

POMP 5 CAREGIVER PROGRAM SUPPORT AND ASSESSMENT SURVEY CODEBOOK

June 3, 2004

CODERS: ONLY ENTER DATA FOR QUESTIONNAIRES THAT HAVE THE OFFICE USE ONLY BOX FILLED IN. CHECK BELOW FOR REQUIRED FIELDS.

ENTER A VALUE FOR ALL QUESTIONS UNLESS "BLANK IS VALID" IS NOTED, OTHERWISE CODE -9 FOR MISSING OR INVALID VALUES. CHECK THE SURVEY MARGIN FOR REMARKS. IF REFUSED (RF) CODE -7. IF DON'T KNOW (DK), CODE -8.

IF MORE THAN ONE RESPONSE IS CHECKED, CODE -9, INVALID.

FOR QUESTIONS THAT ARE "CHECK ALL THAT APPLY", A CHECKED BOX = 1 (YES) AND AN UNCHECKED BOX = 2 (NO). IF ALL BOXES ARE UNCHECKED, CODE EACH CATEGORY AS -9.

AGENCY INFORMATION - AUTOFILL

<u>Variable Name</u>	<u>Variable Description and Codes</u>
Agency	Name of agency that the client is enrolled with (REQUIRED) XXXXXXXXXXXXXXXXX(Maximum of 50 Characters)
State	State that the agency is in (REQUIRED) XX (State abbreviation)

OFFICE USE ONLY BOX

<u>Variable Name</u>	<u>Variable Description and Codes</u>
ClientID	Unique caregiver identifier (REQUIRED) XXXXXXXXXXXXXXXXX(Maximum of 50 Characters)
Method	Interview method of administration (REQUIRED) T = Telephone M = Mail O = Other -9 = Missing
Date	Date the interview was completed (REQUIRED) xx/xx/2004

Result

Result Code

CO = Complete
PC = Partially complete
IN = Ineligible [Caregiver provides no care]
IE = Ineligible [recipient less than 60 yrs; CG less than 18]
RF = Final Refusal/Breakoff
DC = Caregiver Deceased
DR = Care Recipient Deceased
NA = No answer after 5 tries
NL = Not able to locate caregiver
LH = Language/hearing/speech problems
T1 = Termination – Person does not provide care of any kind
T2 = Termination – Respondent does not receive specified services
OT = Other non-response

Enroll

Date caregiver enrolled in services

xx/xx/xxxx

TimeBegin

Record time interview began --:-- AM/PM

##:## XX

TimeEnd

Record time interview ended --:-- AM/PM

##:## XX

Comments

XXXXXXXXXXXXXXXX(Maximum 65,000 Characters)
BLANK IS VALID

QUESTIONNAIRE

Variable Name

Question And Codes

CG1

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

1 = Husband
2 = Wife
3 = Son
4 = Son-in-Law
5 = Daughter
6 = Daughter-in-Law
7 = Father
8 = Mother
9 = Brother
10 = Sister
11 = Granddaughter
12 = Grandson
13 = Niece
14 = Nephew
15 = Other relative [Not a relative mentioned above]
16 = Friend or Neighbor or Another Person
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CODERS: IF CG1 = 15 GO TO CG1OR, ELSE GO TO CG2

CG1OR 1OR) [IF OTHER RELATIVE] SPECIFY

XXXXXXXXXX(Maximum 250 Characters)

- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: BLANK IS VALID FOR CG1OR IF CG1 IS NOT 15. OTHERWISE IF NO DESCRIPTION IS PROVIDED WRITE IN -9. WHEN POSSIBLE, IF DESCRIPTION MATCHES ONE OF THE ABOVE CATEGORIES, 1-14 OR 16, CHANGE THE ANSWER TO THE APPROPRIATE RESPONSE AND LEAVE CG1OR AS BLANK.

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 ...

CG2A 2A. Activities like dressing, eating, bathing, or getting to the bathroom?

- 1 = All the time or Most of the time
- 2 = Sometimes
- 3 = Rarely or Never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG2B 2B. Medical needs such as taking medicine or changing bandages?

- 1 = All the time or Most of the time
- 2 = Sometimes
- 3 = Rarely or Never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG2C 2C. Keeping track of bills, checks, or other financial matters?

- 1 = All the time or Most of the time
- 2 = Sometimes
- 3 = Rarely or Never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG2D 2D. Preparing meals, doing laundry, or cleaning the house?

- 1 = All the time or Most of the time
- 2 = Sometimes
- 3 = Rarely or Never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG2E

2E. Going shopping or to the doctor's office?

