes..... 1
- No..... 2
- Refused -7
- Don't Know -8

Module G: Service and Information Needs

The next two questions ask you to think about what additional services and information may be helpful to you as a caregiver.

CRG1. In addition to the kinds and amounts of services you are receiving, (and the services that [care recipient's name] is receiving), what additional or new kinds of **help** would be valuable to you as a caregiver?

	<u>Yes</u>	<u>No</u>	<u>Refused</u>	<u>Don't Know</u>
a. Housekeeping assistance for (care recipient's name)	1	2	-7	-8
b. Shopping assistance for (care recipient's name).....	1	2	-7	-8
c. Transportation assistance for (care recipient's name)	1	2	-7	-8
d. Assistance in making meals for (care recipient's name)	1	2	-7	-8
e. Assistance in bathing, dressing, grooming, toileting, feeding, and other personal care for (care recipient's name).....	1	2	-7	-8
f. Adult daycare for (care recipient's name).....	1	2	-7	-8
g. Assistance in getting other family members involved in caring for (care recipient's name)	1	2	-7	-8
h. Assistance in administering and monitoring side effects of medicine for (care recipient's name) etc	1	2	-7	-8
i. In-home respite care	1	2	-7	-8
j. Help with money management and financial advice.....	1	2	-7	-8
k. Other services	1	2	-7	-8
(Specify) _____				

l. No additional help needed	1	2	-7	-8

CRG2. What additional or new kinds of **information** would be valuable to you as a caregiver? READ LIST. CHECK YES OR NO FOR EACH ONE.

	<u>Yes</u>	<u>No</u>	<u>Refused</u>	<u>Don't Know</u>
a. A help line/central place to call to find out what kind of help is available and where to get it.....	1	2	-7	-8
b. Someone to talk to/counseling services or support groups	1	2	-7	-8
c. Information about how to care for (care receiver's name)'s condition or disability	1	2	-7	-8
d. Information about changes in laws that might affect your situation	1	2	-7	-8
e. Information about how to select a nursing home, group home, assisted living facility, or other care facility	1	2	-7	-8
f. Information on how to pay for nursing homes, assisted living facilities, adult day care, and other services.....	1	2	-7	-8
g. Information on how to deal with agencies (bureaucracies) to get services	1	2	-7	-8
h. Information on health insurance and/or long-term care insurance	1	2	-7	-8
i. Other information not listed above	1	2	-7	-8
(Specify) _____				

l. No additional information needed.....	1	2	-7	-8