- 1 = All the time or Most of the time
- 2 = Sometimes
- 3 = Rarely or Never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG2F

2F. Arranging for care or services provided by others?

- 1 = All the time or Most of the time
- 2 = Sometimes
- 3 = Rarely or Never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF ALL RESPONSES TO CG2A THROUGH CG2F ARE 3, -7, -8, OR -9 GO TO CG2OR, ELSE GO TO CG3

CG2OR

XXXXXXXXXXXXX(Maximum 65,000 Characters)

- 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: IF THIS PERSON DOES NOT PROVIDE CARE OF ANY KIND FOR THE CLIENT, TERMINATE THE INTERVIEW AT THIS POINT. I.E., IF CG2OR IS NOT -7, -8, OR -9 GO TO CG3.

TERMINATE1

[TERMINATION FLAG TO INDICATE PERSON DOES NOT PROVIDE ANY CARE FOR CLIENT]

- 1 = Provides no care [Terminate]
- 2 = Provides care [Go to CG3]

CG3

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?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF CG3 = 1 GO TO CG3A, ELSE GO TO CG4

CG3A

3A. To what extent have the Respite Care Services you have received helped you as a caregiver?

- 1 = They helped a lot
 - 2 = They helped a little
 - 3 = They didn't help, or
 - 4 = They made things worse?
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG4

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?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF CG4 = 1 GO TO CG4A, ELSE GO TO CG5

CG4A

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?

- 1 = They helped a lot
 - 2 = They helped a little
 - 3 = They didn't help, or
 - 4 = They made things worse?
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG5

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?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF CG5 = 1 GO TO CG5A, ELSE GO TO CG6

CG5A 5A. To what extent has the caregiver training or education you have received helped you as a caregiver?

- 1 = They helped a lot
 - 2 = They helped a little
 - 3 = They didn't help, or
 - 4 = They made things worse?
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG6 6. Has the National Family Caregiver Support Program provided you with any other Supplemental Services to complement the care you provide, such as [INSERT local services or use: home modifications, assistive technologies, or incontinence supplies]?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF CG6 = 1 GO TO CG6A, ELSE GO TO BOX BEFORE CG7

CG6A 6A. To what extent have the Supplemental Services you have received helped you as a caregiver?

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: IF RESPONDENT RECEIVES ANY OF THE ABOVE SERVICES (I.E. "YES" TO CG3, CG4, CG5, OR CG6), GO TO CG7. OTHERWISE, TERMINATE.

TERMINATE2 [TERMINATION FLAG TO INDICATE RESPONDENT DOES NOT RECEIVE SERVICES]

- 1 = Receives no services [Terminate]
- 2 = Receives services [Go to CG7]

CG7 7. Of the caregiver services provided, which one service was the most helpful?

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

CG8 8 .How have the caregiver services that have been provided affected you and your caregiving tasks?

XXXXXXXXXXXXX(Maximum 65,000 Characters)

- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG9 9. Overall, to what extent have these caregiver services helped you to be a better caregiver?

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

CG10 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?

- 1 = Yes, definitely
- 2 = Yes, I think so
- 3 = No, I don't think so
- 4 = No, definitely not
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG11 11. Overall, how would you rate the caregiver support services that have been provided?

- 1 = Excellent
- 2 = Very Good
- 3 = Good
- 4 = Fair
- 5 = Poor?
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG12 12. What is your current employment status?

- 1 = Working full time (Go to Q.13)
- 2 = Working part time (Go to Q.13)
- 3 = Retired
- 4 = Not working
- 7 = REFUSED (Go to Q.16)
- 8 = DON'T KNOW (Go to Q.16)
- 9 = MISSING OR INVALID (Go to Q.16)

CODERS: IF CG12 = 1 or 2 GO TO CG13, ELSE IF CG12 = -7, -8, or -9 GO TO CG16, ELSE GO TO CG12A

CG12A 12A. Did your caregiving responsibilities cause you to quit work or retire early?

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: GO TO CG16

CG13 13. Has providing care for [CARE RECIPIENT'S NAME] interfered with your job?

- 1 = Yes
 - 2 = No (Go to Q.16)
 - 7 = REFUSED (Go to Q.16)
 - 8 = DON'T KNOW (Go to Q.16)
 - 9 = MISSING OR INVALID (Go to Q.16)
- BLANK IS VALID

CODERS: IF CG13 = 1 GO TO CG13A, ELSE GO TO CG16

CG13A 13A. How frequently has providing care for [CARE RECIPIENT'S NAME] interfered with your job?

- 1 = Always or usually
 - 2 = Sometimes
 - 3 = Rarely or never (Go to Q.16)
 - 7 = REFUSED (Go to Q.16)
 - 8 = DON'T KNOW (Go to Q.16)
 - 9 = MISSING OR INVALID (Go to Q.16)
- BLANK IS VALID

CODERS: IF CG13A = 1 or 2, GO TO CG14, ELSE GO TO CG16

14. Because of providing care for [CARE RECIPIENT'S NAME], have you . . .

CG14A 14A. Taken a less demanding job.

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG14B 14B. Changed from full time to part-time work.

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG14C

14C. Reduced your official working hours.

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG14D

14D. Lost some of your employment fringe benefits.

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG14E

14E. Had time conflicts between working and caregiving.

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG14F

14F. Used your vacation time to provide care.

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG14G

14G. Taken a leave of absence to provide care.

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG14H

14H. Lost a promotion .

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG14I 14I. Worked less than your normal number of hours last month because of providing care for [CARE RECIPIENT'S NAME]

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG14J 14J. Other

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: IF CG14J = 1 GO TO CG14OR, ELSE GO TO CG15

CG14OR 14OR. Other Specify

XXXXXXXXXXXX(Maximum 250 Characters)

- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

BLANK IS VALID

CG15 15. To what extent have caregiver support services helped alleviate these work difficulties?

- 1 = They helped a lot
 - 2 = They helped a little
 - 3 = They didn't help, or
 - 4 = They made things worse?
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

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

CG16A 16A. As a caregiver, how often do you feel that you are helping [CARE RECIPIENT'S NAME]?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG16B 16B. As a caregiver, how often do you feel that you are helping your family by caring for [CARE RECIPIENT'S NAME]?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG16C 16C. How often does being a caregiver provide you with a sense of accomplishment?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG16D 16D. How often does providing care for [CARE RECIPIENT'S NAME] give you the satisfaction of caring for someone who cared for you?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG16E 16E. How often do you feel that [CARE RECIPIENT'S NAME] appreciates the care that you are providing for them?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG16F 16F. How often does being a caregiver for [CARE RECIPIENT'S NAME] provide companionship for you?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG16G 16G. Other

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW

-9 = MISSING OR INVALID

CODERS: IF CG16G = 1 GO TO CG16OR, ELSE GO TO THE BOX BEFORE CG17

CG16OR

16OR. Other Specify

XXXXXXXXXX(Maximum 250 Characters)

-7 = REFUSED

-8 = DON'T KNOW

-9 = MISSING OR INVALID

BLANK IS VALID

CODERS: IF ALL OF CG16 ARE "RARELY OR NEVER," "REFUSED," "DON'T KNOW," OR "DOES NOT APPLY," GO TO CG18, ELSE GO TO CG17.

CG17

17. In your experience as a caregiver, what would you say is the one most positive aspect of caregiving? Would you say that the one most positive aspect is ...

1 = Helping your care recipient

2 = Helping your other family members

3 = Feeling a sense of accomplishment

4 = Caring for someone who cared for you

5 = Being appreciated, or

6 = Providing companionship for you?

7 = Other

8 = None

-7 = REFUSED

-8 = DON'T KNOW

-9 = MISSING OR INVALID

BLANK IS VALID

CODERS: IF CG17 = 7 GO TO CG17OR, ELSE GO TO CG18

CG17OR

17OR. Other Specify

XXXXXXXXXX(Maximum 250 Characters)

-7 = REFUSED

-8 = DON'T KNOW

-9 = MISSING OR INVALID

BLANK IS VALID

18. In your experience as a caregiver, how often do you feel that...

CG18A

18. Caregiving creates a financial burden for you?

1 = Always or usually

2 = Sometimes

3 = Rarely or never

-7 = REFUSED

-8 = DON'T KNOW

-9 = MISSING OR INVALID

CG18B 18B. You do not have enough time for yourself?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG18C 18C. You do not have enough time for your family?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG18D 18D. Caregiving negatively affects your health?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG18E 18E. Caregiving conflicts with your social life?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG18F 18F. You are stressed?

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CH18G 18G. Other

- 1 = Always or usually
- 2 = Sometimes
- 3 = Rarely or never
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF CG18G = 1 GO TO CG18OR, ELSE GO TO CG19

CG18OR

18OR. Other Specify

XXXXXXXXXXXX(Maximum 250 Characters)

- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: IF ALL OF CG18 ARE "RARELY OR NEVER," "REFUSED," "DON'T KNOW," OR "DOES NOT APPLY," GO TO CG21, ELSE GO CG19.

CG19

19. Which of these difficulties is the greatest difficulty you have faced in your caregiving? Would you say caregiving's greatest difficulty is that it ...

- 1 = Creates a financial burden
- 2 = Doesn't leave enough time for yourself
- 3 = Doesn't leave enough time for your family
- 4 = Interferes with your work
- 5 = Creates or aggravates health problems
- 6 = Affects your family relationships, or
- 7 = Creates stress?
- 8 = Other
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: IF CG19 = 8 GO TO CG19OR, ELSE GO TO CG20

CG19OR

19OR. Other Specify

XXXXXXXXXXXX(Maximum 250 Characters)

- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID
- BLANK IS VALID

CG20

20. To what extent have the Caregiver Support Services you have received helped alleviate these difficulties?

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

CG21

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]?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF CG21 = 1 THEN GO TO CG21A, ELSE GO TO CG23

CG21A 21A. What is that problem, condition, or disability? [DON'T READ LIST. WRITE RESPONSE VERBATIM OR CHECK ALL THAT APPLY.]

XXXXXXXXXX (Maximum 65,000 Characters)

-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG21A1 21A1. Back problems and other joint problems/ Arthritis

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG21A2 21A2. Heart problems / High Blood Pressure / Hypertension / Stroke

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG21A3 21A3. Diabetes

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG21A4 21A4. Allergies/Asthma/Other breathing and lung problems

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG21A5 21A5. Mental health (all)

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG21A6 21A6. Eye problems

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG21A7 21A7. Other

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CODERS: IF CG21A7 = 1 THEN GO TO CG21AOR, ELSE GO TO CG22

CG21AOR 21AOR. Other specify

XXXXXXXXXXXX(Maximum 250 Characters)
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG22 22. Have your caregiving activities created or worsened any of these problems, conditions, or disabilities?

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

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

CG23MO 23. MONTHS

0-12 = Months
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG23YR 23. YEARS

0-99 = Years
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

- CG24 24. How far away do you live from [CARE RECIPIENT'S NAME]? Do you live...
- 1 = In the same house
 - 2 = Less than 20 minutes away
 - 3 = Between 20 and 60 minutes away
 - 4 = Between 1 and 2 hours away, or
 - 5 = More than two hours away?
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID

CODERS: IF CG24 = 2 – 5, GO TO CG25, ELSE GO TO CG26

- CG25 25. Does [CARE RECIPIENT'S NAME] live alone?
- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

- CG26 26. Can [CARE RECIPIENT'S NAME] be left alone? Would you say
- 1 = He/she can be left alone
 - 2 = He/she needs someone there at least part of the day
 - 3 = He/she needs someone there all or nearly all the time
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID

- CG27 27. In your judgment, how many hours per day of help, care, or supervision does [CARE RECIPIENT'S NAME] need?
- 0-24 = Number of hours per day
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID

- CG28 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?
- 0-24 = Number of hours per day
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID

- CG29 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?
- 0-24 = Number of hours per day
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID

CG30 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]?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG31 31. Do you need (more) time off?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG32 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? Would you say...

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

33. Does [CARE RECIPIENT'S NAME] receive the following service?

CG33A 33A. Adult Daycare (Center-provided daycare)?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG33B 33B. Case Management?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG33C 33C. Homemaker Service?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG33D 33D. Home Health Aide?
1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG33E 33E. Home Delivered Meals?
1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG33F 33F. Chore Service
1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG33G 33G. Transportation Service (includes Assisted Transportation)?
1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG33H 33H. Information about services?
1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG33I1 33I1. Other services or assistance (not listed above)
1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CODERS: IF CG33I1 = 1 GO TO CG33OR1, ELSE GO TO CG34

CG33OR1

33OR1. Other Specify

XXXXXXXXXX(Maximum 250 Characters)

- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID
- BLANK IS VALID

CG33I2

33I2. Other services or assistance (not listed above)

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: IF CG33I2 = 1 GO TO CG33OR2, ELSE GO TO CG34

CG33OR2

33OR2. Other Specify

XXXXXXXXXX(Maximum 250 Characters)

- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: IF ALL OF CG33 ARE "NO," REFUSED, OR "DON'T KNOW," GO TO CG37, ELSE GO TO CG34

CG34

34. Overall, how would you rate the services that [CARE RECIPIENT'S NAME] receives? Would you say...

- 1 = Excellent
- 2 = Very good
- 3 = Good
- 4 = Fair, or
- 5 = Poor?
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID
- BLANK IS VALID

CG35

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?

- 1 = Yes, definitely
- 2 = Yes, I think so
- 3 = No, I don't think so, or
- 4 = No, definitely not?
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID
- BLANK IS VALID

CG36 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.]

XXXXXXXXXX (Maximum 65,000 Characters)

- 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG37 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?

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: IF CG37 = 1 THEN GO TO CG37A, ELSE GO TO CG38

CG37A 37A. Where would [CARE RECIPIENT'S NAME] be living?
[DON'T READ LIST. CHECK ONLY ONE ANSWER.]

- 1 = In your [caregiver's] home
 - 2 = In the home of another family member or friend
 - 3 = In an assisted living facility
 - 4 = In a nursing home
 - 5 = Other
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CODERS: IF CG37A = 5 THEN GO TO CG37AOR, ELSE GO TO CG38

CG37AOR 37AOR. Other Specify

XXXXXXXXXX(Maximum 250 Characters)

- 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

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? How about...

- CG38A 38A. Help with housekeeping
- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- CG38B 38B. Help with shopping
- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- CG38C 38C. Help with transportation, getting places
- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- CG38D 38D. Help with making meals,
- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- CG38E 38E. Help with bathing, dressing, grooming, toileting, feeding, other personal care
- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- CG38F 38F. Help with medicines (administering medicine, monitoring side effects, etc.),
- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- CG38G 38G. Help with getting other family members involved in caring for [CARE RECIPIENT'S NAME],
- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID

CG38H 38H. Financial support, tax break, stipend, government subsidy,

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG38I 38I. In-home respite care for [CARE RECIPIENT'S NAME],

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG38J 38J. Adult daycare for [CARE RECIPIENT'S NAME], or

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG38K 38K. Money management assistance or financial advice

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG38L 38L. Other

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF CG38L = 1 THEN GO TO CG38OR, ELSE GO TO CG38M

CG38OR 37AOR. Other Specify

XXXXXXXXXX(Maximum 250 Characters)

- 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG38M 38M. No additional help needed?

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CODERS: CG38M CAN ONLY BE "YES" IF CG38A – CG38L ARE ALL "NO" OR -7, -8, -9. IF A-L HAVE A YES, THEN CODE CG38M AS "NO".

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? How about...

CG39A 39A. A help line (or central place to call to find out what Kind of help is available and where to get it)

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG39B 39B. Someone to talk to or counseling services or support group

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG39C 39C. Information about [CARE RECIPIENT'S NAME]'s condition or disability

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG39D 39D. Information about changes in laws that might affect your situation

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG39E 39E. Help in understanding how to select a nursing home or group home or other care facility

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID

CG39F 39F. Help in understanding how to pay for nursing homes, adult day care, or other services

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG39G 39G. Help in dealing with agencies (bureaucracies) to get services, or

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG39H 39H. Other

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF CG39H = 1 THEN GO TO CG39OR, ELSE GO TO CG39I

CG39OR 39OR. Other Specify

XXXXXXXXXX(Maximum 250 Characters)
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG39I 39I. No additional information needed?

- 1 = Yes
- 2 = No
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: CG39I CAN ONLY BE "YES" IF CG39A – CG39H ARE ALL "NO" OR -7, -8, -9. IF A-H HAVE A YES, THEN CODE CG39I AS "NO".

CG40 40. What is the age of [CARE RECIPIENT'S NAME]?

- 0-150 = Number of Years
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG41 41. What is the gender of [CARE RECIPIENT'S NAME]?

- 1 = Male
- 2 = Female
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CG42 42. How many other persons total are you caring for, not counting [CARE RECIPIENT'S NAME]?

- 0-99 = Number of persons
- 7 = REFUSED
- 8 = DON'T KNOW
- 9 = MISSING OR INVALID

CODERS: IF CG42 > 0 THEN GO TO CG42A1, ELSE GO TO DEMOGRAPHICS SECTION

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

CG42A1 42A1. Husband or wife

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG42A2 42A2. Son(s) or daughter(s)

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG42A3 42A3. Father

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG42A4 42A4. Mother

- 1 = Yes
 - 2 = No
 - 7 = REFUSED
 - 8 = DON'T KNOW
 - 9 = MISSING OR INVALID
- BLANK IS VALID

CG42A5

42A5. Brother(s) or sister(s)

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG42A6

42A6. Grandson(s) or granddaughter(s)

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG42A7

42A7. Other relative(s) not mentioned above

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG42A8

42A8. Friend(s) or neighbor(s)

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CG42A9

42A9. Other persons not mentioned above

1 = Yes
2 = No
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID

CODERS: IF CG42A9 = 1 THEN GO TO CG42OR, ELSE GO TO DEMOGRAPHICS SECTION

CG42OR

42OR. Other Specify

XXXXXXXXXX(Maximum 250 Characters)
-7 = REFUSED
-8 = DON'T KNOW
-9 = MISSING OR INVALID
BLANK IS VALID